A HEALTH NEEDS ASSESSMENT (HNA)
TO IMPROVE HEALTH OUTCOMES AND REDRESS INEQUITIES
FOR CHILDREN LIVING WITH NEPHROTIC SYNDROME IN VIETNAM

A thesis submitted for the degree of Doctorate of Public Health

By

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August 2021

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DECLARATION

I certify this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made.

The researcher planned the research, obtained appropriate ethics approvals in Australia and Vietnam, collected and analysed the data, facilitated and managed all aspects of the associated activities undertaken throughout the research project and wrote this thesis.

7 March 2021

Kate Armstrong Date

ACKNOWLEDGEMENTS

This thesis has been a long pilgrimage of sorts, and there are many people to whom I would like to extend my sincere thanks for their help along the way.

Thank you to my Supervisors for their constant support. To Prof. Paul Ward, Professor of Public Health and Higher Degrees by Research Coordinator at Flinders University, for his expertise, advice, encouragement, patience and guidance at every step of the journey. Thank you, Paul, for understanding the many twists and turns that my life seemed to take and for remaining optimistic as I repeatedly found myself on the roads less travelled.

Thank you sincerely to Dr Elisabeth Hodson for joining me on those same roads. Your incredible generosity of spirit, travelling with me to Vietnam on multiple occasions over several years, was foundational to the capacity of this research project to benefit the Nephrotic Syndrome (NS) Community of Vietnam. Your calm, warm and kind demeanour, gentle humour and openness to new experiences and innovative ideas made you the most amazing companion and inspired other incredible Australians to engage in CLAN's work. Thank you to Prof. Allison Tong for joining Elisabeth and me on one of the earlier trips to Vietnam and for sharing your qualitative research expertise so generously beyond this. Thank you also to Dr Fiona Mackie and Dr Amelia Le Page for your generosity in supporting activities for the NS Community of Vietnam beyond this research project, and continuing Elisabeth's work building relationships between Australia and Vietnam.

My sincere appreciation is also extended to Prof. Nguyen Thanh Liem for your support, guidance and advice at all stages of the research project. Your wise counsel helped me navigate the appropriate directions to take at every turn and made the entire project possible. Thank you for introducing me to Dr Le Van Hao, who played an invaluable role as my cultural mentor and broker. Thank you, Dr Hao, for sharing your wisdom and insights, and helping me better understand the experiences and perspectives of families and children living with chronic health conditions in Vietnam. Your counsel ensured the project progressed with cultural integrity, safety and competence. Thank you also to Ms Nguyen Van Chi for her expert medical translation of educational resources on NS from English into Vietnamese, and Dr Yen Thanh Mac (CLAN's Community Development Officer) for her invaluable efforts translating and transcribing over 400 parent surveys from Vietnamese into English, as well as assisting CLAN's team with a broad range of other activities to support the NS Community of Vietnam. We could not have done it without your help Yen Thanh – thank you for being such an invaluable member of CLAN's team for so many years!

My profound thanks are also extended to the Directors, health professionals and NS Club Executives at each of the three children's hospitals in Vietnam participating in this research project. Thank you most particularly to:

- The late Prof. Le Thanh Hai (immediate past Director), Dr Do Bich Hanh and Dr Nguyen Thu Huong (Senior Paediatric Nephrologists) and Mr Hoang Quoc Nam (Chairman of the NS Club) of the Vietnam National Children's Hospital (referred to hereafter in this thesis by its previous name, the National Hospital of Pediatrics (NHP)) and Prof. Tran Dinh Long (Head of Pediatric Nephrology and Urology Society in Hanoi)

- Dr Tang Chi Thuong (Director), Dr Huynh Thoai Loan (Senior Paediatric Endocrinologist) and Dr Thi Thanh Binh (Paediatric Nephrologist and Interviewer) of Children's Hospital 1 in Ho Chi Minh City (HCMC) and
- Dr Ha Manh Tuan (Director), Dr Tran Thi Mong Hiep and Dr Hoang Thi Diem Thuy (Senior Paediatric Endocrinologists) and Dr Huynh Thi Vu Quynh (Paediatric Nephrologist and Interviewer) of Children's Hospital 2 in HCMC.

Thank you to these many hospital authorities and health professionals who guided the transition of this research project from Congenital Adrenal Hyperplasia (CAH) to NS in response to local need and provided timely advice regarding the necessary steps that had to be taken to secure the appropriate permissions and approvals at all stages. The dedication and commitment of the staff at all three hospitals to the health and wellbeing of the children they care for was unwavering, and the collective passion of everyone involved to improve health outcomes for the NS Community of Vietnam was integral to every achievement. I learned so much from all of these amazing health professionals, and thank them so much for their patience, generosity and invaluable contributions.

To the many members, volunteers, donors and supporters of CLAN I also extend my most heartfelt thanks. This research would not have been possible without CLAN – be it the five pillars and strategic framework for action that guided CLAN's work; the financial resources that funded all initiatives or the many hands that made light work. On that note, I would particularly like to thank Catherine Cole (Vice President of CLAN) and the late Stephen McClure (Honorary Member of CLAN) for their tireless efforts championing the 45km Jervis Bay walk in 2011 to raise funds for the benefit of the NS Community of Vietnam. Beyond that single event, however, I must also acknowledge the pivotal and long-standing role that Cath has played in the life of CLAN since she first joined in 2007. Cath's unwavering support, compassion, wisdom, expertise and generosity of spirit has made it possible to keep CLAN moving forward these many years. It has been quite the adventure guiding CLAN through the waters of international endeavour, and it would not have been possible without Cath by my side every step of the way. Thank you Cath for always encouraging me to keep going with this thesis and believing anything and everything is possible.

On any journey there are inevitably special people you meet along the way who play a unique role, guiding and encouraging you when you need it most, to help you stay the course. My special thanks go to Sir George Alleyne who committed to being "the tick" under my skin, quietly but steadily reminding me of my promise to complete this thesis. Your leadership in the Non-Communicable Disease (NCD) world has been inspirational, Sir George, and I thank you for being the first to acknowledge the importance of an NCD Child movement on a teleconference call way back in 2010. In many ways Nephrotic Syndrome was perhaps one of the many starfish you warned me about, but I hope you approve of this thesis. Sincere thanks also to Prof. Alicia Jenkins and Eileen Clark for your review of the thesis and close attention to detail that helped refine the finished product. Your capacity to review information rapidly and provide strategic advice is humbling and greatly appreciated. My huge thanks and love also to Jo Ragen, a powerful companion in thesis land these many years. You are an indomitable champion of community development, Jo, and I am grateful to have learned so much from you. Thank you for the sprinkles, pomadoros, solidarity and laughs. It will be fun to reflect and reminisce together once we are both on the other side!

At the end of the day though, it is to my family that I owe the greatest thanks. Their collective generosity, giving me the freedom to follow this dream and dedicate untold hours to this endeavour can never be repaid. Countless hours have gone into this research project, and I am indebted to my family for supporting me so cheerfully at every stage. From my father-in-law and mother babysitting our young children whilst I travelled; to my father, sister, son and mother-in-law assisting with the administrative activities of CLAN; to my incredible husband David not just encouraging me endlessly that it was all possible, but generously giving me the time and space needed to sit at a computer hour on hour, week on week, month on month, until it was done. It took a clan to make this thesis possible, and I thank my beloved family for allowing me to follow the CLAN star for so many years.

And finally… to the children and families living with NS in Vietnam and beyond. Thank you for the opportunity to partner with you all. It is my sincerest hope that life is better now than it used to be for children living with NS in Vietnam. No doubt there is still so much more to be done, and it is my hope that many others join our collective efforts to drive change. As one interviewer reflected, after an hour speaking with one family in 2011:

> *"They are hard-working, but they have too many difficulties. Even though they are sad and scared of losing their kid, they somehow have learned to adapt. Possibly good mental recovery. The child is very weak, the mother and child hold hands from the start of the interview. They are sad but strong and show their courage. They seemed to be trying to overcome the challenge."*

May we all be inspired by your bravery, courage, love and passion for your children to work collectively so that together we #LeaveNoChildBehind and that one day #EveryChild living with NS and other chronic health conditions might enjoy the highest quality of life possible.

Children and families gather at the inaugural Nephrotic Syndrome Club Meeting at the National Hospital of Pediatrics in Hanoi, Vietnam on 9 February 2012

DEDICATION

This thesis is dedicated to the late, great Prof. Le Thanh Hai, Director of the Vietnam National Children's Hospital, who sadly passed away unexpectedly on 31 January 2021 in Hanoi.

Prof. Hai had a deep passion for the children of Vietnam and was open to innovative opportunities to improve their health and wellbeing.

Thank you, Prof. Hai, for the opportunity to work with your staff and the Nephrotic Syndrome Community of Vietnam. It was a privilege and honour to have met you.

Australian High Commissioner Hugh Borrowman and Prof. Le Thanh Hai were the distinguished guests and opening speakers at a Nephrotic Syndrome Club Meeting in Hanoi, Vietnam on 19 May 2016.

FUNDING SOURCES

The researcher acknowledges the following funding sources which supported the researcher and the project work itself:

1) **Flinders University small grants scheme for DrPH students (AUD $5,000)**

These funds were used by the researcher to support costs associated with:

- Printing – of survey instruments
- Translations – from English to Vietnamese and from Vietnamese to English, by suitably qualified and experienced Vietnamese translators approved by the participating hospitals. Materials included, but were not limited to, survey instruments, informational and educational materials for families, Powerpoint presentations to community members and health professionals
- Consultation fees – paid at agreed rates to participating interviewers and cultural brokers
- Software packages – to assist with data management

2) **CLAN Fundraising efforts (estimated at AUD $33,445)**

A 45km walk around Jervis Bay in October 2011 held by CLAN [1, 2] raised funds that were used to cover all costs associated with the conduct of NS Club Meetings in Vietnam for this project, and included:

- Translation and printing of detailed booklets and other educational resources on NS that were given free of charge to families and their treating health professionals
- Stipends – given to families of children living with NS in Vietnam to cover the cost of travel, lost income and food
- Venue hire, entertainment, food and water for families
- Video development – to assist with education and advocacy
- Urinary dipsticks – given free to all families to assist with education and awareness

3) **Prize money of $500 from IPNA for best oral presentation**

This money was used to fund the travel of Dr Nguyen Thu Huong to Shanghai, China to give an oral presentation of the abstract titled *"A community development approach to maximizing quality of life for children and families living with Nephrotic Syndrome in Vietnam"* at the IPNA International Conference in September 2013 [3].

4) **Self-funding and in-kind donations**

The researcher and many other volunteers and CLAN members covered the cost of their own travel, accommodation and discretionary spending whilst travelling to Vietnam in support of this project and other activities for the NS Community of Vietnam. The researcher extends her sincere thanks to all for their generous contributions, with especial mention going to Dr Elisabeth Hodson (who travelled to Vietnam eight times between 2010 and 2015 to support the NS Community) and Prof. Allison Tong (from the Centre for Kidney Research, Sydney Children's Hospital Network); Dr Fiona Mackie and Dr Amelia Le Page (members of ANZPNA, the Australia New Zealand Paediatric Nephrology Association); and Mr Henry Brehm, Dr Rick Kaskel, Dr Luan Truong, Ms Azadeh Issapour and Mr David Cisewski (representing NephCure).

PUBLICATIONS RELATED TO THE THESIS

1) Publications and presentations directly related to the thesis:

Armstrong Kate, Nguyen Thanh Liem, Nguyen Thu Huong, Tran Thi Mong Hiep, Huynh Thoai Loan, Le Van Hao, Hodson Elisabeth, and Tong Allison. *Think BIG! The power of a community development approach to population-wide change for children living with Nephrotic Syndrome in Vietnam.* in *Inaugural NCD Child Conference;* 19–20 March. 2012. Oakland, CA, USA.

Verity, W., *Giving their all*. 2012: Wollongong, N.S.W. p. 10.

Armstrong KL, **Nguyen Huong Thu,** Nguyen Liem Thanh, Le Van Hao, Thoai Loan Huynh, T. Binh, Hoang Thuy Thi Diem, Mac Yen Thanh, Tong Allison, and Hodson Elisabeth. *Understanding the challenges facing children and families living with Nephrotic Syndrome in Vietnam: A survey of families. Poster presentation at the International Pediatric Nephrology Association (IPNA) Conference;* Shanghai, China; 1 September, in *In Pediatric Nephrology*. 2013. Springer: New York, NY, USA.

Armstrong, K.L., **H.T. Nguyen**, L.T. Nguyen, H. Le Van, L.H. Thoai, B. Thanh, T.T.D. Hoang, Y.T. Mac, A. Tong, and E. Hodson. *A community development approach to maximizing quality of life for children and families living with Nephrotic Syndrome in Vietnam. Oral presentation at the Internationa Pediatric Nephrology Association (IPNA) Conference; Shanghai, China; 1 September (awarded prize for best oral presentation)* in *Pediatric Nephrology*. 2013. Springer, New York, NY, USA.

Armstrong K, **Nguyen HT**, Thuy HTD, Loan HT, Nguyen CD, Le Page A, Mackie F, and Hodson E. *Key recommendations from a community development approach to Nephrotic Syndrome in Vietnam: opportunities to redress inequities at a regional and international level. Poster presentation.* In *International Pediatric Nephrology Association (IPNA) Conference;*. 2016.

Presentations back to the NS Community of Vietnam on research findings and progress:

- **Armstrong K.L.,** *Results of November 2011 Nephrotic Syndrome Club Surveys*. Oral presentation to NS Club at Children's Hospital 1, HCMC, 26 February 2013.
- **Armstrong K.L.,** *Results of November 2011 Nephrotic Syndrome Club Surveys.* Oral presentation to NS Club at Children's Hospital 2, HCMC, 27 February 2013.
- **Armstrong K.L.,** *Results of February 2012 Nephrotic Syndrome Club Surveys*. Oral presentation to NS Club at National Hospital of Pediatrics, Hanoi, 28 February 2013.
- **Armstrong K.L.,** *Opening address*. Thai Binh Pediatric Hospital's NS Club Meeting, Thai Binh, Vietnam on 23 June 2014
- **Armstrong K.L.,** *Opening address.* NS Club Meeting at Hue Central Hospital, 18 May 2016.
- **Armstrong K.L.,** *The Hanoi Nephrotic Syndrome Community grows stronger!* Oral presentation, NS Club Meeting at NHP, Hanoi on 19 May 2016.

2) List of other unrelated publications by the researcher during the tenure of candidature:

Warne G, **Armstrong K**, Faunce TA, Wilcken BM, Boneh A, Geelhoed E, and Craig M., *The case for newborn screening for congenital adrenal hyperplasia in Australia.* MJA, 2010. **192**: p. 107.

NCD Alliance, *NCD Alliance calls for Inclusion of Children in NCD outcomes. Available online at https://ncdalliance.org/sites/default/files/NCD%20Alliance%20%20media%20release%20Children%20and%20NCDs%2024%2006%202011-final.pdf*. 24 June 2011: Geneva. p. 2. (**Armstrong K.L.** Chair, NCD Child)

NCD Alliance, *A Focus on Children and Non-Communicable Diseases (NCDs): Remembering our future at the UN Summit on NCDs, September 2011.*, Child focused working group of the NCD Alliance (**Armstrong K.L.** Chair, NCD Child), Editor. 2011: Australia.

NCD Child (**Armstrong K.L.** Chair, NCD Child), *Working Well! Safe-guarding adolescent and youth livelihood in the face of NCDs and their risk factors. Policy briefing paper prepared for the 2012 ECOSOC Ministerial Roundtable, co-organised by UNICEF and PAHO.*

Quynh TV Huynh, Thuy H. T. D., **Armstrong KL**, and Craig ME, Effectiveness of diabetes and congenital adrenal hyperplasia meeting clubs. *International Journal of Pediatric Endocrinology*, 2013. **2013** (Suppl 1): p. P134-P134.

Mitchelhill I., **Armstrong K.,** Craig M., Dung V.C., Thao B.P., Khanh N.N., T.B. Ngoc, T.T.D. Hoang, H. Quynh, D.T.P. Tran, et al., Evaluation of parental knowledge after establishing CAH clubs in Vietnam & Indonesia. *International Journal of Pediatric Endocrinology*, 2015. **2015**(Suppl 1): p. P53-P53.

Finlay SM and **Armstrong KL**, Indigenous languages must play a role in tackling noncommunicable diseases. *Published in the 2019 BMJ collection "Solutions for non-communicable disease prevention and control".* Available online: https://www.bmj.com/NCD-solutions; accessed on 30 August 2020.

Armstrong, K., A. Benedict Yap, S. Chan-Cua, M.E. Craig, C. Cole, V. Chi Dung, J. Hansen, M. Ibrahim, H. Nadeem, A. Pulungan, et al., We all have a role to play: Redressing inequities for children living with CAH and other chronic health conditions of childhood in resource-poor settings. *International Journal of Neonatal Screening,* 2020. **6(4), 76**.

3) List of unrelated presentations by the researcher during the tenure of candidacy:

Armstrong K.L., *Grassroots Collaborations: A means of realising the rights to health for children living with chronic health conditions in resource poor countries. An act of justice, not charity. Oral Presentation*, in *International Conference on Realising the Rights to Health and Development for All*. 2009, Conference report available at https://uscglobalhealth.files.wordpress.com/2015/07/final_conference-_report_english.pdf (Accessed on 30 August 2020). Published by the UNSW Initaitve for Health and Human Rights and the Central Commission for Popularization and Education of the Communist Part of Vietnam, and the Vietnamese Institute for Human Rights: Hanoi, Vietnam.

NCD Child (represented by **Armstrong K.L.**). *Panel discussion: Don't forget our future! Global approaches to NCDs and children* at the *Global Health Council Conference: Securing a Healthier Future in a Changing World*; 13-17 June 2011. Washington, DC.

CLAN (Caring & Living As Neighbours) statement by **Armstrong K.L.** at the United Nations Civil Society Consultation on Non-Communicable Diseases, 5 July 2011 (ahead of the inaugural UN High Level Meeting on NCDs held in New York in September 2011).

Armstrong K.L., *A life-course approach: Advocacy efforts bridging the gaps in the NCD discourse for children and adolescents.* Developmental Origins of Health and Disease (DoHAD) Conference, Singapore, 19 November 2013.

Armstrong K.L., *Working together so we #LeaveNoChildBehind*, in *proceedings of the 9th Biennial Scientific Meeting of APPES (Asia Pacific Pediatric Endocrinology Society)*. 17-20 November, 2016: Tokyo, Japan.

Utari A, Ediati A, Dhaliwal R, Freeman J, and Armstrong K, *Girl power! How a novel booklet developed to provide psychological support for teenage girls living with CAH in Indonesia is helping to redress health inequities regionally* in *Poster presentation (P02.18) at the November 2018 APPES (Asia Pacific Pediatric Endocrinology Society) Conference; Chiang Mai, Thailand*.

Armstrong K.L., Panellist, WHO Global Meeting on NCDs and Mental Health, Muscat, Oman, 9-12 December 2019.

THESIS ABSTRACT

Background

In 2008 and 2009, publications by leading paediatric nephrology staff from two of the largest children's hospitals in Vietnam [4, 5] identified Nephrotic Syndrome (NS) as a significant public health concern in Vietnam. Inequitable, preventable and premature morbidity and mortality were attributed to a range of challenges, including: late referrals from and delayed diagnoses within the primary care setting; financial burdens on families; unaffordable access to essential medicines; loss to follow-up; the absence of a renal registry and accurate data; workforce capacity constraints; and limited facilities for investigation and renal replacement therapy (such as dialysis or kidney transplantation).

Since 2004 the researcher had collaborated with paediatric nephrologists and endocrinologists in Vietnam through the work of Australian NGO CLAN (Caring & Living As Neighbours) to drive large-scale, sustainable change for the community of children living with Congenital Adrenal Hyperplasia (CAH). In 2010 the researcher was invited to focus this doctoral thesis on similar action to benefit the NS Community of Vietnam. Following consultation with colleagues in Vietnam and Australia, it was agreed this research project would focus on strengthening understanding of the felt needs of the NS Community of Vietnam, with a parallel commitment to critical action in real time to improve health outcomes and redress inequities. The NICE Health Needs Assessment (HNA) framework [6] was determined the most appropriate vehicle for translating knowledge to critical action as a priority.

Method

This HNA was conducted in five stages. **Stage One** ("Getting started" – Study One) used a Participatory Action Research (PAR) approach to establish governance processes and develop the evidence base, information gathering tools and other resources needed to successfully conduct the HNA. **Stage Two** ("Identifying Health Priorities" – Study Two) used a mixed methods approach to consult with a range of stakeholders (using interviews and surveys) to better understand the challenges and burdens facing children and families, and identify practical recommendations for change. **Stage Three** ("Assess Priorities for Action") reviewed the evidence base collated in Studies One and Two, reflected on the processes and findings to date and proposed a range of critical actions that might be taken to redress inequities and improve health outcomes for the NS Community of Vietnam. **Stage Four** ("Planning for Change") captured the broad range of collaborative activities that were implemented in real time throughout this HNA, as informed by CLAN's strategic framework for action, and **Stage Five** ("Moving On / Project Review") considered the extent to which the actions taken addressed the priorities identified throughout the HNA consultation process.

Results

Three PAR cycles were used in Study One to facilitate establishment of strong governance processes and commence development of a CHEAR (Child Health Equity Action Resource)

Toolkit, which incorporates a series of information gathering tools that were successfully trialled in pilot interviews ahead of their formal implementation in Study Two.

In Studies One and Two, quantitative and qualitative data were collected using the novel information gathering tools between August 2011 and May 2012 at the three largest children's hospitals in Vietnam. There were 426 parent surveys, 45 semi-structured parent interviews and 45 health professional surveys completed during this time. Families identified financial burdens; the chronic, relapsing nature of NS; lack of knowledge about NS; access to quality care; and the psycho-social burden of NS as amongst their greatest challenges. Priorities and recommendations for change proposed by families were consistently reported back to health professionals and other government and international stakeholders in a timely manner and their insights informed all actions. Key recommendations from families included the need for relief from financial burdens; optimisation of medical management; helping families learn more about NS; provision of support for the most vulnerable families; strengthening health systems to support families; and other NS specific interventions. Health professionals largely echoed the families' priorities but also provided insights into health systems changes and professional development opportunities for change.

In the final two stages of the HNA, the processes used to translate knowledge to action in real time were analysed. CLAN's strategic framework for action was determined effective in pre-emptively identifying critical actions capable of improving health outcomes and redressing inequities for children living with NS in Vietnam, and aligned well with final recommendations emerging from the consultation conducted with families and other stakeholders throughout the HNA. CLAN's Action Plan for NS in Vietnam facilitated a transparent and collaborative approach to the allocation of roles and responsibilities with regards the rollout of critical action in real time, with a clear and strategic focus provided by CLAN's five pillars. Affordable access to medicines (Pillar One) was unexpectedly addressed in August 2011 when the Vietnamese government included all drugs needed to manage NS in the national insurance scheme. Other priorities that were actioned in accordance with the pillars included: translation of educational resources into Vietnamese language; training of health professionals in the management of NS; empowerment of families to conduct urinalysis at home; financial support for as many families as possible to attend NS Club Meetings for encouragement, networking and education; and targeted communication to address widespread myths and misinformation. Clear communication amongst all stakeholders using the CLAN Action Plan minimised duplication, strengthened communication, allowed for rapid sharing of achievements and aided early identification of potential risks and barriers.

Key findings to emerge from this research project, reflections on strengths and limitations, and recommendations for future directions are presented in Chapter 6. The CHEAR Toolkit is presented in Appendix One, and offers a sample of the many tools, resources and products developed throughout the HNA (including final versions of the information gathering templates that were used), with a view to minimising the need for others to reinvent the wheel.

Conclusion

By *focusing this HNA on the felt needs of the NS Community of Vietnam* this research project offered a new lens through which to view the complex array of challenges and burdens facing children and families living with NS in Vietnam. Insights from health professionals most intimately involved in caring for children and families living with NS were critical to the success of the project.

The importance of *partnerships, teamwork and multisectoral collaborative action* were reinforced by *CLAN's strategic framework for action* and the researcher at every step of the project. The unexpected and most welcome legislative change by the Vietnamese government in August 2011, to ensure all medicines needed by the NS Community of Vietnam were included in the national insurance scheme, was a radical game changer and allowed for the redirection of modest resources to initiatives beyond advocating for access to medicines.

Project success has already been demonstrated by the *translation of learnings from urban to regional settings beyond the life of the research project*. The high-level government and health system support for the research project and its findings contributed to the large-scale, sustainable changes that were achieved. Within a few years, anecdotal reports from health professionals, responses from families at subsequent NS Club Meetings and the expressed reality of quieter renal departments all suggested rapid and dramatic changes were underway for the NS Community of Vietnam [7]. Whilst formal evaluation of the outcomes of the HNA were beyond the scope of this project, more recent publications [3, 8-11] suggest relapse and mortality rates have drastically improved – even for children diagnosed with the more severe steroid-resistant forms of NS in Vietnam.

This HNA offers significant findings that should *inspire and inform future action to benefit children living with chronic health conditions in vulnerable circumstances*. Change is possible when we all work together; it is not "all too hard" and critical action is warranted. Successful translation of CLAN's strategic framework from CAH, diabetes and autism to NS speaks to the potential we all have to facilitate change for and with other NCD Communities into the future. It is imperative that we identify and act immediately to *protect, promote and prioritise the rights of children living in the most vulnerable circumstances to life and health*. This research project identified a range of determinants associated with survival when a child is diagnosed with NS in Vietnam, and there are implications from these findings that can and should be translated to other chronic conditions of childhood and other to settings.

In closing, the researcher would highlight the *CHECC (Child Health Equity Check Count) Scorecard* as an innovative tool emerging from this doctoral thesis. The CHECC tool has the potential to prompt all health professionals at the time of diagnosing a child with a chronic health condition to consider the range of factors identified in this HNA (be it from the literature or data presented herein) associated with survival. The researcher believes this tool warrants further use and research, as it offers a strategic approach to the rapid and scalable identification of children who are most at risk of premature and preventable death.

ACRONYMS AND ABBREVIATIONS

ACCHS	Aboriginal Community Controlled Health Service
AH&MRC	Aboriginal Health and Medical Research Council
AIDS	Acquired Immunodeficiency Syndrome
AFPHM	Australian Faculty of Public Health Medicine
ANZPNA	Australia New Zealand Paediatric Nephrology Association
APPES	Asia Pacific Pediatric Endocrinology Society
ASD	Autism Spectrum Disorders
AUD	Australian Dollar
CAH	Congenital Adrenal Hyperplasia
CCM	Chronic Care Model
CFWG	Child Focused Working Group
CH1	Children’s Hospital One
CH2	Children’s Hospital Two
CHEAR	Child Health Equity Action Resources
CHECC	Child Health Equity Count Check
CHW	Children’s Hospital at Westmead
CKD	Chronic Kidney Disease
CLAN	Caring & Living As Neighbours
CQI	Continuous Quality Improvement
DM	Diabetes Mellitus
DPI	Department of Public Information
DrPH	Doctorate of Public Health
EML	Essential Medicines List
ESKD	End Stage Kidney Disease
FSGS	Focal Segmental Glomerulosclerosis
HCFP	Health Care Fund for the Poor
HCMC	Ho Chi Minh City
HCP	Health Care Professional
HIC	High-Income Country
HIV	Human Immunodeficiency Virus
HLM	High Level Meeting
HNA	Health Needs Assessment
ICCC	Innovative Care for Chronic Conditions
IMCI	Integrated Management of Childhood Illness
IPNA	International Pediatric Nephrology Association
KTA	Knowledge To Action
LIC	Low-Income Country
LMIC	Low-Middle Income Country
LOS	Length Of Stay
MCNS	Minimal Change Nephrotic Syndrome
MDGs	Millennium Development Goals
MOH	Ministry of Health
MPH	Master of Public Health

NCD	Non-Communicable Disease
NGO	Non-Government Organisation
NICE	National Institute of Clinical Excellence
NHP	National Hospital of Pediatrics
NS	Nephrotic Syndrome
NSW	New South Wales
OI	Osteogenesis Imperfecta
OPD	Outpatient Department
PAR	Participatory Action Research
PHP	Public Health Physician
RAPIA	Rapid Assessment Protocol of Insulin Access
RCH	Royal Children’s Hospital (Melbourne)
RHD	Rheumatic Heart Disease
SDG	Sustainable Development Goal
SDOH	Social Determinants of Health
SLE	Systemic Lupus Erythematosus
SRNS	Steroid Resistant Nephrotic Syndrome
SSNS	Steroid Sensitive Nephrotic Syndrome
TB	Tuberculosis
T1d	Type 1 diabetes
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children’s Fund
USA	United States of America
VND	Vietnam Dong
WHO	World Health Organization

CHAPTER 1 - INTRODUCTION

1.1 Background to the study

This doctoral research was designed to promote a better understanding of the challenges and burdens facing children and families living with Nephrotic Syndrome (NS) in Vietnam and provide realistic recommendations for multisectoral action to optimise quality of life for these children (and their families). Wherever possible, the aim was to facilitate and support action in real time to redress inequities and improve health outcomes for children living with NS. In Vietnam, not just report on research conducted for its own the sake. The window of opportunity for affecting the lives of children is brief, and the researcher was committed to implementing key learning in real time wherever possible to benefit the NS Community of Vietnam.

1.1.1 What is Nephrotic Syndrome (NS)?

Nephrotic Syndrome (NS) is one of the most common causes of Chronic Kidney Disease (CKD) in childhood [12]. Damage to the microscopic filtering apparatus of the kidney (the glomerulus) results in protein leaking from the bloodstream into the urine (proteinuria) (Figure 1). Loss of protein in the blood (hypoalbuminaemia) results in generalised swelling (oedema), most usually around the face and eyes, lower legs and scrotum (in boys). Swelling is the most usual reason children affected by NS are brought to the doctor at their initial presentation [13, 14].

Figure 1 – Representation of microscopic damage to kidney glomeruli in Nephrotic Syndrome resulting in proteinuria [15] – redacted for copyright

With access to quality care and essential medicines, more than 90% of children diagnosed with NS have an excellent prognosis and high likelihood of entering adulthood with normal kidney function. Boys are more likely to be affected than girls, and the median age of the most common type of NS (Minimal Change NS) is 4 years [14]. Ethnic disparities in the burden of NS have been noted, with children from South Asian and African backgrounds experiencing higher incidence rates than European children, whereas children from South Asian and Southeast Asian countries have better health outcomes, including more remissions and fewer relapses than children of European backgrounds [16, 17]. These differences are relevant in the context of understanding the underlying aetiology, with genetic causes less relevant in NS that responds to steroid therapy, and environmental triggers (such as respiratory infections) more relevant in the case of children living in resource-poor circumstances [17].

Diagnostic criteria for NS include proteinuria (with 3–4+ protein on dipstick urinalysis, and quantification achieved through urine protein: creatinine ration [PCR], albumin: creatinine ratio [ACR] or 24 hour urine collection), hypoalbuminaemia (quantified by measuring serum albumin) and oedema [18]. Once a child is diagnosed with NS, referral to a nephrologist is recommended and the NS is treated primarily with immunosuppressing corticosteroid tablets for a period of weeks (prescribed according to evidence-based guidelines and protocols), where after remission with loss of proteinuria and oedema will be achieved in most cases. Kidney biopsies are generally indicated where there has been no response to steroid therapy at 6 weeks [19]. Whilst 80–90% of children who are diagnosed with NS achieve remission with steroid therapy and go on to have steroid sensitive NS (SSNS) [20], the majority of children with NS (80%) will relapse at some point. These relapses are often triggered by infections, but in some cases there will be no apparent cause. Quality of life measures are improved with fewer relapses, complete proteinuria remission, reduction in symptoms and shorter disease duration [21].

A subset of patients (approximately half of the 80% of children who have a relapsing course) experience frequent, relapsing SSNS, and a smaller minority (the remaining 10–20% of all children with NS who continue to have proteinuria after four weeks of steroid therapy) are considered to have steroid-resistant forms of NS (SRNS). The children in this latter category have a poor prognosis, with 50% of children with SRNS developing End Stage Kidney Disease (ESKD) within 15 years [22]. These children may benefit from non-corticosteroid immunosuppressive medications that can promote remission and reduce the dose of steroids required [20]. These second line medications include alkylating agents (such as cyclophosphamide), calcineurin inhibitors (such as cyclosporin), levamisole, mycophenolate mofetil and rituximab, all of which have significant side effects that need frequent monitoring [2, 3, 6] and are associated with costs of administration (such as a day stay visit). Children with SRNS must attend clinics regularly and may have significant school absences and disruption of normal activities during relapses.

More information on NS is provided in section 1.1.3 b.

1.1.2 An introduction to the researcher's journey

As with any doctorate, there is a story behind the topic selection process, and the author (hereafter referred to in the first person) will take this opportunity to introduce the reader to the series of events and decisions that led to this dissertation focusing on NS in Vietnam.

a) Rationale for a doctorate

The decision to undertake a Doctorate of Public Health (DrPH) was made in 2008 and reflected a desire to bring scientific rigour to the voluntary work I was undertaking as the President and Founder of CLAN (Caring & Living As Neighbours) [23]. CLAN is an Australian-based Non-Government Organisation (NGO) founded in 2004, incorporated in 2007 and committed to helping children living with chronic health conditions in low- and middle-income countries of the world to enjoy the highest quality of life possible.

Whilst CLAN's early focus was helping children living with Congenital Adrenal Hyperplasia (CAH) in Vietnam, by 2008 the organisation was responding to requests to expand our focus to include a range of conditions (initially Type 1 diabetes and then Autism Spectrum Disorders [ASD]) across a number of countries (including the Philippines, Indonesia and Pakistan). Invitations to speak to CLAN's novel strategic framework for action at conferences and symposiums were likewise increasing.

As a medical practitioner with a Master of Public Health (MPH) qualification, I found great satisfaction in my voluntary activities with CLAN. However, as the scope of the organisation's work grew, and donations and in-kind contributions increased, I became increasingly mindful of my professional, moral and ethical responsibility to expose CLAN's strategic framework for action to academic and public health scrutiny. Flinders University's strong commitment to the Social Determinants of Health (SDOH) through the work of Dr Fran Baum and the World Health Organization's Commission on the SDOH [24] were relevant to CLAN's comprehensive primary health care approach to redressing the inequities faced by children living with chronic health conditions in low- and middle-income countries (LMICs). The Flinders University Public Health Department's DrPH offered the academic rigour, ethos and structure I was seeking, and so I enrolled in the course and commenced the coursework component in 2008.

b) Rationale for an early focus on Congenital Adrenal Hyperplasia (CAH)

My initial plans were to focus the thesis component of the DrPH on CAH, the most common adrenal condition of childhood and the condition CLAN had been working on since 2004. CAH is an inherited, autosomal-recessive condition involving an enzyme deficiency within the adrenal glands (21-Hydroxylase in 90% of cases) that disrupts adrenal biosynthesis of two hormones (cortisol and aldosterone) essential for life [25]. Fortunately, cortisol and aldosterone can be replaced in tablet form, and treatment is inexpensive, effective and has been readily available in developed countries since the 1960s. With access to these essential medicines and quality healthcare, children with CAH can expect to enjoy a high quality of life and normal life expectancy.

Despite medical training and postgraduate study in child health, my first real exposure to CAH was a personal one. In 1999 our son was born, and his ongoing failure to thrive at three weeks of age was diagnosed as CAH, whereafter he was admitted to neonatal intensive care for stabilisation. Such a traumatic start to life for boys living with CAH in Australia was routine at the time (female babies with CAH are usually diagnosed early as a result of ambiguous genitalia, whereas male infants with CAH are harder to identify on clinical grounds alone), and it is disappointing to note that even in 2020 Australia still did not have universal newborn screening for CAH [26].

With support from our son's health professionals, we gradually grew in confidence managing his newly diagnosed chronic condition and were able to access all resources, essential medicines and support necessary to ensure he grew and developed to his full potential. By early 2004 our son had started school and was excelling in every respect. He was achieving academic, sporting, social and developmental milestones with ease.

In July 2004 I read stories in the Australian [27] and United States CAH Family Support Groups [28] newsletters about life for children living with CAH in Vietnam [29, 30]. The situation could not be more different to our own family's experiences. Children were dying of CAH and experiencing morbidity, disability, stigma, poverty and hardship on a scale that was incomprehensible when compared with our own experience of life with CAH in Australia. I wanted to understand more about the barriers to equity these children and families faced and do what I could to ensure children in Vietnam had the opportunity to enjoy their basic human rights to the highest quality of life possible – and ultimately, the same quality of life as that enjoyed by our own son.

The 2004 newsletter articles indicated access to affordable medicines was one of the most pressing burdens for families living with CAH in Vietnam, and this was confirmed in conversations with Professor Garry Warne, the author of one of the articles. Prof. Warne was a long-time supporter of the Australian CAH Support Group and a paediatric endocrinologist working at Royal Children's Hospital (RCH) in Melbourne and Director of RCH International, a philanthropic arm of the hospital at the time (since closed). RCH had a long-term relationship and partnership with the National Hospital of Pediatrics (NHP) in Hanoi, and Prof. Warne welcomed my offer to investigate possible solutions to improve access to medicines for the families of children living with CAH in Vietnam.

To the joy and surprise of us all, after (literally) just a few phone calls to two drug companies in Australia (Alphapharm – now Mylan [31] – and Bristol–Myers Squibb [32]), I secured generous donations of hydrocortisone and fludrocortisone tablets; enough, in fact, to treat all children living with CAH in Vietnam (at that time estimated to be just over 300 children across the country) for the next three years. This was clearly a wonderful outcome. However, it presented me with two moral challenges. The first challenge related to the apparent ease of this early success. The fact that it had been so easy to help so many children living with CAH in a LMIC to escape death was in some ways as troubling as it was rewarding…. If it was so easy, was there not a moral responsibility to do more to help other children also? Should I be satisfied with two weeks' work?

The second challenge answered the first in many ways. The availability of free drugs for all children living with CAH in Vietnam was fantastic, but it meant that someone would need to be responsible for ensuring their safe delivery over the next three years. It gradually became clear "that person" was going to be me. In choosing to embark on this journey, I determined that I wanted to make full use of public health knowledge that I had (at that point my MPH), and where possible, use the generous donations from Alphapharm and Bristol–Myers Squibb to drive long-term, sustainable change for the CAH community of Vietnam. In this way, I felt that I would make the most of any future involvement.

c) An introduction to CLAN (Caring & Living As Neighbours)

With growing acceptance of a longer-term personal commitment to help children living with CAH in Vietnam, there was increasing discomfort in re-telling my personal and family story at every introduction. I was also very keen to formalise processes and ensure total transparency and accountability for all donations received to date. As a result, in late 2004 my husband and I co-founded CLAN (initially an acronym for "CAH Living As Neighbours" and later changed to "Caring & Living As Neighbours" when CLAN's work expanded beyond CAH).

In 2005 I travelled with Prof. Warne to Vietnam for the first time to distribute donated drugs (we carried many suitcases and boxes over with us, having received special permission from the government to do so) and to conduct a survey of the CAH community attending a CAH Support Group meeting to be held at NHP in Hanoi (with ethics approvals from the relevant Committees in Australia and Vietnam). The questionnaire was translated into Vietnamese and included comprehensive questions about the situation, challenges and burdens facing families.

The survey was completed by 54 families (estimated to account for approximately 20% of the 290 children registered for management of CAH at NHP at the time) and survey responses were translated into English for analysis. In the interests of community development (and respecting clear emerging messages in the responses that families were keen for the international community to better understand their plight), the results were not only reported back to families and health professionals in Vietnam but also published in an international peer reviewed journal in 2006 [33]. Root cause analysis of the feedback from families using a But Why (also known as the "Five Whys") retroductive analysis [34] clearly identified five key actions and conditions considered necessary to help children living with CAH in Vietnam achieve the highest quality of life possible:

1. Affordable access to essential medicines and equipment
2. Education (of children, parents, health professionals, policy makers and national and international communities); research and advocacy
3. Optimal medical management
4. Strong family support groups
5. Financial independence and freedom from poverty

Such clear instruction from the CAH community of Vietnam provided a blueprint for action. The "five pillars" became central to the development of CLAN's strategic framework for action (Figure 2). Informed by a rights-based, person-centred, community development approach, CLAN's framework acknowledged the imperative of multisectoral collaborative action in achieving sustainable change and optimising quality of life for the CAH community of Vietnam.

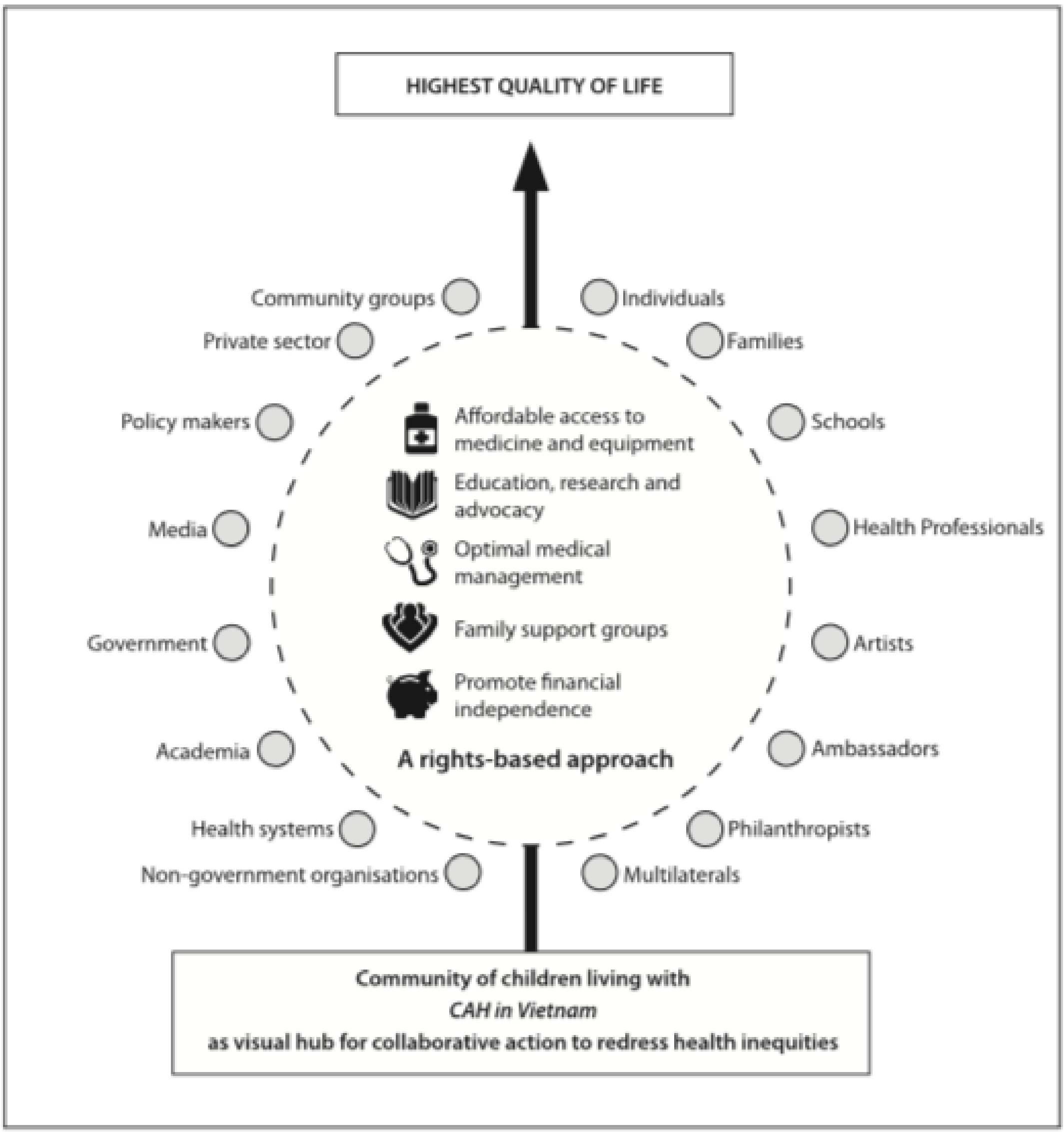


Figure 2 - CLAN's Strategic Framework for Action (as used to support the CAH Community of Vietnam)

A business plan for CAH in Vietnam was developed by CLAN (called the "*Plan for CAH CLAN*") using this novel strategic framework for action and was shared amongst a broad range of multisectoral stakeholders as a means of engaging partners and communicating a shared vision. In this way, progress on an array of innovative activities addressing the five pillars, all rapidly undertaken at the same time (achieved by working collaboratively with multiple partners), was able to be recorded, monitored and communicated to all involved.

In a relatively short period of time, key achievements for the CAH Community of Vietnam included donation and dissemination of free medicines to all families over a three-year period whilst sustainable local solutions were investigated; translation of educational resources into Vietnamese; training of health professionals; development of advocacy videos; introduction of routine use of growth charts; conduct of regular CAH Club meetings with educational sessions for families; engagement with international CAH communities and supporters; implementation of a national rapid assessment protocol investigating the barriers to access to medicines; and successful application to the World Health Organization (WHO) for inclusion of hydrocortisone and fludrocortisone tablets on the WHO Essential Medicines List for Children [35-38].

By 2008, the impact of CLAN's work with the CAH Community in Vietnam was significant. Doctors were reporting profound improvements in quality of life for the CAH Community, and it was becoming clear (anecdotally and with the rapid increase in prevalence) that the high mortality previously associated with CAH (as evidenced by the age distribution of children registered at NHP in 2005 for the management of CAH, where only 7% of those registered for care were aged over the age of 13 years - see Figure 3 [39]) was preventable.

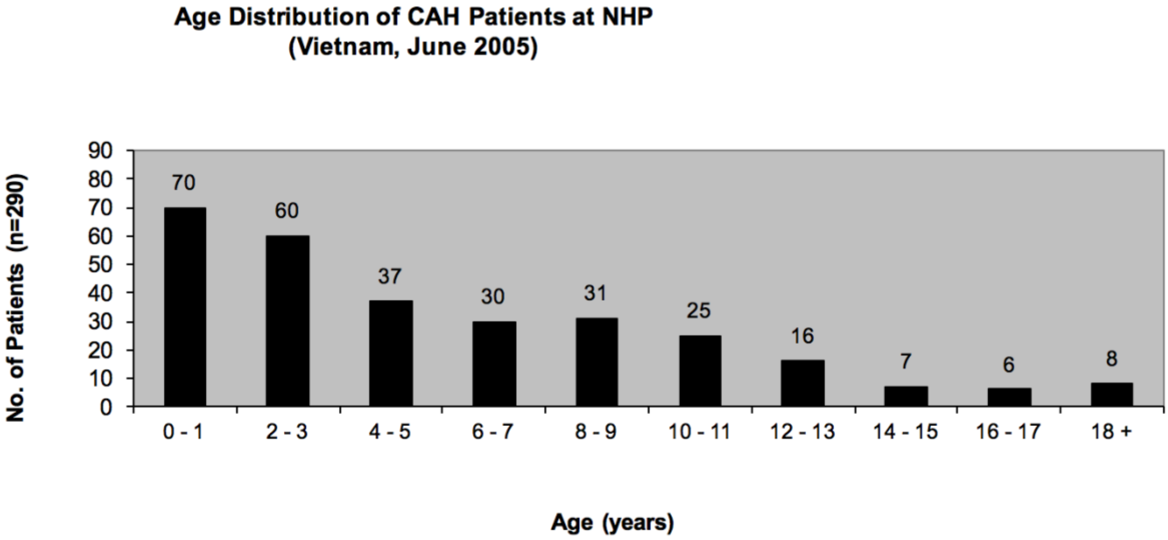


Figure 3 - Age distribution of children with CAH registered for care at National Hospital of Pediatrics (NHP), Hanoi in 2005

Not only was loss to follow-up and mortality reducing, but awareness was increasing, and incidence was also rising. As a result, patient numbers were growing steadily. By May 2014 there were 715 children receiving care for CAH at NHP [40]). As the age profile of the CAH Community shifted in line with improvements in survival, CLAN took steps to consult with young people living with CAH to understand their needs [41]. More broadly, Ministry of Health officials were responding with national and system-wide changes to support quality care. Registration of drugs in-country, introduction of newborn screening for CAH and improved availability of blood tests to assist with monitoring were specific examples.

d) Transferring learnings from CAH in Vietnam to other countries and chronic health conditions

Interestingly, the main way news spread about CLAN's work during these early years was word of mouth. Even before findings from further consultations with the CAH Community in

Vietnam were shared at the 2008 APPES (Asia Pacific Pediatric Endocrinology Society [42]) biennial Conference in South Korea [43], paediatric endocrinologists in the Asia Pacific region clearly had been communicating amongst themselves about the impact of CLAN's work on health outcomes and quality of life for the CAH community in Vietnam. Between 2004 and 2007 requests were received from (and responded in the affirmative to) paediatric endocrinologists from southern Vietnam (2004), the Philippines (2005), Indonesia (2006) and Pakistan (2007), all requesting CLAN's support for their CAH communities.

In 2007, health professionals in Vietnam approached CLAN and asked if we would work with them to translate our model from CAH to help children living with Type 1 diabetes. This was an unexpected request and one that was initially declined in recognition of the large number of international NGOs already working in the field of diabetes at the time. The doctors in Vietnam were very persistent with their requests however, and in July 2007 a Diabetes Support Group meeting was scheduled to be held in Hanoi a day after the annual CAH Club meeting that CLAN was attending, so that CLAN might attend both meetings and learn more from families about the plight of children living with diabetes in Vietnam [44].

The Diabetes Club meeting in Hanoi in 2007 was a desperately sad affair. Children blinded by years of poorly controlled diabetes moved aimlessly about the room, bumping into furniture. Young teenagers stood up requesting help to access insulin only to be told "Sorry, there's no help". CLAN returned to Australia extremely moved by the experience, and after confirming with Life For A Child (the largest international NGO working in the field of childhood diabetes) [45] that they could not assist in Vietnam currently due to capacity constraints, an executive decision was made by CLAN's committee to use what we had learned from our model with the CAH community to facilitate change for children living with diabetes in Vietnam.

By this stage the scale and duration of CLAN's activities made it necessary to formalise operations, and so began the process of establishing CLAN as an independent, not-for-profit NGO. CLAN was officially incorporated as CLAN (Caring & Living As Neighbours) in December 2007, and in 2008 the incoming Executive Committee of CLAN supported my decision to undertake a DrPH at Flinders University.

In 2009 CLAN was requested to again expand our efforts, this time to support work in the field of Autism Spectrum Disorders (ASD) in Vietnam. ASD had only recently been recognised by health professionals in Vietnam, and the health system was struggling to cope with the very large numbers of children presenting for assessment [46]. By this stage CLAN was also working in several countries across the region, supporting CAH and diabetes communities in Pakistan, and CAH communities in Indonesia and the Philippines.

e) Rationale for a shift from CAH to NS

Despite early expectations that this research project would focus on CAH, two key events in September 2010 influenced a subsequent shift in focus to better understanding the experiences of children and families affected by Nephrotic Syndrome in Vietnam.

i) The 63rd UNDPI/NGO Conference, Melbourne

At the start of September 2010 CLAN hosted a panel at the 63rd Annual Conference for the United Nations Department of Public Information for NGOs (UNDPI/NGO) in Melbourne, Australia. Titled *Advance Global Health: Achieve the MDGs*, this conference was the first United Nations (UN) conference held in Australia and represented a unique opportunity for small NGOs such as CLAN to participate in advocacy for children living with chronic conditions in LMICs from such a powerful platform. The most important outcomes of our involvement in this event were successful advocacy action resulting in the inclusion of children in the final conference Declaration [47] and networking with other NGOs and learning about the upcoming *UN High Level Meeting on Non-Communicable Diseases* (UNHLM on NCDs) planned for New York in September 2011.

As only the second health-specific HLM of the UN (the first being on HIV/AIDS in 2001), it was clear this Meeting was of enormous relevance to CLAN, given its focus on chronic health conditions. A preliminary reading of the early UNHLM Declaration draft in late 2010 confirmed for the researcher that children were not being considered in the context of future global efforts to prevent or manage NCDs. This was a potential disaster. A life-course approach is essential for the prevention of chronic health conditions of adulthood, with many behavioural risk factors relevant to children and adolescents, such unhealthy diet and alcohol misuse. Furthermore, many of the NCDs typically referred to as only affecting adults also affect children, for example cancer, diabetes, heart disease and asthma.

Concerned that the final Declaration might not include any mention of children, nor reference to a life-course approach to the prevention and management of NCDs, CLAN reached out to the NCD Alliance (a civil society alliance of the International Diabetes Federation, World Heart Federation, Union for International Cancer Control and The Union for TB and Lung Disease [48]) and highlighted the need to integrate children and young people within the global NCD health and development discourse. CLAN's experience with using a single strategic framework for action to promote better health outcomes across a range of NCDs (by this stage CAH, diabetes and autism) meant we were uniquely placed to appreciate the common challenges facing children and adolescents living with different NCDs and open to engaging with a range of partners to advocate as a single voice at an international level.

As a result of these early discussions with NCD Alliance, in January 2011 I was invited (as President of CLAN) to chair a newly formed Child-focused Working Group (CFWG) of the NCD Alliance and immediately committed our working group to an ambitious 10-month timeline to advocate for the inclusion of children and a life-course approach to NCDs in the final Declaration from the September 2011 UNHLM in New York. Over 23 civil society and multilateral organisations engaged in the activities of the Working Group, and initiatives included the development of briefing papers [49], presentations at events and social media activity highlighting the relevance of NCDs for children and young people. In July 2011 I was also invited to speak at the UN's Civil Society Hearing on NCDs on the work of CLAN [50, 51]. The advocacy efforts of the CFWG were ultimately successful, with the final resolution adopted by Member States at the inaugural HLM on NCDs in 2011 acknowledging new statements relating to children, young people and NCDs [52] (Appendix 4).

Increasingly, in my role as Chair of the CFWG of the NCD Alliance, and later as Inaugural Chair of NCD Child (the global movement founded by CLAN when NCD Alliance closed the

CFWG after the UNHLM on NCDs in September 2011) [53] I found myself in positions where it would not be appropriate to speak exclusively of CAH. As a relatively rare and little known NCD of childhood, the broader challenges facing children and young people living with NCDs in resource-poor settings needed an advocate willing to look beyond CAH. In this way, CAH remained at the heart of CLAN, but our outward messaging needed to be more inclusive in scope.

ii) Nephrotic Syndrome emerges as a priority for action

In email discussions, colleagues and executives at the three children's hospitals in Vietnam CLAN was working with had suggested a research project on CAH was appropriate and would proceed as expected. However, it became clear that we could not finalise arrangements online. I was asked to wait until my next visit to Vietnam so that we could have face-to-face meetings before any final approvals would be granted.

In late September 2010 I flew to Vietnam to attend the annual CAH and Diabetes Club meetings that CLAN was supporting and consult with key authorities and decision makers around the exact nature of my proposed doctoral dissertation. Paediatric endocrinologists at all three major children's hospitals in Vietnam (the National Hospital of Pediatrics in Hanoi; and Children's Hospitals 1 and 2 in Ho Chi Minh City) had indicated they were keen to collaborate on the research proposal relating to CAH that had been shared, but final approval had yet to be secured from hospital executives.

From early discussions with the hospital directors and staff it emerged that the real priority for them was not CAH and they requested a new focus on Nephrotic Syndrome (NS). Having experienced profound reductions in mortality and morbidity for both the CAH and diabetes Communities, health professionals in Vietnam were keen to focus on a condition that was placing great stress on their health system. Visits to the renal wards and discussions with local health professionals and families rapidly confirmed for me the situation for children living with NS in Vietnam was in fact quite dire, and any improvements to their situation would be a positive step.

Each of the three participating children's hospitals in Vietnam was providing care for large numbers of children who had been diagnosed with NS (with estimated cohorts of between 400–1,500 children *at each centre,* totally eclipsing the 40 children diagnosed with NS in the preceding three years at the largest Children's Hospital in Sydney). Outpatient and inpatient numbers were overwhelming hospital capacity and anecdotal reports of morbidity and mortality suggested enormous inequity compared with health outcomes for children with NS in Australia. Health professionals in Vietnam were concerned that families were experiencing disproportionately high emotional and financial hardship as a result of their children being diagnosed with NS, given it is a condition that should, in the majority (90%) of cases, be associated with a positive longer-term prognosis. In many cases in Vietnam, however, children with NS were dying and experiencing morbidity to an extent not reported in the literature from high-income countries. Doctors in Vietnam particularly noted and respected the work of one Australian paediatric nephrologist, Dr Elisabeth Hodson (of The Children's Hospital Westmead in Sydney), and asked me to connect with her on my return to Australia and see if she might be willing to work with CLAN and others on this research project.

Whilst CLAN had no previous experience with NS, as an organisation we were by this stage confident enough in our community development model and strategic framework for action to consider the request very seriously. On return to Australia, I sought out Dr Hodson and discussed the situation with her at length. She generously agreed to support me in my dual roles as researcher and President of CLAN, and work with our partners in Vietnam to develop and implement CLAN's model for NS. CLAN's executive also agreed to take on NS as our fourth chronic condition and committed the organisation to fundraising in support of critical action to benefit the NS Community of Vietnam.

There was acknowledgement that timelines would be tight. Work undertaken to date on the previously proposed CAH thesis (a literature review, ethics applications and research proposal) had to be rapidly revised given the new focus on NS, and expert advice and guidance on this was generously provided by Dr Hodson. Email correspondence with colleagues in Vietnam enabled discussions to progress smoothly and informed the development of an adapted research proposal and ethics application which was submitted to Flinders University's Ethics Committee in December 2010, ahead of a proposed visit to Vietnam in February 2011, at which time face-to-face meetings with hospital executives and health professionals would enable final submissions to be prepared for review by the appropriate Ethics Committees in Vietnam.

1.1.3 Background context to the research project

a) Acknowledging the broader context of child health in Vietnam

It is useful to describe some of the broader socio-economic and cultural determinants of health relevant to a thesis on child health in Vietnam. This section provides a snapshot of Vietnam at the time this research project commenced in 2010.

i) *Geography*

Vietnam occupies the easternmost part of the Indochinese peninsula of South East Asia, and is comprised of six regions and 96 provinces (Figure 4) [54]. The six regions are:

1) Northern Midlands and Mountains (14 Provinces)
2) Red River Delta (11 Provinces, including Hanoi)
3) North and South Central Coast (14 Provinces)
4) Central Highlands (5 Provinces)
5) Southeast (6 Provinces, including Ho Chi Minh City)
6) Mekong River Delta (13 Provinces)

Figure 4 - Map of Vietnam (Sourced from the 2009 Population and Housing Census of Vietnam [54]) – redacted for copyright

ii) National demographic profile

In 2009 the population of Vietnam was 85,790,000 persons, making it the thirteenth most populous country in the world, and the third most densely populated country in South East Asia (with 259 persons/km^2). Only two cities in Vietnam had a population over three million people: Hanoi City and Ho Chi Minh City.

Almost half (43%) of the population of Vietnam lives in the Red River and Mekong River Delta regions, where agriculture is enhanced by fertile lands. Indeed, the majority (70%) of persons live in rural settings, with 30% of the population living in urban areas (up from 24% in 1999). Rural population growth has been declining (0.4% per year versus 3.4% urban growth), with migration of the rural population to the urban areas a recognised trend.

The sex ratio in Vietnam is 98.1 males to every 100 females, a figure that has steadily been increasing since 1979 (when it was 94.2). There is evidence of an increased proportion of male children born since 2006, particularly in more urban, wealthy regions where medical services and equipment to support sex selection are more readily available and accessible, and this is cause for concern for future sex balance in Vietnam.

Vietnam is still a relatively young country, with 25% of the population aged 0–14 years of age (down from 33% in 1999). However, fertility rates are declining (down from 2.33 children in 1999 to 2.03 children in 2009) and life expectancy is increasing (life expectancy at birth was 72.8 years in 2009), so the population pyramid is shifting over time, with a steady increase in the proportion of the population aged 15–64 years (Figure 5). Infant mortality rates have continued to decrease in Vietnam (16 per 1000 live births in 2009, down from 44.4 per 1000 live births in 1999), although there are inequitably high levels (around 25 deaths per 1000 live births) still seen in the Northern Midlands, Mountains and Central Highlands. Approximately 7% of the population is now over 65 years of age.

Figure 5 - Vietnam Population Pyramid [54] – redacted for copyright

iii) Socio-economic determinants of health

Ethnicity

Kinh is the dominant ethnic group in Vietnam, accounting for 85% of the population. Ethnic minority groups comprise more than 50% of those living in poverty, and children from ethnic minority backgrounds are almost three times more likely to be poor than children from Kinh backgrounds and less likely to complete their education. Ethnic minority populations tend to live mostly in the Central Highlands and Northern Midlands and Mountains of Vietnam [54, 55].

Household size

Virtually all Vietnamese people aged 60 years and over have been married at some stage in their life (99.5% of men and 98% of women). Divorce rates are relatively low (1.8% persons in urban areas and 1.3% in rural areas divorced or separated) compared with widowhood (5.6% in urban areas; 6.8% in rural areas). The average household size was 3.8 persons (3.7 in urban areas and 3.9 in rural areas), with 72% of households nationally (76% in urban areas) having 4 or fewer family members.

Income and equity

Vietnam achieved middle-income country status in 2010, and the gross national income per capita in Vietnam was USD$890 in 2008 (up from $620 in 2005). The gross domestic product per person employed was $5,676. It was estimated that 21% of the population were living in poverty (less than $1.25 a day) [56]. In 2009 most families did not use a computer (86.5% total; 68.2% urban and 94.6% rural), and only half had a land-line telephone (54.3% total; 38.3% urban and 61.4% rural). Use of a motorcycle was fairly commonplace (72.3% total; 83.2% urban and 67.5% rural) and living standards were higher overall in urban areas [54].

Although poverty rates in 2009 (as determined using small area estimates of expenditure [57]) were around 14% (down from 58% in 1993), progress had not been achieved equitably. Women made up just under half (48%) of the workforce in Vietnam, and the majority of the workforce was based in the rural areas (73.1%). The majority (77%) of persons aged 15 years and older participated in the workforce, and participation rates were higher in rural areas (81% versus 67%). A small proportion of workers were engaged in professional roles (9%) [54].

Education

Education has been a success in Vietnam, with 100% of primary school aged children enrolled to attend school in 2009 (constant since 1989). Literacy rates are high at 94%, with gender and geographic disparities narrowing over time (currently 96% for males and 92% for females; 97% in urban areas and 92% in rural areas). Completion of school varies by location, and is generally higher in urban areas [54]:

- Never attended 5.1% (2.6% urban; 6.2% rural)
- Incomplete primary 22.7% (16.7% urban; 25.3% rural)
- Completed primary 27.6% (22.9% urban; 29.6% rural)
- Completed lower secondary 23.7% (20.4% urban; 25.1% rural)
- Completed upper secondary and higher 20.8% (37.4% urban; 13.8% rural)

Overall, 13.3% of people have technical / professional qualifications, and only 4.4% of people have university level higher education [54].

iv) Vietnam's Health System

As at 2008, Vietnam's health system had four administrative levels [58]:

- Central – 21 health facilities led by the Ministry of Health (for example National hospitals, Institutes, Medical Universities and Colleges)
- Provincial – 64 provincial departments of health (including Provincial hospitals, medical schools, district general hospitals and polyclinics)
- District – 622 district departments
- Commune level – 10,917 commune health centres (CHCs) which also oversee Village Health Workers.

Private health care provision was legalised in 1989 in Vietnam, and in a 2002 study private health care providers were found to account for 60% of all outpatient contacts in Vietnam, serving paediatric populations in particular [59]. Management of more complex conditions generally occurs at the higher levels of Vietnam's health system, and this (together with the movement of health professionals into the private healthcare sector) contributes to the overcrowding that is seen at central and provincial public hospitals and health centres [58].

Trust is another key consideration affecting use of health care, with evidence that health literacy and varying degrees of trust in local health professionals influence health-seeking behaviours of families caring for unwell children in Vietnam [60].

Health insurance

Utilisation of health care has also been linked to insurance status [61, 62]. Health insurance was introduced in 1992, but by 2010 only about 42% of the population had insurance [58]. Uptake of insurance has been associated with education and income [63]. Rates of hospital admission and length of stay in hospital are positively associated with health insurance status, particularly for the very poor and middle-income groups [64]. Over the years a series of changes to health insurance and funding have been made, with the aim of increasing access to health care for the poor.

The Health Care Fund for the Poor (HCFP) was established in 2002 to increase health services for the poor and marginalised [65]. This was administered by provincial health offices and beneficiaries were issued with a free health care card. By 2007, 18% of the country's population was covered by HCFP, however, because the program was funded by lower levels of government, funds were often stretched, and reimbursement was not always complete. In 2009 a new National Health Insurance Law was introduced, and HCFP was converted to the compulsory Social Health Insurance scheme (SHI), which entitled beneficiaries (the poor – identified by set criteria and confirmed by local authorities) to care funded by the central government.

In 2006 health insurance for all children under 6 years was launched in response to the revised Law on Care, Protection and Education for Children (2004), which noted "*Children* *under six years are entitled to primary health care and free medical examination and treatment at public medical establishments*". Whilst well-intentioned, shortfalls in the capacity of this scheme to cover all heath costs for eligible children have been acknowledged (for example, not all care is provided at central hospitals), and as a result newborn babies were issued health cards (given to parents on provision of proof of identity with the child's birth certificate) which entitled children to free care at public health care centres up to six years of age [65].

Child health inequities in Vietnam

There is consistent evidence of health inequities within Vietnam, with children from rural, poor and ethnic minority households more likely to have malnutrition (17.6%, 10.9% and 14.1%) and diarrhoea than their urban, non-poor and majority Kinh counterparts [66-69], as well as reduced immunisation coverage [70]. At the same time, a double burden of disease is emerging in Vietnam, with higher rates of childhood overweight and obesity seen in wealthier cohorts [71, 72].

Inequities associated with the sex of children in Vietnam have also been noted, with cultural norms that favour male children well documented [73]. Whilst sons are favoured traditionally, the evidence suggests preferences have become more pronounced in modern times with policies requiring parents to restrict their families to one or two children only, and widespread easy access to ultrasound facilities and legalised abortion [74]. Parents are more likely to take out health insurance for male children [63].

In studies looking at utilisation of health care for management of diarrhoeal illnesses, mothers from ethnic minority groups and those with lower educational levels were found to be less likely to seek medical advice or treatment for their children [75], and ethnic minority mothers expressed decreased satisfaction with medical services available. Targeted interventions and programs to meet the needs of, and increase uptake by, these groups of mothers have been recommended [76], with evidence that broadly focused initiatives often fail to reach those with the greatest need [77].

Vaccines offer significant opportunity for reducing the burden of infectious disease for children living with NS, preventing relapses and improving health outcomes. The Expanded Programme for Immunisation was introduced in 1981 and in 2010 vaccination rates sat at higher than 90%. Encouragingly, immunisation rates for measles (as an indicator tracking progress against Millennium Development Goals) in Vietnam sat at 92% in 2008 [56]. There has been evidence to suggest vaccination uptake is reduced in families where literacy and incomes are higher [78], so strong educational messaging needs to be a focus of initiatives to increase vaccination rates.

Uptake is also influenced by which vaccines are included in the national scheme. In 2010, pneumococcal, hepatitis B, varicella and H. influenzae vaccines were not included. Unfortunately, these exclusions did not reflect need. For example, relatively high rates of hepatitis B infection have been noted in Vietnam [79] among children as well as adults. In one 2003 study, current infection (HBsAg+) rates were calculated as 12.5% in infants, 18.4% in children, 20.5% in adolescents, and 18.8% in adults. Rates of current or previous infection (HBsAg+, anti-HBc+, or anti-HBs+) increased with age (infants = 19.6%, children = 36.4%, adolescents = 55.3%, adults = 79.2%). Rates of HBeAg (inactive HBV carrier state) among those who were HBsAg+ were infants = 85.1%; children = 88.1%, adolescents = 71.1%; and adults = 30.4%. Routine immunisation of infants has been strongly recommended to reduce this enormous burden associated with hepatitis B [80].

Support for children living with chronic health conditions

Approximately 20% of children in Vietnam have a mental health disorder, and 10% have a chronic physical health condition [81]. There has been growing recognition of the rights of children to health in Vietnam, with a number of policy initiatives designed to increase access to healthcare for the poorest children and reduce health care expenditure for families [65]. These included launch of the government's HCFP policy in 2002 [82].

Chronic health conditions are often associated with stigma and social isolation in Vietnam [83-85]. Serious health conditions and premature mortality have been viewed culturally as retribution for past transgressions, with negative outcomes deserved for those involved. As a result, fear of stigma and discrimination is known to affect reporting of children's deaths or sharing of information relating to health conditions. In rural areas particularly, parents often conceal aspects of their child's diagnosis or condition to avoid negative community perceptions [86].

Predictably, chronic conditions also have a negative impact on child and parental wellbeing [87]. Children with chronic health conditions in Vietnam are twice as likely to experience a mental health disorder (95% CI 1.2 to 3.6, p=0.006) than their peers who do not have long-term physical health problems [81], and mothers of children with chronic conditions are significantly more stressed and worried for the future of their children [88]. Despite the potential for chronic conditions to have negative effects on child and parental psychological wellbeing, and the impact of maternal psychological distress on child health being well documented [89], specialist support in this field has been limited to date [90].

Whilst social support and cognitive social capital (such as trust and social harmony) have been positively associated with child health outcomes [91, 92], more research is needed to understand this more fully in Vietnam. In a 2006 study a random sample of 4,000 children, comprising 100 one-year-olds and 100 eight-year-olds taken from 20 sentinel sites across Vietnam, was used to explore associations between maternal social capital and child health, in particular the value of belonging to groups. Researchers identified 14.3% of children in the cohort as having a long-term health condition, although there was no definition cited for a "long-term condition", nor were "groups" clearly defined (women's union groups were discussed, but participation in specific support groups for children's health conditions was not mentioned). The fact that belonging to a "group" had negative associations with health and wellbeing was not considered relevant to the NS Clubs proposed in this doctoral research. The cross-sectional nature of the study did not allow for an examination of causality underpinning associations, and the authors acknowledged reverse causality was possible "whereby the mother reports lower levels of cognitive social capital or receives more social support because her child is sick" [93]. A more recent study specifically looking at support groups for children with cognitive delay clearly demonstrated reduced levels of stress for parents who participated [94], and others have demonstrated positive outcomes for mothers diagnosed with HIV or AIDs in Vietnam [95]. Peer education is well-established in Vietnam for HIV and AIDS, but concerns around sustainability and effectiveness have been raised, and the importance of training and setting specific goals identified [96].

Broader community understanding and favourable social norms have positive effects on care provided to children by caregivers; “positive, reinforcing beliefs and attitudes” were identified as important determinants, and extended family members had a role to play in helping primary caregivers provide optimal care [97]. Paternal involvement in particular has been demonstrated to have positive associations with child health in Vietnam [98].

b) What are we aiming for? The experience of NS in high income countries

The researcher had not worked in the field of NS prior to this study, so it was necessary to acquire knowledge and understanding of it rapidly. In learning about NS, the researcher was especially keen to identify the gold standard treatment options enjoyed by children in high-income countries so that the project could set as high a bar as possible when determining critical actions to achieve equity for children in Vietnam. The researcher sought high-quality evidence to facilitate a comprehensive understanding of NS and strengthen her own knowledge regarding best approaches to the diagnosis and management of NS as a chronic health condition of childhood, to inform planning and implementation of the research project. Information was sought to inform an understanding of the following:

- What is Nephrotic Syndrome?
- Epidemiology
- Aetiology and pathophysiology of NS
- Types of NS
- Natural history of NS
- Definitions used to describe NS
- Optimal management of NS
- Complications, challenges and burdens

i) What is Nephrotic Syndrome?

A “***syndrome***” has been defined as “*a recognizable complex of symptoms and physical findings which indicate a specific condition for which a direct cause is not necessarily understood.”* The term syndrome does not speak to underlying aetiology. Indeed, “(o)*nce medical science identifies a causative agent or process with a fairly high degree of certainty, physicians may then refer to the process as a* ***disease****, not a syndrome*” [99].

Nephrotic Syndrome (NS) is therefore a cluster of signs and symptoms characterised by three key features [13, 14]:

1) *Proteinuria (protein in the urine)* – occurs when protein (in the form of albumin) leaks into the urine because glomeruli (the smallest filtering units in the kidneys) are damaged and the kidney tubules are unable to fully reabsorb the great excess of albumin that filters through. Protein in the urine can be diagnosed with a simple and rapid point of care dipstick test (whereby a coloured square on litmus paper changes

colour when protein is detected) and is usually confirmed by more detailed laboratory tests of the urine.

2) *Hypoalbuminaemia (low protein in the blood)* – protein (in the form of albumin) leaks from the blood into the urine when the blood is filtered by damaged kidney glomeruli. Low levels of albumin in the blood are quantified with a venous blood test.

3) *Oedema (swelling caused by fluid retention)* – most usually affects the lower limbs (ankles and feet) and face (periorbital region) of children, and the scrotum in boys. The cause of oedema in NS is debated: the "underfill" theory attributes the swelling to decreased intravascular oncotic pressure resulting from reduced albumin in the blood; the "overfill" theory attributes swelling to an aberration of salt excretion [12]. Either way, distribution of retained fluid is influenced by gravity and severity of swelling can be monitored by checking body weight regularly. Onset of oedema is often a subjective diagnosis and most usually noticed first by affected persons or their families. It is the most common presenting symptom of nephrotic syndrome.

ii) Epidemiology

NS is the most common chronic kidney disease of childhood, with a reported incidence (from countries with the most accurate data available) of 2–7 cases per 100,000 children; an overall prevalence rate of 2–5 cases per 100,000 children and a cumulative prevalence of nearly 16 cases per 100,000 during childhood [12, 100].

NS is more common in some populations than others and is among the most common kidney conditions of childhood seen by doctors in resource-poor settings. The increase in NS seen in low-income countries is hypothesised to be associated with higher infection rates affecting children in these settings, and accounts for the higher hospital admission rates associated with paediatric kidney disease [101-105]. Indeed, there are suggestions that chronic kidney disease in low- and middle-income settings requires especial consideration because of increased rates of disease and capacity constraints on caring for those most affected [106, 107].

iii) Aetiology and pathophysiology of Nephrotic Syndrome

NS is the most common glomerular disease of childhood, and results from damage to the glomeruli which adversely impacts on the kidneys' capacity to filter waste and water from the blood [108]. The triad of features seen in NS is the result of a shift in the permselectivity barrier of the kidney's glomerular capillary wall, rendering glomeruli unable to restrict protein loss into the urine. The exact cause of glomeruli damage can be varied and is often not well understood.

Since the 1960s, histologic classification of NS (based on renal biopsy findings) has given increasing insight into the different types and causes of NS. From initial reports in the International Study of Kidney Disease in Children in 1970, understanding of NS has strengthened and had positive impact on management over time [12, 13, 109, 110]. Kidney biopsies are not routinely conducted when a child is first diagnosed with NS, but are generally indicated when there are atypical features, such as older or younger age at the time of diagnosis (less than 12 months or older than 12 years); persistent hypertension or impaired renal function; gross haematuria (as opposed to microscopic levels of blood in the urine, which can be seen in up to 25% of children with NS); low plasma Complement C3 levels; and / or a positive test for Hepatitis B or C [14].

iv) Types of NS

The most common types of NS include:

1) *Minimal Change Nephrotic Syndrome* (MCNS)

MCNS is the most common cause of NS in children, accounting for approximately 77% of children diagnosed with NS. On histological examination the glomeruli appear largely normal, and the underlying cause is not well understood. The majority of children with MCNS are young (70% under 5 years of age; median age at presentation is 4 years [14]), and only 20–30% of adolescents presenting with NS are diagnosed with MCNS.

Most cases of MCNS are idiopathic (no cause identified), however, some drugs and tumours have been associated with this type of NS. Male children are affected more than females (ratio of 3:2) [14] for reasons that are not well understood. Nearly all children with MCNS respond to corticosteroid treatment (95% respond to an eight-week course of prednisone, and 75% of children achieve remission within two weeks) and can reasonably expect to stop relapsing over the longer term and enter adulthood with normal renal function.

2) *Focal Segmental Glomerulosclerosis* (FSGS)

FSGS results in scarring of the glomeruli and is diagnosed on kidney biopsy. FSGS affects approximately 8% of children diagnosed with NS and the median age of onset of FSGS is 6 years. FSGS is largely idiopathic, but can result from other diseases, genetic abnormalities or medications. Fewer children with FSGS respond to corticosteroid therapy (20% of children after eight weeks of prednisone treatment) although there are now reasonable data to suggest calcineurin inhibitors such as cyclosporin (CsA) and tacrolimus should be the first line of treatment in children with FSGS or SRNS. Levamisole (an anti-helminthic drug) does not have a role in SRNS and the efficacy of mycophenalate mofetil (an immunosuppressive drug) and rituximab (a monoclonal antibody) is probably limited. Cyclophosphamide (an alkylating agent) is not used in high income countries and less commonly used now in LMICs because of documented potential toxicities (such as infertility, tumours and cystitis) with cumulative dosing [111-113].

3) *Membranous Nephropathy* (MNNS)

MNNS is relatively uncommon in children (accounting for around 6% of all cases of NS), and results in thickening of the glomeruli. MNNS is usually immunologically mediated and can be associated with other conditions (such as systemic lupus erythematosus, hepatitis B or C, congenital syphilis, malaria and Epstein Barr Virus) or be idiopathic in nature [114].

4) *Other causes*

These include a range of isolated rare genetic disorders and secondary diseases caused by drugs, infections or neoplasia, and account for about 9% of cases in children. Congenital NS usually presents in the first year of life and is generally associated with a positive family history or genetic abnormality. Genetic causes of NS are increasingly well understood; inheritance patterns are not always evident (given many mutations are recessive), and podocytes genes are commonly affected in hereditary types of NS [22].

The work described in this thesis focused primarily on idiopathic childhood Nephrotic Syndrome (NS), where it has been diagnosed in children presenting between the ages of 1 to 18 years with the triad of features described above, and where other possible causes of proteinuria, hypoproteinaemia and oedema (such as systemic lupus erythematosus or lymphoma) have been excluded [13].

v) Natural history of NS

The natural history of NS depends on the underlying cause and nature of the NS. For the majority of children, where optimal treatment is available, the longer-term outlook is positive. The majority of children diagnosed with NS have MCNS (80%), and more than 90% of these children respond to steroid therapy, and can be expected to transition into adulthood with normal renal function with few longer-term consequences [14]. Recurrent (or relapsing) episodes of proteinuria, hypoproteinaemia and oedema occur in 60–80% of children with steroid sensitive NS (SSNS) and the majority of these children will have more than five relapses [12].

Because of its relapsing nature, NS meets criteria to be considered a “chronic health condition” [115-118] in that it is:

- *long-standing* – most definitions of a chronic condition suggest duration longer than 12 months (some definitions state 3 months)
- *ongoing in nature* - be it a physical, behavioural or cognitive disorder (including chronic illnesses, impairments and disability) “continuing or occurring again and again for a long time”
- *associated with more than the usual amount of medical care* - resulting in dependency on one or more of the following: medications, diet, medical technology / devices or personal assistance
- *responsible for bringing about significant change in the life of a child* (for the purposes of this thesis includes persons aged up to 18 years) - with limitations of function, activities or social role in comparison with healthy peers in the areas of physical, cognitive, emotional and social growth and development.

The most important predictor of a positive prognosis is the responsiveness of NS relapses to steroid treatment, so the nature and frequency of relapses are a major concern to families and health professionals caring for children with NS. The cause of relapses is not well understood, although they are frequently associated with viral infections [14]. Fortunately, the majority of children with SSNS will experience fewer relapses over time, and natural history studies have demonstrated that 84% of children with SSNS will stop relapsing altogether after ten years' duration [119]. In this regard, treatment of NS offers positive cost benefits. The majority of children with NS can expect to enter adulthood with normal renal function and enjoy a normal quality of life, with full life expectancy. With optimal management, mortality in high income countries is negligible and there are few longer term sequelae from treatment [14, 108].

For children with FSGS NS, the prognosis is generally less favourable. A small proportion of the children who are resistant to steroid therapy will respond to second line medications (which are generally more expensive), but end-stage renal failure (ESRF) is inevitable for many, and renal transplantation is the only real hope for this cohort of children. Even then, for reasons not well known, about a quarter of children with FSGS NS who have a transplant will relapse again with their grafted kidneys. Likewise, for children with congenital and other less common forms of NS, renal transplants offer the greatest hope of a high quality of life.

vi) Definitions used to describe NS

Terms used to describe the nature and frequency of relapses include [13]:

- **Initial diagnosis** – proteinuria, hypoproteinaemia and oedema, with diagnosis of NS
- **Remission** – resolution of proteinuria (as per dipstick testing for three days) after treatment
- **Relapse** – recurrence of proteinuria (as per dipstick testing) following remission
- **Frequently relapsing NS** – two or more relapses within six months after initial therapy, or 4 or more relapses in any 12-month period
- **Steroid dependent NS** – relapses during tapering of steroid treatment, or within two weeks of stopping steroid treatment
- **Steroid resistant NS** – inability to induce a remission despite four or more weeks of daily steroid treatment.

Other definitions relevant to NS are [120]:

- **Chronic kidney disease (CKD)** – is the functional abnormality of the kidneys lasting more than three months and is categorised into five stages of increasing severity based on evidence of kidney damage (as defined by increased creatinine levels in the blood; protein in the urine; or imaging / pathologic abnormalities) and altered glomerular filtration rate (GFR < 60ml/min/1.73m^2). Persons with CKD are at risk of progressing to ESKD. It is estimated that 1 in 10 American and Australian adults have CKD. No accurate data were available for Vietnam.

- **End Stage Kidney Disease (ESKD)** – denotes a stage of renal disease where renal replacement therapy (such as dialysis and transplantation) is required to sustain life. It is estimated that for every one person with ESKD in America, there are another 200 people with overt CKD (stage 3 or 4) and almost 5000 with covert disease (stage 1 or 2). No accurate data were available for Vietnam.

vii) Optimal management of NS

Steroid therapy is the mainstay of NS treatment and approaches to therapy have varied widely internationally [121]. International treatment guidelines became available in 2012, but at the time of this research project review articles [12-14, 108, 111, 122-125] and emerging results from the latest randomised controlled trials were keenly sought by health professionals to guide increasingly complex approaches to treatment regimens. Clinical protocols that enable medical, nursing and other health professionals to work together to support children and their families have been demonstrated to be very effective [123].

The goals of steroid therapy are to induce remission, maintain remission, and minimise side effects. Whilst steroids have been associated with short-term effects (such as immunosuppression, gastrointestinal symptoms, behavioural change and weight gain), longer-term follow-up studies indicate steroid therapy for NS does not have negative impact on bone health and growth [126], and likewise no studies have conclusively demonstrated any association with increased fracture risk nor any reduction in bone mineral density, although steroid therapy which is prolonged (either because non-corticosteroid agents are not used or are not effective) may impair longitudinal growth so that children may be short as adults [111].

Second-line therapies to manage FSGS NS are continually being researched, with a broad range of drugs and combinations of drugs possible [111]. These drugs have varying side-effects (including immunosuppression) and risk profiles, and are generally associated with much of the reported morbidity associated with NS in developed countries [14].

Children with NS are much more susceptible to infections than other children [127], and this is thought to be due to the effects of the medicines used to treat NS, and the inherent impact of NS itself. Cellulitis and peritonitis are especial risks [12], and indeed serious infection remains the major cause of mortality for children with NS. Infections are also demonstrated to trigger relapses, so prevention of infections is a key priority for families and health professionals alike, and vaccination against preventable diseases is widely recommended [12]. Children should be vaccinated according to immunisation schedules, and pneumococcal vaccine is particularly important. Live vaccines (such as measles, mumps, rubella, rotavirus and varicella) must not be given whilst children with NS are receiving high dose steroid or cytotoxic treatment, but can be given safely once the child is in remission or on lower doses of drugs (as per treatment protocols) [13, 14, 108].

Children with NS should be encouraged to enjoy a normal diet [14], and while “no extra salt” is reasonable for those with sustained oedema, and low-fat intake considered for those with dyslipidaemia [13], no special dietary requirements are routinely recommended for children with NS [14, 122].

Family support and education is vital. Parental reassurance that the majority of children diagnosed with NS have a positive prognosis is important [122]. Family climate (particularly maternal wellbeing) is linked to health outcomes and quality of life for children diagnosed with NS, so health professionals have a vital role to play in helping families help their children [128]. Parental education and training should ideally strengthen their capacity to [108, 122, 128, 129]:

- test urine each morning with a dipstick
- follow an action plan if and when protein is detected in the urine (early treatment can reduce the severity and risk of relapse)
- maintain a diary, to track relapses, symptoms and progress
- comply with treatment guidelines
- help the child return to school and maintain normal physical activity
- manage behavioural and other side effects associated with steroid treatment
- minimise fear associated with future relapses (especially when testing urine daily)
- ensure vaccinations are up to date
- support their child and other siblings emotionally and socially.

viii) Complications, challenges and burdens

Prevention of complications associated with NS is a priority of treatment, and thromboembolic episodes (blood clots) are a serious threat (because of loss of anti-thrombin III during periods of massive proteinuria), albeit relatively uncommon in children (estimated to affect 2–5% of children) [13]. Mobilisation should be encouraged and bed rest avoided where possible [108]. Other complications, such as heart disease and toxic drug effects are generally considered rare [12]. Children with NS routinely achieve their height potential, with no increase seen in renal failure in adulthood for those who achieve remission [108].

The negative impact of NS on the social and emotional wellbeing of children and families [130] is recognised as significant and should be taken into account within a holistic approach to NS management. Behavioural challenges are not infrequently noted by parents of children receiving high doses of steroids to manage their NS. Many younger children become overactive, aggressive and emotionally labile, and parents require support to anticipate and respond to these quite usual and expected side effects [14].

1.2 What did this thesis set out to achieve?

1.2.1 Clarifying the research questions

It was agreed early that the essential starting point would be consultation with key stakeholders in Vietnam (with specific focus on the families of children living with NS) to better understand their situation and identify priorities for action. To this end, a Health Needs Assessment that facilitated systematic consultation with a range of key stakeholders in Vietnam was required, to:

- better understand the situation, challenges and burdens experienced by children and their families living with NS in Vietnam
- identify recommendations for critical action and resource allocation, and
- guide collaborative action (in real time wherever possible) to reduce health inequalities and improve quality of life.

1.2.2 Identifying tools and resources to support the research

The NICE HNA was chosen as the ideal framework to inform such a consultation process, and the five clear stages to follow in the conduct of HNA were considered relevant to the research project:

1) Stage 1 – Getting started (identify the population; planning)
2) Stage 2 – Identify health priorities
3) Stage 3 – Assess priorities for action
4) Stage 4 – Planning for change
5) Stage 5 – Moving on / review

A brief review of the literature and consultation with experts in the field suggested there were no existing products or tools currently available to facilitate rapid, large-scale, nation-wide, systematic consultation with families of children living with NS in Vietnam and other key stakeholders to better understand the situation of families and children living with NS in Vietnam, as required for a HNA. CLAN had already been involved in the *de novo* development of survey templates for use in Vietnam to consult with the CAH Community, but the tool had not been adapted for NS, and no other comparable tool was identified to support consultation with parents of children living with NS in resource-poor settings. Similarly, there were no existing templates available to guide consultation with other stakeholders, such as health professionals, Ministry officials, or insurance representatives.

It was therefore apparent at an early stage that the templates, tools and resources needed to complete a HNA to better understand the situation of the NS Community of Vietnam would require *de novo* development. It was determined that a minimum of three separate templates would be needed, to facilitate consultation with:

1) Parents of children living with NS in Vietnam
2) Healthcare professionals
3) Policy makers and other stakeholders.

In designing the templates to facilitate consultation, the researcher reflected on the NICE definition of a HNA, which stipulates three features be present. The HNA should:

1) Provide a systematic method for reviewing the health issues facing a population
2) Lead to agreed priorities and resource allocation
3) Improve health and reduce inequalities.

For this reason, it was not enough for the templates to help build an understanding of the challenges and burdens facing families and children. The templates should also facilitate the consultation's capacity to identify recommendations for change so they could be translated to action in real time. Conduct of the HNA would require extensive and meaningful participation and collaboration with a range of stakeholders, notably members of the NS

Community, health professionals in Australia and Vietnam, hospital executives in Vietnam, Ministry of Health and other government and non-government organisations. The vital role that NS Club Meetings would play as a public sphere in enabling a participatory action approach was clear to the researcher and colleagues in Vietnam from an early stage.

1.2.3 Showcase the role of NS Club Meetings

The conduct of NS Club Meetings in 2011 was identified early as a key priority for several reasons:

i) Clubs as a public sphere for participatory action research

The researcher's experience consulting with CAH families in Vietnam had always involved family support group (usually referred to as "Club") meetings, with approval and support from participating hospitals and hospital Ethics Committees. Overall, CLAN's experience to date with Club meetings had been very positive, with CAH Clubs offering an effective and efficient mechanism for overcoming a range of challenges relating to consultation with families. Many of these challenges appeared relevant to consultation with the NS Community and included:

- Large numbers - anecdotally, the population of children living with NS in Vietnam was sizable, but there were no specific data available (for instance, no patient registers) to determine prevalence or incidence with accuracy. Local experts estimated there were several thousand families in total in Vietnam, with between 400–1,000 children at each of the largest children's hospitals in the country (which placed an upper estimate of prevalence at around 3,000 children nationally in 2010–11) and an additional 600 children newly diagnosed with NS each year.

- Language barriers - very few families in Vietnam spoke English in 2010, particularly families from lower socio-economic groups. Because the researcher did not speak Vietnamese, a structured consultation process at Club Meetings provided the best chance of overcoming this barrier.

- Distance – many families travelled long distances to attend tertiary children's hospitals in Vietnam, so it was important to make any trip to a Club meeting worthwhile to families. For this reason, extensive planning of events to ensure they represented good value and benefit overall for the families (including coverage of transport costs and stipend to cover loss of income for those living in the most vulnerable circumstances) was important for CLAN.

- Limited communication platforms – few families in Vietnam in 2010 had internet access or smart phones (particularly low-income families), so face-to-face meetings offered the best chance for communicating effectively.

- Literacy – interestingly, this is not (theoretically at least) an insurmountable challenge in Vietnam, with official statistics demonstrating high literacy levels (90%), even for the very poor. This strength of the people of Vietnam could theoretically be leveraged by consulting families in written format at Club meetings. The issue was not quite so simple unfortunately, given the difference between basic literacy and health literacy, with the latter providing some challenges when discussing complex health conditions such as NS. Having health professionals attend Club Meetings and available to assist families with literacy challenges to participate in consultations was one strategy planned to overcome this barrier.

- Poverty – anecdotally 21% of families in Vietnam are living in poverty [56], so in planning Club meetings it was imperative to CLAN that there be no (or minimal) cost to families who were participating. The cost–benefit of attending for families should always fall in the families' favour.

- Limited capacity / time of health professionals – was a constant theme for health professionals at the three children's hospitals, with outpatient (OPD) and inpatient departments constantly reporting overcrowding and staff stretched beyond capacity. Anecdotally, families spent approximately 2 minutes with health professionals, so it was vitally important not to compromise this precious time for families in any way. One benefit of Club meetings, therefore, was that health professionals could educate large numbers of families in detail at one time. Key themes relevant to large numbers of families (such as widely held myths that needed to be redressed) could be addressed in one sitting.

- Politics – some topics are challenging and potentially political, and beyond the scope of understanding for visiting health experts or CLAN. One classic example of this relates to questions around access to medicines – the topic is vitally important to families, but answers reflect more complex issues at a national and local level. A benefit of Club meetings was that they provided an open forum for difficult discussions. Hospital executives could attend and ensure messaging was appropriate and in line with broader hospital and health systems policies and considerations.

- Limited resources of the researcher – there were very limited resources available for this project both as a researcher and through CLAN. It was essential to seek cost-effective, sustainable solutions and work with as many other stakeholders as possible, to leverage the support that might be available from others.

In summary, Club Meetings offered low cost, culturally safe and appropriate forums for communicating and consulting with large numbers of NS Community members in an effective and efficient manner. Colleagues in Vietnam and CLAN's Committee agreed that it would be essential to run NS Club Meetings in Vietnam in 2011 to facilitate consultation.

ii) Showcase Clubs as key to CLAN's strategic framework and critical action

In parallel with work on the research project and template development, CLAN's Committee supported planning of NS Club Meetings, noting they were instrumental to the success of implementing activities around the five pillars of CLAN's strategic framework for action.

Conduct of NS Club Meetings at each of the three children's hospitals would be invaluable for maintaining the NS Community as a visual hub for all planning. This was included in the draft *CLAN Action Plan for NS in Vietnam* that was developed to facilitate CLAN's effective engagement with a range of stakeholders in collaborative action with and for the NS Community in Vietnam.

Fundraising was identified as an urgent priority. CLAN's Committee was very aware of the time, energy and resources that had gone into supporting annual Club Meetings with and for the CAH, diabetes and autism Communities of Vietnam over many years, and resource constraints were an ongoing consideration, so it was important to focus on sustainable solutions and set realistic expectations for all stakeholders from the very start.

1.2.4 Stakeholder consultation beyond the NS Club Meetings

The remaining barriers to consultation with families – notably the long distances travelled for care, the burden of poverty and limitations of health literacy – could not confidently be overcome with Club Meetings alone. Moreover, consultation with additional stakeholders (such as health professionals, Ministerial officials and health insurance representatives) were also considered important. For these reasons, early planning included a focus on finding the most appropriate way to speak with families, health professionals and other stakeholders in face-to-face, semi-structured interviews, so that deeper understanding of challenges, burdens and recommendations could be assured.

Ethics submissions were required in Australia and Vietnam. An application was submitted to the Flinders University Social and Behavioural Research Ethics Committee in Australia and to hospital executives at each of the participating children's hospitals in Vietnam in late 2010, with agreement that face-to-face meetings with the researcher would be required before hospital executives were able to give final approval for the project. It was agreed I would travel to Vietnam in February 2011 with Dr Hodson to meet with hospital executives, finalise requirements for the research project, and work with local health professionals to progress planning for the inaugural NS Club Meetings at the three hospitals (tentatively planned for November 2011 and February 2012).

1.2.5 Aims and objectives of the study

In late 2010 the aims and objectives of this research project were finalised and agreed amongst key stakeholders in Australia and Vietnam.

<u>The research project had two aims:</u>

1. To understand the challenges and burdens facing families and children who are living with Nephrotic Syndrome (NS) in Vietnam

2. To identify recommendations for realistic multisectoral action that could be taken to optimise quality of life for children (and their families) living with NS in Vietnam.

The objectives of this research project were:

1. To identify and /or develop the tools and resources needed (Study One) to support consultation with key stakeholders (Study Two) as part of a Health Needs Assessment to facilitate:

    a. An understanding of the situation, challenges and burdens experienced by families and children living with NS in Vietnam (and potentially other chronic conditions and in other LMICs)

    b. Identification of practical, realistic actions that could be taken to optimise quality of life for young people living with NS in Vietnam.

2. To document and learn from the development, implementation and findings of the HNA to inform the real-time selection, tailoring and implementation of practical, cost-effective interventions to reduce the burden of NS experienced by children and families living with NS in Vietnam (Translation Findings / Chapter Five).

3. To consider relevance of these findings to other childhood chronic health conditions and resource-poor settings, and how they might inform identification and prioritisation of actions to protect and promote the rights of all children to health and life through sustainable, scalable efforts to fast-track equity.

1.3 The significance of the research project

As the parent of a child living with a chronic health condition in a high-income country, and as a medical professional aware of the relatively inexpensive and effective therapeutic options open to children affected by NS even in LMICs, the anecdotal reports of suffering and death associated with NS in Vietnam were deeply disturbing. Whilst no accurate databases or patient registers were available, personal communication with experts in the field, visits to the renal wards of three children's hospitals and early review of the literature indicated the preventable morbidity and mortality associated with NS in Vietnam was significant. Early estimates suggested at least 3,000 children with NS were known to the three largest children's hospitals in the country, with 600 new children diagnosed each year. All three institutions were expressing an interest in collaborating with CLAN and international partners to effect sustainable, affordable, population-wide, scalable change.

As President of CLAN and a public health researcher, the opportunity to apply scientific rigour to CLAN's strategic framework for action was appealing. With the shift of this research project from CAH to NS there was a unique opportunity to take an objective look at CLAN's rights-based, community development model as used for CAH, and translate it *de novo* to a novel chronic health condition of childhood. With no personal ties to NS and with the involvement of external stakeholders to promote objectivity, there was an opportunity to view CLAN's work through fresh eyes and determine the extent to which our current strategic framework for action would address recommendations to emerge from an independent assessment of the most appropriate way to respond to NS in Vietnam.

As Chair of NCD Child, a research project committed to better understanding the burdens and challenges experienced by children and families living with an NCD in a LMIC, and opportunities to identify concrete recommendations for change, were of great interest to me. NS had been identified by local experts as a chronic condition of childhood causing significant burden for families and the health system, yet it had received little attention internationally. As of late 2010 there was minimal reference to chronic kidney conditions in adults or children in the international NCD discourse, and no mention or consideration of less common NCDs such as NS. Realistically, the researcher did not expect global interest in NS to change significantly, but the opportunity to take an in-depth look at a childhood NCD that was responsible for enormous suffering yet languishing almost exclusively “in the shadows” captured the imagination. Examination of a largely untouched landscape also offered the chance to consider, perhaps for the first time, what might be possible if policy and practice were to change.

Whilst the researcher was keen to balance realism with a desire to dream big, achievements seen previously for children living with CAH in LMICs gave optimism and confidence to the project. Indeed, the fact that the researcher was prepared to swap from one chronic condition of childhood to another somewhat late in the DrPH process was a lived demonstration of strongly held personal and professional beliefs that the historically paralysing paradigm of “complexity” and “it’s all too hard” relating to the management of childhood NCDs in LMICs needed to change. The researcher was not, however, prepared to do “research for the sake of research”. For this reason, the decision was made to present the thesis as a health needs assessment that that may be useful to others seeking to translate knowledge to action in different countries and across different chronic health conditions of childhood. To this end, the CHEAR Toolkit (Appendix 1) contains the key tools, resources and products developed and used in this HNA to support critical actions that improve health outcomes and redress inequities for children living with chronic health conditions in resource-poor settings.

1.4 Thesis structure

This thesis is organised into six chapters (Table 1).

<table>
<tr><th colspan="5">Table 1 - Overview of the DrPH Thesis structure</th></tr>
<tr><th>Chapter Number</th><th colspan="3">Structure of thesis</th><th>Stages of the Health Needs Assessment</th></tr>
<tr><td>1</td><td colspan="3">Introduction</td><td>Introduction to the HNA</td></tr>
<tr><td>2</td><td colspan="3">Literature review and initial consultations</td><td>Background context - NS and other chronic conditions of childhood in Vietnam and other resource-poor settings</td></tr>
<tr><td>3</td><td colspan="3">Research methods</td><td>Underlying axiology, ontology and epistemology</td></tr>
<tr><td rowspan="4">4</td><td colspan="4">Study One and Study Two (HNA Stages 1–3)</td></tr>
<tr><td colspan="3">Study 1
Participatory Action Research (PAR) approach to the development of project foundations and information gathering templates to facilitate consultation with key stakeholders to strengthen understanding of challenges and burdens facing children and families living with NS, recommendations for change and identification of critical actions that could be taken within this HNA.</td><td>Stage 1 – Getting started
- Identify the population (who, where, why?)
- Aims and objectives
- Who was included in the project team?
- Who was included in the stakeholder group?
- What resources were required?</td></tr>
<tr><td colspan="3">Study 2
Implementation of HNA templates</td><td rowspan="2">Stage 2 – Identify health priorities
- How was a profile of the population developed?
- What data were available on the health of the population?
- How was information gathered about the population’s and the service providers’ perceptions of needs?
- What barriers were encountered?
- How were these barriers overcome?
- What were the key issues for the population?
- What priorities were chosen and why, in terms of impact and changeability?
- What evidence informed your decision?</td></tr>
<tr><td>Part A - Parent surveys</td><td>Part B – Parent interviews</td><td>Part C - Health professional survey</td></tr>
</table>

	Summary of Study 1 and Study 2	**Stage 3 – Assess priorities for action** - What interventions were considered most effective and acceptable? - How were resource needs met?
5	**Translation Findings** - Translation of insights from consultation into critical action to improve health and reduce inequalities - What did we learn? - Recommendations for NS in other countries / for other chronic conditions of childhood	**Stage 4 – Planning for change** - Summary of the action planning process
		Stage 5 – Moving on / Project review - How well was the action plan implemented? - What was achieved by the project? - How did it contribute to reducing inequalities? - What was learned through the project's successes and challenges? - What needs to happen next? - What new priority was chosen for the population? - What main message from the last HNA will you take forward to the next?
6	**Conclusion**	
	References	
	Appendices	

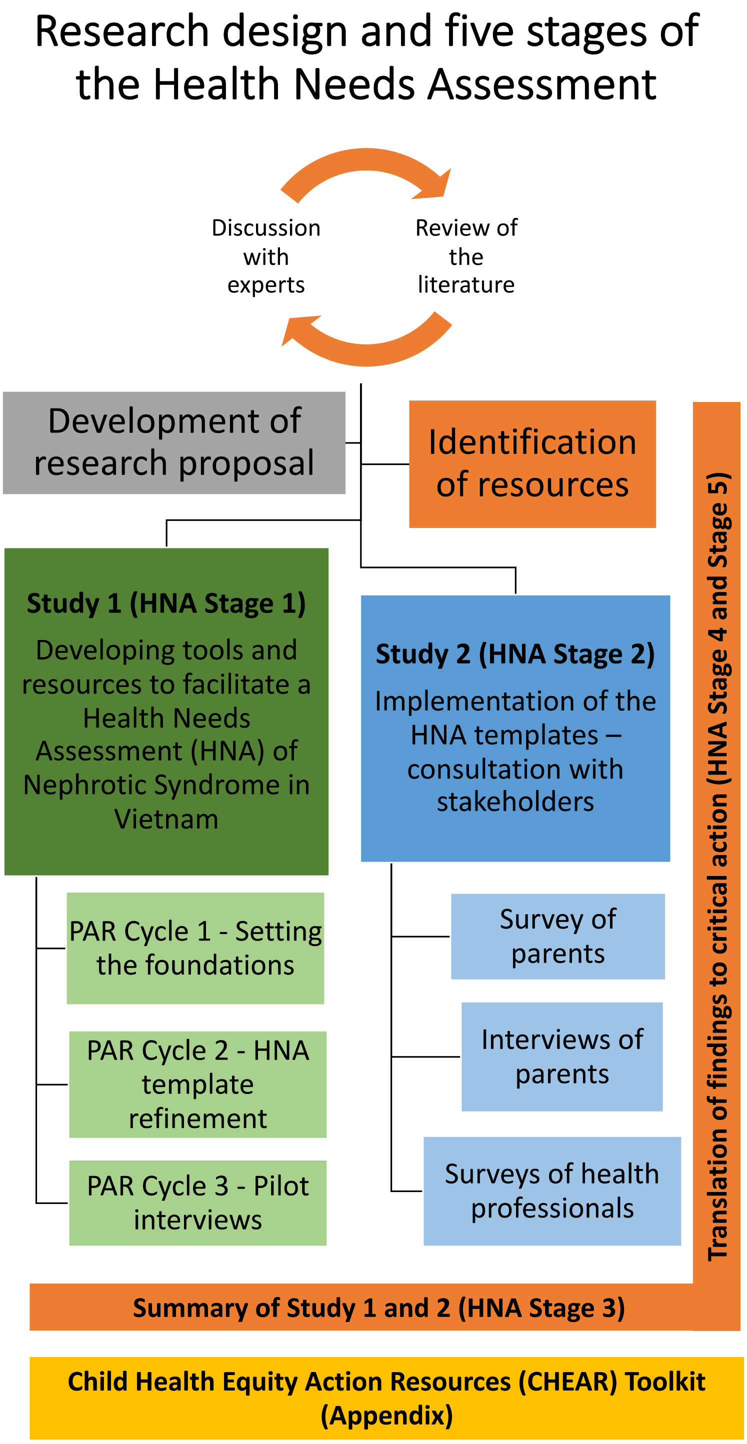


Figure 6 - Synthesis of the DrPH thesis and five stages of the HNA

The six chapters of the thesis are structured as follows:

1.5.1 Chapter One – Introduction

This chapter offers an introduction to the research project, commencing with background information on the rationale for undertaking this research project, topic selection and the overall aims and objectives. The background context to the study, significance of the research and overview of the dissertation structure are also presented.

1.5.2 Chapter Two – Literature Review

The literature review presents an analysis of existing evidence (including peer review, grey literature and information gleaned from consultation with key experts in the early stages of preparing for the HNA) before commencement of the research project and identifies specific gaps in this knowledge base that the HNA sought to fill.

1.5.3 Chapter Three – Research Methods

The research methods section describes the underlying ontology, axiology and epistemology informing Study One and Study Two. Chapters Two and Three contribute to the foundation of the HNA and provide insights into the population being studied and the rationale for the approaches taken to planning and implementation over the course of the doctorate.

1.5.4 Chapter Four – Study One and Study Two (HNA Stages 1–3)

This chapter addresses the first three stages of the HNA and presents the methodology and key findings of Studies One and Two as they relate to the two key research questions.

Study One constitutes Stage One of the HNA (“Getting started”) and sets the foundations for the research. Study One focuses on establishing the governance processes and project management aspects of the HNA and development of tools and products needed to facilitate consultation with key stakeholders and identify key health priorities of the NS Community in Vietnam.

Study Two contributes to Stage Two of the HNA (“Identify health priorities”) and presents the findings from the consultation with key stakeholders in three parts (A, B and C) using the templates developed in Study One. Quantitative and qualitative data are presented to profile the NS Community of Vietnam and identify health priorities of the Community Members and service providers.

A summary of Study One and Two informs Stage Three of the HNA (“Assess priorities for action”) and synthesises the findings from data collated to date to inform an understanding of the challenges, burdens and recommendations for change. A range of critical actions that might be taken in real time to redress inequities and improve health outcomes for the NS Community of Vietnam is proposed.

1.5.5 Chapter Five – Translation Findings

This chapter presents the final two stages of the HNA. Stage Four (“Planning for change”) presents the key actions implemented throughout the HNA to improve health outcomes and redress inequities for the NS Community of Vietnam, as informed by CLAN’s strategic framework for action and CLAN’s five pillars. Stage Five (“Moving on / Project review”) reflects on the critical actions taken during the HNA and analyses the extent to which CLAN’s framework was able to inform the identification and implementation of critical action appropriate to the challenges, burdens and recommendations that emerged from the HNA.

1.5.6 Chapter Six – Conclusion

The dissertation concludes with a brief summary, reflection on strengths, weaknesses and public health significance of the research findings. The conclusion also considers the potential for health needs assessment tools and resources developed in this research project to support future efforts for children living with NS and other chronic health conditions for children living in vulnerable circumstances.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

2.1.1 Background to the literature review

The aim of this thematic literature review was to examine, in a systematic and reproducible way, the existing evidence and knowledge base relevant to the research aims and objectives and identify knowledge gaps needing to be addressed. The literature review was completed in late 2010, and insights from the review informed the research project's design and implementation. The researcher revisited the literature in 2020, and insights from this second review are presented in the concluding section (Section 2.4.1) of this literature review.

2.1.2 Search scope

The literature review undertaken in 2010 primarily reviewed the available evidence published between 2000 and 2010, with manual tracing of references and information published before 2000 that were considered relevant. The review of published articles was limited to English language and human studies involving children and adolescents up to the age of 18 years. MeSH (Medical Subject Headings) terms were searched using AND and OR.

2.1.3 Sources of information

The review was rapid and broad, and considered the following sources:

1) Bibliographic databases
    a. Medicine
        i. PubMed (Ovid MEDLINE)
        ii. Cochrane Library
        iii. PsychINFO
    b. Multidisciplinary
        i. Scopus
        ii. Web of Science
    c. Nursing and Allied Health
        i. CINAHL
    d. Other
        i. Google Scholar
2) Manual searching of reference lists

3) Grey literature
    a. Dissertations and theses
    b. SOCPUS – Conference proceedings
    c. Web search engines
4) Online reports
    a. WHO
    b. CLAN
    c. NephCure
    d. Others
5) Expert opinion

2.1.4 Consultation with experts

In addition to reviewing published literature, consultation with key experts in the field was invaluable in guiding and informing the early planning stages of the research. Using the information gathering templates developed and submitted as part of the Ethics Application process in Australia and Vietnam to ensure a standardised and strategic approach, the following experts in Australia and Vietnam were consulted: medical (paediatric nephrologists) and research specialists; families of people living with NS in Vietnam (with the aid of local health professionals as translators); NGO representatives (in Australia and the USA) and hospital executives (at all three children's hospitals). This consultation informed planning in the context of conducting a HNA and was undertaken to facilitate a rapid analysis of the landscape.

Consultation with experts sought always to acknowledge and respect the following:

- All insights must be de-identified.

- Hospital staff in Vietnam were already overwhelmed with workload. It was essential not to duplicate processes or unnecessarily add to existing burdens. Consultation should be brief, strategic and streamlined.

- Hospital executives had to be kept informed at all times of all consultations and approaches being taken by the researcher to ensure appropriate and ethical research processes. In particular, any discussions with families in the planning stages had to be approved by hospital executives and conducted with a local health professional present to ensure no confusion or harm was caused.

- Because available quantitative data were of limited quality (patient files were in paper format only, and language barriers made these files inaccessible to the researcher without assistance from local health professionals), the research project would minimise reliance on these data.

- The researcher had limited capacity (time and material resources) to undertake exhaustive consultation with stakeholders beyond the planned surveys and interviews with families.
- Early consultation with health professionals and hospital executives soon revealed data saturation regarding insights.

2.1.5 Screening criteria

Where large numbers of articles were identified, the following practical criteria were applied in selecting those resources that would be included in the literature review:

- Can the search be refined further (e.g. with additional MeSH headings)?
- Does the resource help answer the research questions?
- Have all appropriate exclusion criteria been applied, viz:
- Date of publication – publications between years 2000 to 2010 prioritised
- Participants / subjects – children aged between 0–18 years
- Location – global versus specific focus on Vietnam where appropriate
- Language – English (and Vietnamese where feasible)
- Research design – studies on humans only

The following methodological screening criteria were considered:

- Does the information help answer the research questions?
- Is the study design valid?
- Are data sources reliable?
- Are study methods appropriate?
- Are results meaningful?

However, given the overall paucity of literature available, the researcher tended to err on the side of caution and did not apply these criteria strictly. The researcher preferentially respected the positionality of documents and authors from LMICs nd privileged insights from these information sources wherever possible.

2.1.6 Focused search questions

To capture existing insights and knowledge relevant to strengthening an understanding of the challenges and burdens facing families and children who are living with Nephrotic Syndrome (NS) and other chronic health conditions of childhood in resource-poor settings, the researcher asked the following questions to guide the search process:

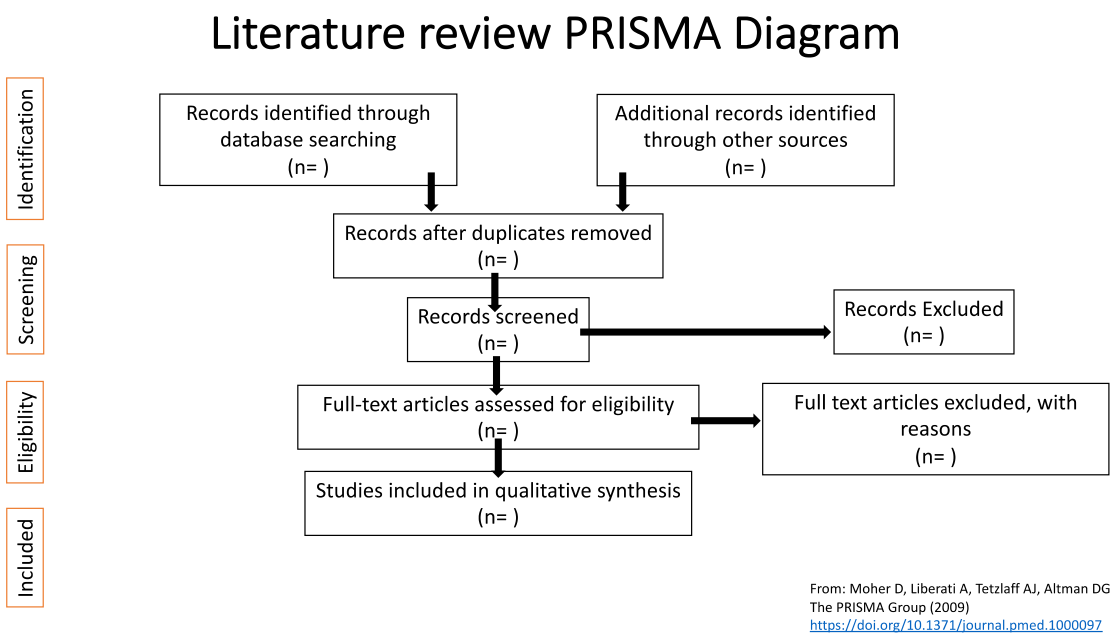
I. What is already known about NS in Vietnam?

II. What is known about the burdens and challenges associated with NS and other chronic health conditions of childhood in resource-poor settings?

III. What recommendations have already been made with regard to reducing burdens and optimising quality of life for children living with NS and other chronic health conditions in LMICs?

2.1.7 Search strategy for the literature review

A summary of the overall approach to the literature search process, using PRISMA Flow Diagrams [131] for each of the search questions is outlined in Figure 7 - Use of PRISMA Diagram to document the literature review.



From: Moher D, Liberati A, Tetzlaff AJ, Altman DG
The PRISMA Group (2009)
https://doi.org/10.1371/journal.pmed.1000097

Figure 7 - Use of PRISMA Diagram to document the literature review

More details about the approach to the two focused search questions are provided in the following sections.

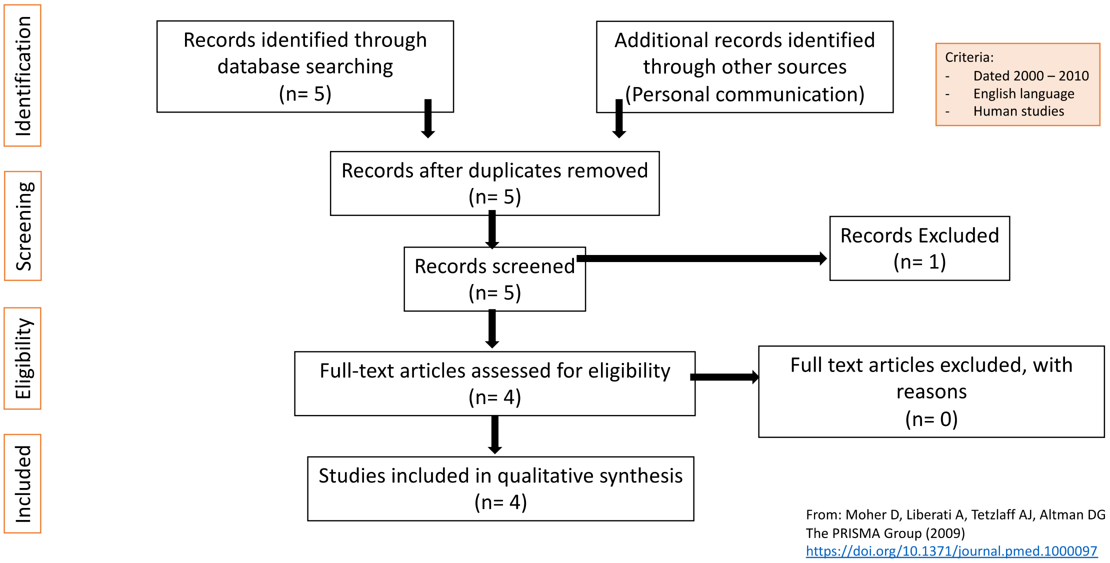
2.2 Search findings

2.2.1 Search question 1 - What is already known about NS in Vietnam?

Search strategy

An overview of the approach taken to this question is presented in Figure 8.

PRISMA Diagram 2.2.1 - What is already known about NS in Vietnam?



From: Moher D, Liberati A, Tetzlaff AJ, Altman DG
The PRISMA Group (2009)
https://doi.org/10.1371/journal.pmed.1000097

Figure 8 - Use of PRISMA Diagram to document search question 1

A search of the literature as it related to NS in Vietnam was undertaken, however as expected, very few articles (n=5) relating to NS in Vietnam were found. For this reason, insights relating to this search question emerged predominately from information shared by experts in Vietnam. In the main, consultation with these experts occurred by email and during face-to-face meetings with health professionals and hospital executives at each of the three participating children's hospitals in Vietnam during the project planning phase (September 2010–February 2011) and preparation of the ethics committee applications for each of the three hospitals.

Consultation with experts in the field of paediatric nephrology in Australia was also undertaken to answer this and other review questions. Their insights helped the researcher identify highly regarded resources that may have been missed in the search strategy. In particular, experts helped clarify gold standard treatment guidelines used in Australia and other high-income countries to manage NS, which helped contextualise the management of NS in Vietnam (given there were no official guidelines for the management of NS in Vietnamese language at the time). The *Kidney Disease: Improving Global Outcomes 2012 Guidelines* (KDIGO) [132, 133] were not available at the time of this review, but are described in a later section (see section 2.4.1) and were used in the development of the research project's final recommendations. One of the supervisors of this research project (EH) was actively involved in development of the KDIGO Guidelines and was able to share useful insights and directions to key resources.

Search findings

Findings are presented as follows:

- Review of the published literature
- Consultation with experts
- Management of NS within the Vietnamese health system
- Epidemiology
- Complications, challenges and burdens
- The vicious cycle of NS in Vietnam
- Recommendations for optimising quality of life for children

Review of the published literature

There was limited information in the peer-reviewed literature specifically relating to NS in Vietnam prior to this research project, and only four articles were identified for detailed analysis [4, 5, 134, 135]. The 1967 paper by Berger [135] was a case presentation describing a possible link between malaria and NS in one child and was not reviewed further.

In a conference poster presentation, D Duong *et al* in 2007 [134] highlighted the significant challenges associated with bacterial infections for children living with NS in Vietnam, and reported on the infections experienced by a cohort of 132 children with NS who were followed for a year (June 2004 to June 2005). In this time, 27 children (21%) developed bacterial infections (pneumonia, urinary tract infections, cellulitis and peritonitis).

Tran Thi Mong Hiep *et al* [4] examined the aetiology and outcomes associated with chronic renal failure (CRF) at Children's Hospital Two (CH2), in Ho Chi Minh City, Vietnam. In the review of 310 patients diagnosed with CRF between January 2001 and December 2005, NS was identified as the underlying cause in 19% (60/310) of cases (steroid resistant diagnosed without biopsy in 53 children, and FSGS NS in 7 children). The incidence of CRF in Ho Chi Minh City (HCMC) was calculated at 4.8 per million child population (pmcp), and likely represented an under-estimation. The median age of children with CRF was 14 years, 54% were male and 85% of children were in ESRF at first presentation. Challenges relating to delayed diagnosis and referral, and failure of primary health care services to identify and treat renal conditions appropriately in the early stages were highlighted. Financial, resource and technical restraints meant not all underlying aetiologies could be identified, and health outcomes were not ideal; 75% of all children diagnosed with CRF were managed conservatively in this study and the overall mortality rate was 15% (47/310), with the majority being boys (61%).

A 2009 paper from Hanoi by Nguyen Thi Quynh Huong *et al* [5] had a similar focus. The records of 152 children with chronic kidney disease (CKD) who were hospitalised between

January 2001 and December 2005 were analysed. The incidence of CKD in Hanoi City was estimated at 5.1pmcp (a likely under-representation probably associated with higher prevalence of bacterial, viral and parasitic infections affecting the kidneys [136]); the median age was 11.29 years, 60.5% were male and 65% were in ESRF at the initial presentation. Steroid resistant NS was the underlying cause of CRF in 21.7% of cases (33/152; 60 males and 41 females) reviewed.

Treatment refusal rates for CKD were noted to be high in the Hanoi study (50%), especially where families were uninsured (72.5%; $p<0.05$) and did not change across aetiology, metabolic or geographic status ($p>0.05$). This is not surprising given treatment costs (USD$469/month for haemodialysis, with insurance paying 80% and leaving a $94 gap each month) greatly exceeded average income (between USD$30/month in rural areas to USD$113/month in urban areas). In addition, transport, accommodation and other treatment costs were considerable, especially for families from rural areas. There were high rates of families seeking alternative therapy, and this was considered likely to contribute to late presentations. Limitations in the quality of care provided in the primary health care settings was also discussed (for example limited use of growth charts, unavailability of urine dipstick testing and training of health professionals).

In a 2003 paper examining nephrology across South East Asia that was not specifically focused on children, MCNS was noted as the most common cause of nephrotic syndrome in Indonesia and Vietnam [102]. The authors also noted the low incomes paid to nephrologists in Vietnam (USD $2,800 per annum in 2003), low numbers of nephrologists per head of population ($1:1.3 \times 10^6$), high costs for health professionals travelling to international meetings for ongoing education, and the high cost of treatment (with dialysis treatment costing 13 times the average national income each year) as just some of the challenges faced [102].

Consultation with experts

Given the limited information available in the published literature, the researcher conducted face-to-face meetings with key stakeholders at each of the three children's hospitals as part of the planning process for the overall project. This consultation revealed there were additional unpublished data available on NS in Vietnamese language. Although translations of the papers were not available to the researcher, the key findings were discussed during the face-to-face meetings and email correspondence. Research undertaken to date was described as having covered the following topics:

- Steroid resistant nephrotic syndrome
- Infectious complications in nephrotic syndrome
- Factors associated with lupus nephritis in children
- Histopathology in lupus nephritis
- Factors associated with frequent relapse in nephrotic syndrome
- Percutaneous renal biopsy in children: eight years' experiences
- Efficacy of cyclophosphamide for induction treatment of lupus nephritis in children

- Cyclophosphamide treatment for diffuse proliferative lupus glomerulonephritis: the role of reversal of renal histology
- Neuropsychiatric manifestation in lupus of children
- Congenital nephrotic syndrome
- Complications of NS
- General outlook

The true burden of illness associated with paediatric kidney disease in Vietnam was not well documented at the time, and although there were no databases or patient registers available for analysis each hospital generously provided the most accurate estimates they had available at the time. Senior paediatric nephrologists and hospital executives from each of the three children's hospitals (deidentified as Hospitals A, B and C) clearly communicated a dire situation. The following deidentified insights were shared with the researcher between July 2010 and February 2011 to facilitate planning for the project [137]:

Management of NS within the Vietnamese health system

Given its complexity as a chronic health condition of childhood, virtually all children diagnosed with NS in Vietnam are referred from primary and secondary health care settings to one of three tertiary children's hospitals for care. The only exception is Hue Central Hospital which also manages children with NS in the central part of the country. For the purposes of this research project, it was agreed that a separate hub would not be established at Hue, and that Hue would be included in collaborations with NHP in Hanoi.

Where possible, staff from the three national hospitals support health professionals in the provinces with training and expert advice. Children with milder forms of NS are gradually transferred to paediatricians in provincial hospitals for ongoing care wherever possible, to reduce the burden on families and the tertiary healthcare system. Children are transferred to receive care at adult hospitals when they reach the age of 15 years [4]. A limitation to this process is often the families' lack of trust in the local health settings and local health care professionals, which sees them self-referring their children back into the tertiary hospital system.

Epidemiology

The exact incidence and prevalence of NS at each hospital was difficult to determine without accurate patient registers and databases. To complicate matters, health professionals found it hard to follow up all cases. Some children may be in full remission, others may be in the competent care of a local health professional, some may have passed away, while some may just have been missed because of limited databases. Health professionals mostly discussed the burden of NS as it related to inpatient and outpatient presentations, staffing and dialysis.

Each hospital shared estimates of their patient numbers and experiences of managing NS as follows:

Hospital A

- **Incidence** – there had been 185 children newly diagnosed with NS in the last year. By comparison, the largest children's hospital in Sydney had diagnosed 40 new cases of NS over a recent three-year period.

- **Prevalence** – an estimated 1,562 children with NS were considered regular outpatients of this hospital; 88% (1,377/1,562) were longer term patients (no specific dates available), and there were approximately 128 additional children who were considered lost to follow-up (with no information as to whether this was due to resolution or mortality).

- **Types of NS** – a breakdown of the types of NS was not available.

- **Outpatients** - approximately 1,900 children each year presented to the outpatient department with renal conditions. Most of these children came from provincial regions (1500/1900; 79%), and approximately 21% (400/1900) lived in the inner city. Of the 1,900 children presenting to outpatients with renal conditions, it was estimated that 80% (1,500/1,900) were living with NS.

- **Inpatients** - approximately 1,500 children were admitted annually as inpatients to the renal ward of Hospital A. Of these, 20% (300/1,500) had a diagnosis of NS. Other conditions for admission included: acute glomerular nephritis (200), lupus (100), renal infections (100) and others not specified (800). Approximately 100–250 renal biopsies are conducted each year at Hospital A. It was estimated that NS accounted for 3.1% (498) of all admissions to the hospital in 2009; CKD accounted for 0.31% (50) of all admissions. Staffing of the renal ward and outpatients department was stretched to capacity, with 5 doctors overseeing the care of all renal patients at the hospital.

Hospital B

- **Incidence** – not certain

- **Prevalence** – it was estimated that approximately 400 children with NS received care at Hospital B for NS on a regular basis.

- **Types of NS** - Of the 400 children with NS cared for at hospital B, it was estimated that 85% (340/400) had steroid sensitive (SS) NS, and 15% (60/400) had steroid resistant NS (SRNS). Of the 340 children with SSNS, 50% (170/340) had frequently relapsing and steroid dependent NS, and 50% (170/340) had infrequent relapses.

- **Outpatients** - each day approximately 50 children with a range of renal conditions would be seen in outpatients, and on average, 60% (30/50) of these would have NS (clinics operate Monday to Friday, so this averages out to 150 children with NS seen in outpatients per week, or 7,800 presentations each year).

- **Inpatients** - on average, one child would be admitted to the renal ward each day (approximately 7 children a week; 364 each year). On average, 50% of children admitted to the renal ward each year (182/364) would have NS; 30% (109/364) would have lupus; 15% (55/364) ESRF and the remaining 5% (18/364) would have urinary tract infections, pyelonephritis or haematuria. More children were generally admitted in winter when there were more viral infections circulating.

Hospital C

- **Incidence** – it was estimated that they see 150–200 new cases of NS each year. Numbers have been increasing in recent years (before 2000 they were seeing 100 new cases each year, so there has been a 50% increase over the last decade), and this may represent increasing awareness.
- **Prevalence** – not certain
- **Types of NS** - more than 70% of the children with NS at Hospital C had SSNS, and around 30–40% of these were frequently relapsing. Patients with NS represented 70% of all renal patients seen at Hospital C (both inpatients and outpatients). Lupus would be the next most common condition (estimated at 1–2 new children each month; more than 10 new patients in the last year), followed by urinary tract infections and tubulopathies.
- **Outpatients** - estimated they would see 60–80 outpatient presentations of NS each week (just over 4,000 each year).
- **Inpatients** - bed occupancy rates in the renal ward at Hospital C were consistently over 100%, ranging from 100–170% occupancy.

In general terms, it was reasonable to assume there were about 3,000 children with NS in Vietnam at the time of this research project, with at least 600 new children diagnosed with NS in Vietnam each year. These numbers suggested the burden of NS in Vietnam was several magnitudes greater than in Australia (even accounting for a four-fold greater population base in Vietnam). Whilst male children were more likely to be affected by NS independent of external factors, there was also acknowledgement of male sex preference by parents in Vietnam [74].

Complications, challenges and burdens

Key challenges and burdens relating to NS as described by paediatric nephrologists and hospital executives in Vietnam in 2010 included:

Overburdened health systems

Anecdotally, virtually all children with NS in Vietnam relapse at some stage (one doctor shared that in 12 years they had only ever had one patient who did not relapse after the initial diagnosis). As a result, there were large numbers of patients to be managed, and the consequent impact of this on inpatient and outpatient cases of NS at each hospital represented an enormous burden on the health system. Each hospital reported average bed occupancy rates in the renal wards as above 100%.

To complicate the large numbers of patients, existing recall and follow-up systems that had been established to review and manage children with NS were onerous. Children without symptoms were required to present monthly for routine checks (admittedly, this would often also be to collect medicines they could not purchase locally), and this further burdened already stretched outpatient clinics.

Historically, hospitals used to keep children with NS as inpatients until proteinuria had cleared completely. Whilst approaches to care were being streamlined, even in 2010–2011 the length of inpatient stay for children with NS in Vietnam appeared significantly longer when compared with Australia, where children were either not admitted or were admitted overnight only for an albumin transfusion and discharged next day. It was postulated this may have reflected different education levels of families, with more highly educated families who knew how to test urine at home generally appearing to spend less time in hospital. However, the health insurance system was also implicated because it did not cover cost of medications for FSGS NS in outpatient settings.

Poverty and disadvantage

The average monthly income of families was low, particularly for those in rural and remote areas (USD$30/month for rural families, USD$113 for urban families with CKD [5]) and this was believed to have major impact on families' capacity to travel to the hospital and afford essential care for their children. Particularly for families living far from the hospital and experiencing dire poverty, transportation and care (notably medicines for FSGS NS) were too expensive to maintain over the longer term and there were very few charitable organisations offering support for the department or individual families in need of urgent support.

Whilst health insurance was relatively accessible to all (with specific insurance for the poorest families covering 100% of treatment costs), a range of complex barriers and bureaucratic misalignments meant very few families found health care affordable or sustainable. Essential medicines were not available on the national insurance list, and whilst steroids were relatively affordable for families, all treatments for FSGS and some vaccines were largely beyond the means of poorer families. Although some families were eligible for insurance (such as insurance for the poor), complex policies often presented barriers to families accessing medicines. For example, medicines for FSGS were only available on insurance schemes during inpatient care (if at all – levamisole and rituximab were not covered in 2011), which resulted in prolonged admissions for poor families who were unable to afford the cost of purchasing the medicines as outpatients. Another example related to families having to follow strict referral processes through provincial hospitals prior to their arrival at a tertiary centre for care. Decisions by parents to bypass these interim steps (e.g. if a child was critically ill and a family did not want to risk local treatment) resulted in their expenses being ineligible for reimbursement by the insurance system. Doctors estimated up to 80% of families elected to bypass formal referral processes in this way. Yet another example related to school insurance; ironically, if a child was sick and did not attend school, health insurance would be removed for non-attendance.

It was acknowledged that families of children living with NS in Vietnam were in urgent need of support and networking. Health professionals familiar with CLAN's work to support children living with CAH, diabetes and autism in Vietnam were keen to see the establishment of similar platforms and processes for families living with NS.

Health literacy

Health professionals were of the general view that very few families understood how to manage NS. Because of the large numbers of children presenting to inpatient and outpatient departments at hospitals and the small number of trained doctors, the time available to teach individual families about NS was limited. Staff estimated each family was allocated about two minutes per outpatient appointment, and minimal time beyond the delivery of essential care was available to families during inpatient admissions. For a chronic condition as complex as NS, there was acknowledgement this situation was less than ideal, yet stakeholders felt that a range of structural factors made it almost impossible to operate differently.

Wealthy families had the luxury of seeing specialist doctors in less rushed private consultations and could spend more time with health professionals to have more questions answered, but this did not help the poorest families, who all relied on the national hospitals for health care. To make matters worse, there were no educational resources available to share with families in Vietnamese language, and at the time of this research project most poor families did not have access to the internet in their home nor capacity to read English, and thereby were denied access to quality, accurate educational materials.

Workforce challenges

Generally speaking, the most senior paediatric nephrologists in Vietnam had studied overseas at some point in their career [5]. Senior doctors were keen to support their junior staff to have similar international experiences, but such placements were proving increasingly hard to identify. Certainly, positions in Australia were less commonly available in 2010–11 than they had been in previous years (perhaps due to stricter registration and training position requirements). Current training for paediatric nephrology in Vietnam required doctors to complete six years training as an undergraduate (to be a general doctor) then six months training to be a general paediatrician. Once a doctor became a general paediatrician, further sub-specialty training in paediatrics would involve 66 hours of training to achieve a paediatric nephrology certification [5]. Doctors keen to work as specialists in tertiary University and government hospitals would need to complete two years of training under the Ministry of Health (practical experience) and three years through the Ministry of Education (requiring a Master's degree as a minimum and practical experience).

Despite the many years of training, paediatric nephrology was not considered a lucrative specialty (particularly compared with surgical specialties such as Ear Nose and Throat surgery). This view was confirmed in the literature, with Vietnamese nephrologists estimated to earn just USD$2,800 per annum in 2003, the lowest wage in South East Asian countries included in the analysis [102]. To compound the low pay, paediatric nephrology was generally acknowledged as a demanding specialty. In addition to caring for children with renal conditions, nephrologists had historically also provided specialist care for children living with endocrine conditions in Vietnam (paediatric endocrinology was a relatively recent specialty field in the country at the time), so this further increased the workload of these doctors and was felt to make the specialty less attractive to young graduates looking for a rewarding career.

Nursing staff were similarly keen for training opportunities, and CLAN's previous experience in Hanoi had demonstrated the effectiveness of investing in training nursing staff in specialist roles [44]. In the current environment there were clear opportunities to drive more efficient practices. For example, urine dipsticks were not available on wards, so although staff were trained and could use dipsticks effectively, current systems and processes required ward staff to send urine samples to the laboratory for testing, thereby delaying results by up to a day, unless the request was marked urgent.

Dialysis and renal transplantation for children in Vietnam

For children with ESKD in Vietnam, treatment options were very limited. A small number of dialysis machines was available at two participating hospitals [4, 5] but capacity did not meet demand. For example, at one centre, a maximum of 28 children at any time could access haemodialysis and machines were in constant use at the time of this research project. Peritoneal dialysis was an emerging option (with five children receiving treatment since June 2010 at one centre), but infection was acknowledged as a significant risk. Renal transplants for children were a very recent achievement. The first paediatric renal transplant was completed in 2004 (with support from French colleagues), with another seven paediatric transplantations completed using living donors over the next five years [5]. Doctors in Vietnam were extremely keen to connect professionally internationally to further strengthen their capacity in this regard.

Data management and research

None of the participating hospitals had software available to document patient movements through the system. Admissions, follow-up and outpatient care were difficult to track, and this was acknowledged as a limitation to research [4, 5]. Health professionals were keen to publish their work in recognised paediatric nephrology journals, and it was noted that collaboration with expert researchers internationally would be a great support. Staff were keen to learn more about the Cochrane Kidney and Transplant group from Dr Elisabeth Hodson. Topics identified as future research priorities included congenital NS, steroid resistance NS, lupus and genetic aspects of NS.

The burden of communicable diseases

Infections were widely acknowledged as a particular burden, especially in wintertime. Most families were believed to be up to date with the national vaccination schedule, this did not cover additional vaccines (such as pneumococcal vaccine, varicella or hepatitis). These vaccines were not free, and no systems were in place to help families afford access to these medicines to ensure all children were optimally immunised.

Professional networking

Paediatric nephrologists in Vietnam considered they had limited opportunities for connecting, communicating and collaborating with peers. With the limited number of paediatric nephrologists nationwide (estimated to be 10 at the time), a national society would be very small, so there were considerable benefits to collaborating internationally. There were some international contacts with colleagues in France and Singapore, but more support was considered crucial. International training opportunities were highly sought after by young doctors, with current training requirements in Vietnam not meeting recommendations of the European Society for Pediatric Nephrology [4, 5]. Strengthening connections with colleagues in the International Pediatric Nephrology Association (IPNA) and the Australian and New Zealand Paediatric Nephrology Association (ANZPNA) were identified as priorities. Barriers to participation in professional conferences and networks included expense (USD$175 membership annually; travel to conferences) and access to online journals (the transition of Vietnam to middle-income country status means the Cochrane Library is no longer free; likewise, when doctors are not members of professional societies, they are unable to access the journal *Pediatric Nephrology*).

Steroid resistant NS

SRNS is intrinsically challenging to treat even for health professionals and families in Australia. In Vietnam, the situation was compounded by the high cost of medicines needed to manage FSGS. Especially for poorer families, access was unaffordable to evidence-based gold standard treatment regimens, which resulted in children being prescribed drugs that were known to be less effective (as opposed to no treatment at all) or staying in hospital for prolonged periods so they could receive medicine as inpatients only to have the child frequently re-presenting soon after discharge with another relapse. The impact of these long hospitalisations was significant. Children could not attend school and consequently were no longer eligible for health insurance, and so families would be caught in a vicious cycle of despair, ill health and poverty.

End of life considerations

Despite the limited treatment options and challenges facing families, no real palliative care options existed for children with renal failure in Vietnam at the time of this research. Huong *et al* acknowledged that whilst in-hospital mortality rates were low for children with CKD, the figures did not reflect the high mortality rates outside of the hospital setting [5].

One paediatric nephrologist (Dr Hoang Thi Diem Thuy from Children's Hospital 2 in Ho Chi Minh City) summed up the challenges and barriers by sharing an acronym they had developed to explain what families of children living with NS were scared of (GHOST!):

G – Growth retardation

H – Hospitalisation (because of fees and duration)

O – Other drugs (all drugs not on insurance – expensive)

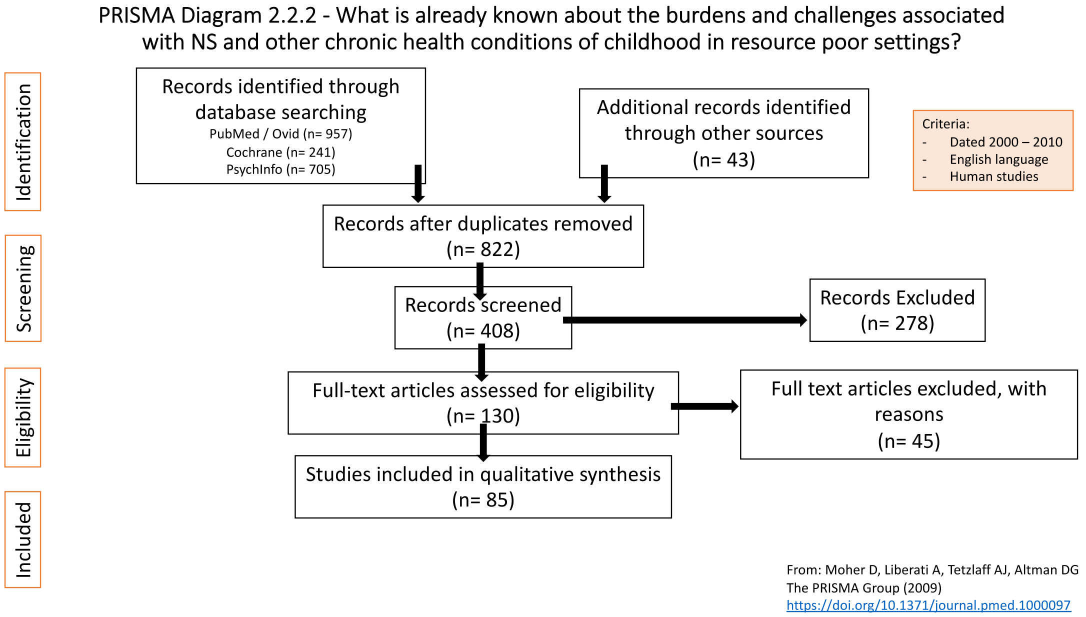
S – Society (challenges with integration / many do not go to school)

T – Transport to and from hospital (more than 50% of families travel long distances with three or four family members (child and parents, siblings etc) which makes travel very expensive in terms of time, money and loss of income.

2.2.2 Search question 2 - What is known about the burdens and challenges associated with NS and other chronic health conditions of childhood in resource-poor settings globally?

Search strategy

An overview of the approach take to this question is presented in Figure 9.



From: Moher D, Liberati A, Tetzlaff AJ, Altman DG
The PRISMA Group (2009)
https://doi.org/10.1371/journal.pmed.1000097

Figure 9 - Use of PRISMA Diagram to document search question 2

Because of the limited information available relating to NS in Vietnam, the literature review was expanded so that evidence relating to the impact not only of NS but of chronic health conditions of childhood more generally in resource-poor settings around the world could inform the project. There was acknowledgement that chronicity, and not just the innate nature of NS itself, was relevant to understanding the burden and challenges being experienced by the NS Community of Vietnam.

Sources of information used to research this question included: published literature, grey literature (including organisational reports, conference papers and posters, and other unpublished materials), web sites and expert opinions. Search terms used when reviewing the literature to answer this question included:

- Child* OR adolesc* OR pediatric* OR paediatric* OR teen*
- nephrotic syndrome OR renal OR kidney
- Chronic OR chronic disease OR non-communicable disease OR chronic health condition
- quality of life

- morbidity OR mortality OR burdens OR challenges OR barriers OR fears OR burden of illness OR impact OR problem
- low income OR developing OR resource-poor OR poverty
- Vietnam

In some cases, additional searches were conducted to identify articles specifically relating to the main types of NCDs and other chronic health conditions affecting children in resource-poor settings, including type 1 diabetes, rheumatic heart disease, asthma, HIV/AIDS, cancer, epilepsy and other types of chronic kidney disease.

Search findings

a) Burdens and challenges of Nephrotic Syndrome and other renal conditions in other resource-poor settings

The inequities associated with renal disease are enormous. Limited accurate data from low- and middle-income countries make it difficult to quantify the true burden of nephrotic syndrome, with estimates based on extrapolations from high-income countries sometimes offering best-guess insights of the enormous gaps that exist. For example, in 2009 it was estimated that 1.8 million people worldwide were alive currently because they had access to renal replacement therapy of some kind; of these, 90% were living in high-income countries [106], a stunning inequity considering only 15% of the world's population live in high-income countries [136].

Exact incidence and prevalence figures of NS (or any renal conditions) of childhood are rarely available from low-income countries [120], and crude estimates primarily rely on data emerging from tertiary referral centres. As a consequence, most data are usually limited to analysis of ESKD (because much CKD is asymptomatic and not diagnosed until late in the course of the disease), and this contributes to under-reporting of the true burden of CKD by an estimated factor of 50 [138]. Late stage diagnosis of paediatric renal disease is a major challenge in resource-poor settings [121-123]. The absence of paediatric nephrology societies in low-income countries compounds matters, and strong calls have been made to strengthen the epidemiological data available on renal disease in children [138].

Estimates of CKD prevalence in resource poor settings are informed by an examination of the situation in high-income settings. Data from America, Australia, Europe and Japan suggest between 6% and 16% of the total populations were affected in 2007 [138]; in 1997 the incidence of CKD in children under the age of 16 years in Sweden was estimated at 7.7 per million each year [120]. The limited available evidence suggests the burden of CKD in resource-poor settings is likely higher than that seen in high-income settings, and whilst data limitations make it hard to determine the exact reasons for this, likely factors include: the higher levels of infection in resource-poor settings; limitations in prevention, screening, early diagnosis and treatment of NCDs; unaffordable access to healthcare; limited health literacy and a paucity of health promotion activities[102, 106].

Similarly, whilst the prevalence of ESKD (all ages) in the USA was estimated in 2006 at around 1500 per million population, in low-income countries the evidence suggests numbers range from below 100 (sub-Saharan Africa and India) to 400 (Latin America) and

600 (Saudi Arabia) per million population. These documented differentials in prevalence do not reflect differences in the true burden of disease so much as inequitable mortality rates [120, 136], and indeed the especial challenges associated with transplantation for children in developing countries (most particularly the financial barriers) are well documented [107, 139]. An estimate of the prevalence of ESKD (and renal replacement therapy) for children under the age of 14 in Europe was 43 per million in 2005 [120]. In the USA, children under 20 years of age account for less than 2% of all patients with ESKD [140]. Best estimates of incidence of ESKD in developing countries in 2006 were approximately 150 per million population, while rates of 330 per million in high-income countries probably reflected a combination of genetic factors and the higher burden of NCDs in high-income countries at the time. This is likely to change over time as the double burden of NCDs in low-income countries increases [120].

The inequitably high morbidity and mortality of renal disease experienced by adults and children in Africa have been estimated to account for 2–3% of all medical admissions, with NS identified as the most common renal condition overall (usually presenting in children between the ages of 5 to 8 years) [141]. Indeed, NS has been identified as a common cause of renal disease in childhood in many countries [103, 105, 110, 142-145], researchers documenting large cohorts of children with NS to study in resource-poor settings. One Indian study from 2002 in Lucknow involved 600 children with idiopathic nephrotic syndrome from a single centre over a ten-year period [106, 146], while a study in Iran investigated 1,358 children with renal disease treated between 1993 to 2000, of whom 19% (252) had NS [104]).

Treatment modalities for renal disease are limited in resource-poor settings, and at the far end of the spectrum renal transplantation and dialysis are almost uniformly beyond the reach of the world’s poorest peoples [102]. At one facility in India, up to 40% of patients with ESKD opted out of further care [147] with cost identified as the major barrier. Another study in South Africa determined the majority (60%) of patients with ESKD were denied renal replacement therapy because of socio-economic factors [148]. High mortality rates associated with renal disease in resource-poor settings are clearly a direct result of the unaffordable nature of renal replacement therapy, but despite this there is no evidence to suggest widespread, systematic protocols and programs are in place to support people dying from ESKD in resource-poor settings to ensure they experience humane deaths. Solutions are urgently needed; experts estimate the prevalence of persons requiring maintenance dialysis will continue to increase by 7% annually [148].

More generally, sustainable funding for renal health programs – even those demonstrated to be effective – can be hard to secure in resource-poor countries [149]. The lack of screening, diagnostic and therapeutic capacity is widespread, and the resource and technical capacity required for some aspects of care (such as renal biopsies, dialysis and transplants for ESRF) is limited. Workforce challenges are another major concern, with small numbers of adequately trained or remunerated clinicians available to meet the need [102]. Language barriers, training opportunities, financial burdens and cultural gaps have also been noted as key challenges.

There are limited data in the literature regarding the burdens, challenges and felt needs experienced by families of children living with NS in resource-poor settings. One study in

2008 of the psychological health of parents caring for children with NS in China showed that parents of children living with NS (especially those experiencing financial distress, and parents with higher education levels) had higher rates of anxiety and depression than their counterparts in society ($p<0.01$), and simple support measures during their child's admission to hospital could have positive benefits for their wellbeing [130].

There is sharing of general advice about topics to discuss with families at the time of diagnosis, such as information about NS, prognosis, urine testing at home, side-effects of medicines and what to do if there is a relapse [14, 108, 150]. However, specific educational resources to empower families caring for children living with NS were rarely referred to in the literature and no such resources were available in Vietnamese language at the time. This was of relevance given that each family had, on average, two minutes with their treating doctor in busy outpatient departments, during which oral transfer of knowledge and information would be necessarily limited.

From the perspective of health systems and policies, there are challenges relating to definitions and awareness. The complexity of chronic conditions of childhood has been well documented, particularly the lack of clear definitions and categories [116, 118]. To compound this, paediatric nephrology is a complex sub-specialty within paediatrics, and in most resource-poor settings the absence of qualified professionals and accurate patient registers further compromises the capacity of most countries to communicate clearly to politicians the full extent of the burden of illness, inequity and needless suffering that is occurring every day. Impoverished families, depressed and exhausted, have minimal capacity to advocate and raise awareness, and the children themselves, if not dead, have no voice to use. So the vicious cycle of inequity associated with paediatric renal disease in low-income countries continues.

b) Challenges and burdens associated with other chronic conditions of childhood in resource-poor settings

There was limited information in the literature on the epidemiology of chronic health conditions of childhood in resource poor settings. One source estimated 15% of adolescents globally were living with a chronic condition [151]), although chronic disease of adulthood were acknowledged as a major public health challenge. Chronic diseases were noted as the major cause of death and disability worldwide, resulting in 59% of all deaths and 46% of the global burden of disease, with 80% of deaths caused by chronic conditions occurring in developing countries [151, 152].

Beyond simple definitional challenges [99, 116, 118, 153], conceptual challenges loomed large. From a policy perspective, the exclusion of children and adolescents from the international discourse relating to "chronic disease" and "the prevention of chronic disease" by United Nations Member States and policy makers was problematic. As at December 2010, the draft Declaration for the UN High Level Meeting on NCDs planned for September 2011 had no mention of children or young people with regard to the prevention or management of NCDs [51].

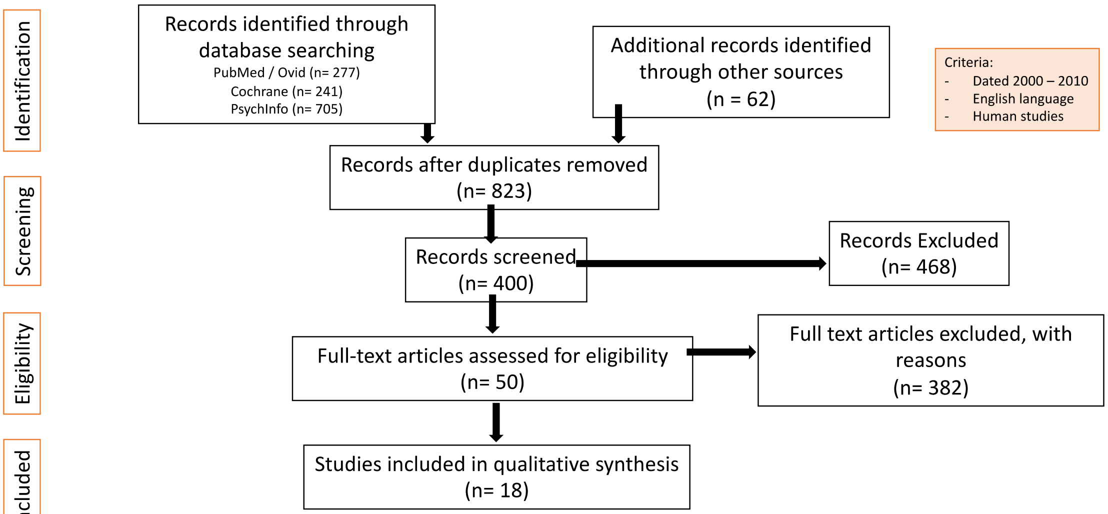
At a grassroots level, the challenges and burdens experienced by children and young people living with chronic conditions, and the families and health professionals who care for and support them, appear almost universal. Whether it be diabetes [149, 154-158], epilepsy [159], cancer [26, 160], asthma [159, 161-167], heart disease [159, 168], CAH [27, 29, 33, 43, 169, 170], osteogenesis imperfecta or other conditions, the challenges facing those involved are similar. These include inability of the poor to afford quality care, lack of affordable access to essential medicines and equipment, lack of data and patient registers to facilitate research, lack of community awareness leading to stigma and social isolation, limited health literacy and specialist expertise in the field of childhood chronic conditions within resource-poor countries (at all levels of society and health systems – including parents and families), lack of education and training opportunities, and the challenges of poverty and inequity more broadly. These all contribute to preventable morbidity and mortality. Whilst there were some innovative calls by paediatric societies to redress these inequities [171], very little coordinated global action was documented.

2.2.3 Search question 3 - What recommendations have already been made with regard to reducing burdens and optimising quality of life for children living with NS and other chronic health conditions in LMICs?

Search strategy

An overview of the approach take to this question is presented in Figure 10.

PRISMA Diagram 2.2.3 - What recommendations have already been made with regards reducing burdens and optimising quality of life for children living with NS and other chronic health conditions in LMICs?



From: Moher D, Liberati A, Tetzlaff AJ, Altman DG
The PRISMA Group (2009)
https://doi.org/10.1371/journal.pmed.1000097

Figure 10 - Use of PRISMA diagram to document search question 3

Again, where possible, this search was not limited to specific health conditions, nor any specific geographic or economic group. Given the scant published data relating to NS available at the time (much less NS in Vietnam), a decision was made to explore key learning that may have arisen also from other chronic conditions of childhood in LMICs. This decision also reflected a recognition from CLAN's experiences to date that "chronicity" was a shared feature of most NCDs, and in this way experiences across a range of childhood NCDs in LMICs might inform recommendations on collaborative actions to protect and promote the rights of all children to health and life through sustainable, scalable efforts to fast-track equity.

It is important to note that this time period was a very dynamic one in terms of the terminology in use around “chronic disease”. During the course of this literature review, the terminology around “chronic disease” was shifting gradually to refer instead to “non-communicable diseases” (NCDs) and this was in large part attributable to the United Nations High Level Meeting on Non-Communicable Diseases planned for September 2011. The researcher was leading global advocacy efforts for children living with chronic health conditions in LMICs throughout the period of 2011 to 2014, and NCD Child was formally launched as a global coalition by CLAN in October 2011. Some publications co-authored by the researcher as part of this advocacy effort were included in Section 2.4.1, because they were not reflected in the pre-2010 literature review.

Sources of information used to research this question included the published literature, grey literature, online reports and expert opinions. Search terms used when reviewing the literature to answer this question included:

- nephrotic syndrome OR renal OR kidney
- quality of life OR health OR wellbeing
- morbidity OR mortality OR burdens OR challenges OR barriers OR fears OR burden of illness OR impact OR problem
- child OR adolescen* OR pediatric OR paediatric
- low income OR developing OR resource-poor OR poverty
- Vietnam
- chronic OR chronic disease OR non-communicable disease OR chronic health condition
- recommendations OR enablers OR guidelines

Search findings

In the first instance, the literature review was used to identify realistic recommendations that could inform multisectoral collaborative action to effect long-term, sustainable change to benefit the children and families most affected by NS in Vietnam and address the challenges and burdens they experience. Whilst such recommendations would be focused on Vietnam in the first instance, the overarching goal was to identify solutions that could be replicated internationally, to address situations facing families living with NS and other childhood NCDs in other LMICs.

Learning from experts in Vietnam

Discussions with paediatric nephrologists and health executives in Vietnam established there was clearly an urgent public health crisis. Hospitals were extremely busy, there were unmanageably high patient loads and health professionals could only spare limited time with patients and families, poverty (in many cases caused by desperate efforts to care for their child with NS) reduced families' capacity to afford the care their children continued to need to survive, health outcomes were suboptimal and children missed school as a result of being ill or travelling to the tertiary referral hospital regularly for care, families were losing income caring for their children, and children were suffering from preventable morbidity and mortality. Children and families, health professionals and health systems alike were trapped in a vicious cycle, with the only escape being the death of a child or an elusive, magical cure (that never happened, despite monies spent on alternative therapies).

- Some of the many recommendations emerging from consultation with stakeholders (health professionals, hospital executives and families) in Vietnam during the planning phase of this project included:
- Affordable access to essential medicines for NS management is needed (notably mycophenolate mofetil (Cellcept), cyclosporin (Neoral), tacrolimus and rituximab)
- Train health professionals in primary and secondary medical centres in the treatment of NS to minimise transport costs for families to tertiary centres; run regular academic programs to strengthen workforce capacity nationally
- Develop and share national guidelines on the management of NS in Vietnam
- Reduce unnecessary hospitalisations (to ease burdens on families and hospitals alike)
- Communicate and promote clear guidelines for referral to tertiary referral centres
- Campaign for families
- Strengthen education and support for families, including counselling and formal psychiatric interventions where needed
- Targeted education and support for families with low levels of health literacy and those living long distances from the hospital; promote / verbally reinforce key messages to families regularly
- Test for gene disorders in SRNS (Vietnamese staff would be keen to collaborate internationally on this) to help better understanding underlying causes
- Invest in the formation of young nephrologists, for example with PhDs or short-term scholarships, promote training placements at sister centres internationally, provide fellowships and research opportunities in pathology
- Promote dipstick testing by local family doctors – for early and easy diagnosis and referral to a paediatric nephrologist
- Provide transport, housing and food gratuities for the child and accompanying adult when a child requires dialysis treatment
- Strengthen disability benefits and travel subsidies for children with chronic conditions
- Investigate stress factors and design support systems to provide true holistic care
- Support the formation of support groups, and include families of children that have "grown out of NS" of differing severities to promote hope and awareness of the good prognosis most children can hope to enjoy)

Whilst not specifically focused on chronic conditions affecting children, one model shared suggested a focus on seven themes (using "SCIENCE" as an acronym) to guide action to enhance global capacity in chronic disease surveillance, prevention and control [172]:

- **S**trategy – to guide action plans

- **C**ollaboration – with focus on multidisciplinary expertise and dialogue between countries
- **I**nformation – use of data
- **E**ducation – based on user needs and priorities
- **N**ovelty – new ideas and ways of thinking
- **C**ommunication – two way using range of media
- **E**valuation – to track progress, with focus on participatory action research that puts knowledge into action

Models relevant to improving health outcomes for people living with chronic health conditions

Community development

In the 1970s, the Alma Ata Declaration changed the way health care and health systems were considered, and highlighted the importance of "community" and primary health care providers and systems in the context of sustainable health solutions [173]. The Ottawa Charter for Health Promotion [174] built on the developments of the Alma Ata Declaration, and called for proponents to advocate, enable and mediate for health, in the context of acknowledging the following conditions and resources as pre-requisites to health: peace; shelter; education; food; income; a stable ecosystem; sustainable resources; social justice and equity. The Ottawa Charter identifies five action areas as key to health promotion, and interestingly, the five action areas align strongly with CLAN's five pillars, and both models reflect a holistic ›and comprehensive approach to health promotion (Table 2).

Table 2 - Comparison of the Ottawa Charter Action Areas and CLAN's Five Pillars

Ottawa Charter Action areas	CLAN Strategic Framework for Action pillars
1) Building health public policy	Pillar 2 – Education, research and advocacy
2) Creating supportive environments	Pillar 1 – Affordable access to essential medicines and equipment Pillar 5 – Promote financial independence
3) Strengthening community action	Pillar 4 – Encourage family support groups
4) Developing personal skills	Pillar 3 – Optimisation of medical management Pillar 2 – Education (of children, families, health professionals, government and community), research and advocacy
5) Re-orientating health care services toward prevention of illness and promotion of health	Pillar 3 – Optimisation of medical management, with a focus on prevention

The Wagner Chronic Illness Care Model (CCM)

The Wagner Chronic Illness Care Model [175] shown in Figure 11 also promotes community involvement and focus, with active involvement of informed patients. Wagner identified six essential elements of a health care system that promotes quality chronic health care and improved functional and clinical outcomes:

1) Community – including organisations and resources for patients
2) Self-management support
3) Delivery system design
4) Decision support
5) Clinical information systems
6) Health system – organisation of health care

An evaluation of the Wagner model in 2009 suggested that whilst helpful, its complexity was a burden, and its success with paediatric chronic conditions (asthma) was not strong [152].

Figure 11 - The Wagner Chronic Illness Care Model (CCM) [175] – redacted for copyright

Innovative Care for Chronic Conditions (ICCC)

In 2002 the WHO shared an expanded framework for chronic care, known as the innovative care for chronic conditions framework (ICCC) [176], shown in Figure 12. This strengthens focus on the policy environment. Whilst later articles spoke to the importance and value of the ICCC in scaling efforts for NCDs in resource-poor settings [177], specific examples or success stories relating to the use of this model to redress inequities for children living with chronic conditions were not identified.

[redacted]

Figure 12 - The Innovative Care for Chronic Conditions (ICCC) framework [176] – redacted for copyright

Aboriginal Community Control

Commitment to community development, primary health care and the Wagner model were features of approaches to CKD adopted by Aboriginal and Torres Strait Islander Communities in Australia [149]. Primary health workers ran programs that addressed community priorities and were evaluated. Aboriginal health workers followed algorithms for testing and treatment with support from nurse co-ordinators. Identified success factors included the active involvement of community in all stages of the program, with community control and authority promoted at all times [178]. The focus on adults, use of computer databases and preventable health conditions made the findings somewhat less relevant to this research project. Indeed, with the international literature focusing on NCDs in adults more generally, the focus on screening as a solution was a strong theme overall [106]. Whilst relapses can be prevented in patients with NS, and preventive measures (such as vaccination) may help in reducing the high mortality rate and the need for dialysis [143], such an exclusive focus on preventive action was not relevant to this research project looking to benefit the NS Community of Vietnam.

Integrated Management of Childhood Illness (IMCI)

The WHO's Integrated Management of Childhood Illness (IMCI) [179] is a useful tool to facilitate quality care for children with chronic conditions such as HIV and AIDS, however it does not provide specific advice for all chronic conditions (and certainly not NS). Review of IMCI when national treatment guidelines for NS are developed could be worthwhile.

Overall, there was strong acknowledgement in the literature that health is influenced by social and economic circumstances and any improvements in health will necessarily require integrated, comprehensive action against all the determinants of ill health [141].

CLAN's Strategic Framework for Action

CLAN's work with clinicians and hospital administration in Vietnam over the preceding five years suggested children living with chronic health conditions did better when five key pillars (see Figure 1) were addressed for the entire community of children living with that same condition in a country [180]. The pillars were:

1) Affordable access to essential medicine and equipment
2) Education (for the children, families, health professionals, government and communities locally, nationally and internationally), research & advocacy
3) Optimal medical management (with a commitment to primary, secondary and tertiary prevention)
4) Encouragement of family support networks
5) Reduced financial burdens, and promotion of financial independence for families.

Whenever any of the five pillars were not addressed, stakeholders agreed the adverse situation would continue. Children would experience more frequent and severe relapses of

NS, families would visit hospitals seeking help, hospitals would be busier, children would have more complications, and ultimately, children would die. Until the five pillars were addressed, families and hospitals caring for children with NS in Vietnam would continue to be locked into a vicious cycle of death and despair (see Figure 13). It would take a commitment to change the status quo, and an investment of time, resources and energy would be required from many stakeholders to break the vicious cycle.

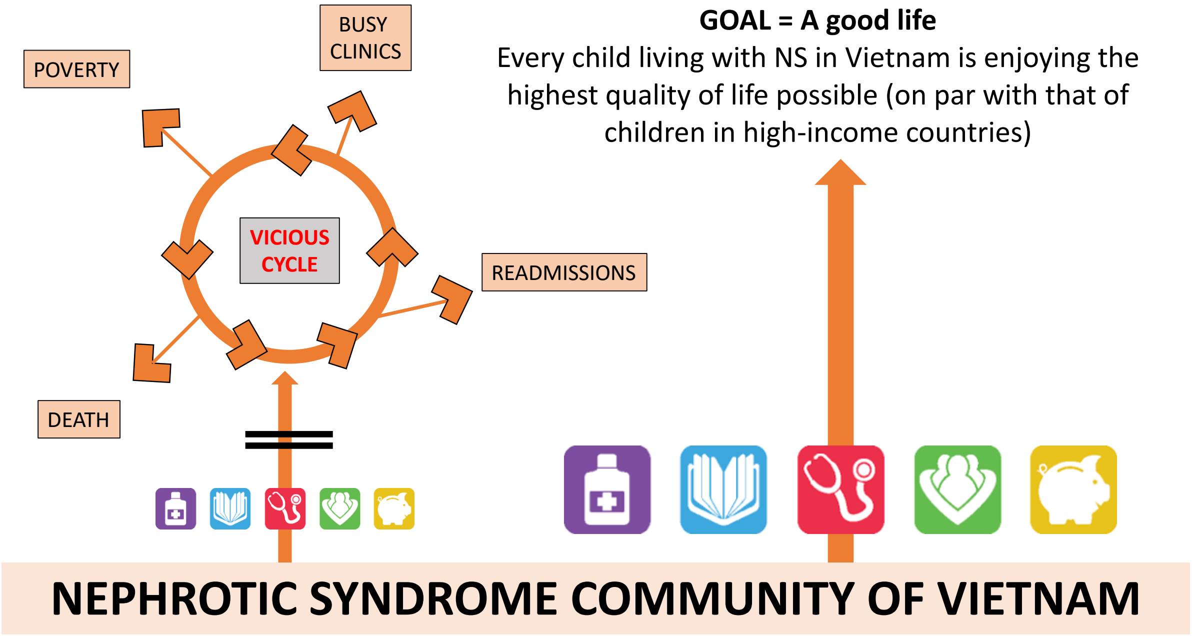


Figure 13 - The vicious cycle associated with Nephrotic Syndrome (NS) in Vietnam

Other specific initiatives to improve outcomes for people living with chronic conditions

Additional specific initiatives for driving change were identified in the literature.

Self-management

Detailed understanding of the medicines and other management required to manage chronic conditions of childhood can be low in resource-poor settings and use of traditional medicines can be high, so initiatives that strengthen patient and family engagement and health literacy were considered essential [163]. Chronic conditions have the potential to reduce the capacity of children to attend school, so targeted home and school education can be very powerful [167]. Information and support at the time of diagnosis of significant childhood conditions was particularly important [181]. Whilst strong evidence for the benefits of self-management in high-income countries was readily available, limited evidence was identified relating to childhood chronic conditions in resource-poor settings.

Patient and family education and support

Not surprisingly, the psychological health of parents is affected by NS and there is evidence to show psychological state is linked to education level and NS relapses (in the case of anxiety) and economic income (for depression). Simple interventions by health professionals during hospital admissions, such as cognitive interventions, reassurance, encouragement, listening and providing comfort had a statistically significant effect on parental wellbeing [130].

Harnessing data, research and patient registers

There was universal acknowledgement of the power of data and information and establishing the epidemiological profile of a chronic health condition is an important step that should be prioritised. Understanding the determinants of disease should guide actions and solutions [163]. The quality of research available relating to HIV and AIDS undoubtedly reflected the funding allocated to it, but serves as a useful target for the NCD movement to aim for [182].

Policy and advocacy

The evidence indicated clear messages should be shared with policy makers and inform collaborative efforts to drive change and promote access to affordable essential medicines. Treatment guidelines were effective in resource-poor settings, and advocacy to enhance affordable access to healthcare for children with chronic conditions was considered important [167].

Health insurance

The importance of health insurance for children and families living with chronic health conditions was well established and can directly affect health outcomes and access to care at a national level [64, 159, 183, 184]. The need to identify and address gaps in health insurance cover are critically important [63], although insurance is not a panacea and other barriers (including non-financial barriers) to care must be considered [185, 186], particularly for the very poor [187]. The special needs of adolescents living with chronic health conditions of childhood should especially be considered [188].

A strengths-based approach

There is limited literature highlighting the strengths to be found in resource-poor settings, but they can provide powerful insights [189]. The importance of stakeholders working together across borders and cultures for the benefit of all is imperative. High-income health systems have much to learn from colleagues and practices in low-income settings, and strengths as well as gaps should be researched and shared.

The imperative of a focus on inequities and cumulative disadvantage

Whilst not specifically referring to chronic conditions of childhood, one concerning observation in the literature was the acknowledgement that perhaps worse than a complete lack of specific action to redress child health inequities was the growing realisation that many actions to improve child health in resource-poor settings risk strengthening existing inequities. Through an examination of achievements to date of IMCI initiatives to manage pneumonia in children, it was seen that interventions systematically prioritising and targeting those who were most easily reached – as opposed to those with the greatest need – risked widening existing divides. Poverty, ethnicity, geography and limited access to highly functioning health facilities were acknowledged as key determinants of health inequities that negatively affect child survival [190]. Ethnicity, family structure (with single parent families at especial risk), poverty, and low parental education were proven to have cumulative effects on the life chances of children and should not be considered simple proxies of underlying disadvantage [185].

2.3 Search summary

This literature review was undertaken to facilitate the development of a sound research project. The literature review sought to identify existing gaps in the current international literature as it related to NS in LMICs and inform the ongoing development and conduct of the research project to address this important public health problem.

An introductory review of existing literature confirmed the wisdom of local health authorities in requesting a focus on NS in this research project. There was considerable information on NS and how to manage it in children in high-income settings, very little of which was relevant to children, families or health professionals living in resource-poor countries where medications, investigations and therapies were largely unaffordable (if not completely unavailable) and health systems struggled to deliver quality care in busy, over-crowded outpatient departments.

The decision to expand the search beyond NS to other chronic conditions of childhood was also important. References to chronic kidney disease (CKD) in low-income settings were primarily focused on adults, and evidence relevant to the prevention of renal disease was limited to adult-onset disease rather than child health (for example reducing the impact of smoking and hypertension). In fact, the plight of children living with NS in LMICs was limited largely to descriptive studies, with little in the way of practical recommendations to drive sustainable change in resource constrained settings.

2.3.1 Key themes

Key learnings emerging from the literature review process were summarised as follows:

NS is a major burden on the health system of Vietnam and other low-income countries

The chronic, relapsing nature of NS means this condition places enormous strain on health systems in low-income countries. When affordable treatment is not available, children relapse more frequently and severely, and require more hospital care.

Investment in NS makes sense

NS is a common cause of renal failure in children and seems to be more common in resource-poor settings because of the high prevalence of infectious disease. With access to quality treatment, the majority of children (>90%) with NS should expect to enter adulthood with normal renal function. For most of these children, treatment with oral steroids (cheap and widely available) is effective. Without appropriate treatment, almost all children with NS will die. Management of NS is somewhat complicated, but the cost–benefits of treatment would appear to be very favourable.

ESKD in low-income countries is challenging

The cost of renal replacement therapy is high, and beyond the means of most families in low-income countries. It is not currently feasible to treat all children with ESKD around the world. Where children cannot access appropriate treatment for ESKD, palliative care options must be made available.

There is a need to prioritise the voices of people living with NS

There is very limited information in the literature about the experiences of people living with NS in resource-poor settings. There were no existing, validated tools available to facilitate consultation with families of children living with NS in Vietnam to better understand their situation at the time of this literature review.

Current models of care to address chronic conditions of childhood are limited

Beyond CLAN's Strategic Framework for Action, existing chronic condition frameworks have not been demonstrated effective to scale change and promote positive health outcomes for children living with chronic health conditions in resource-poor settings, nor redress health inequities. There was value in documenting CLAN's model and considering how findings relating to NS could be relevant to other chronic conditions of childhood.

2.3.2 Remaining gaps in the knowledge base

More research and data are required to inform a better understanding of:

- The experiences of families living with NS in Vietnam and other resource-poor settings.
- The felt needs of families of children living with chronic health conditions in resource-poor countries.
- Successful examples of comprehensive, integrated approaches to chronic conditions of childhood are needed.
- Successful and realistic examples and recommendations of actions that can be taken to improve health outcomes and redress inequities for children living with NS and other chronic conditions of childhood in resource-poor settings are needed.
- Information relating to the implementation (i.e. the "how") of the aforementioned critical and realistic actions that can be taken to redress health inequities associated with NS in resource-poor settings is needed.

2.3.3 Implications for this research project

<u>It was appropriate that this research project focus on:</u>

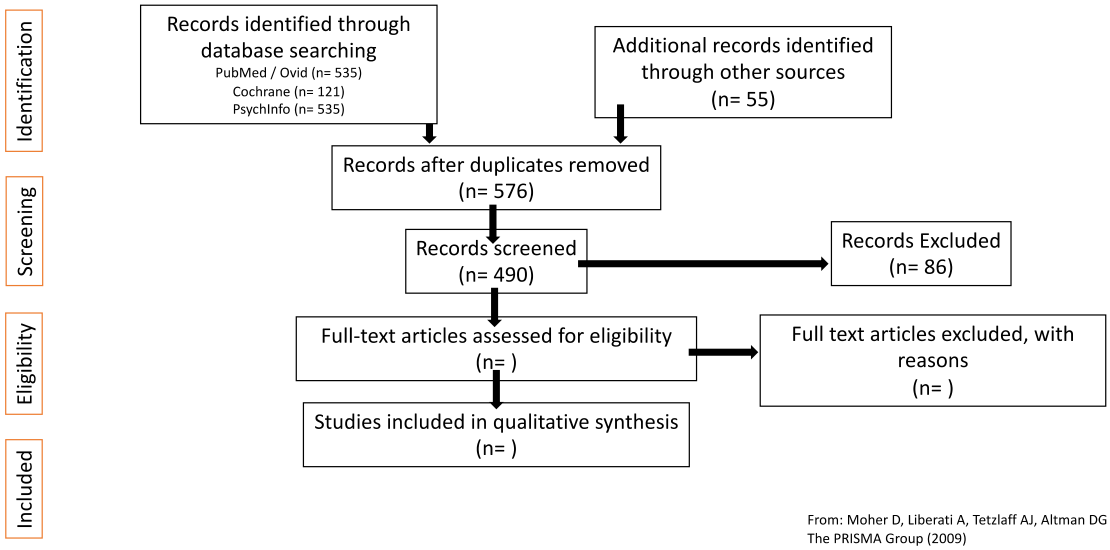
- A strengths-based approach to the conduct of a health needs assessment to better understand the burdens and challenges facing families of children living with NS in Vietnam.
- Identification of recommendations for practical action that can be taken to optimise quality of life and redress inequities for children living with NS in Vietnam and other resource-poor settings.
- Consider the relevance of these findings to other chronic conditions of childhood in resource-poor settings around the world to fast-track equity at scale for persons living in the most vulnerable circumstances.

2.4 Search context

2.4.1 What other insights have emerged in the literature since 2010 about reducing burdens and optimising quality of life for children living with NS and other chronic health conditions in LMICs?

An ongoing review of the literature and active engagement in the global NCD discourse enabled the researcher to stay updated on emerging insights and learnings. A formal rapid review of the literature was undertaken in 2020 to scan for other documents that might offer fresh insights, as shown in the PRISMA diagram in Figure 14.

PRISMA Diagram 2.5 – What have we learned since 2010?



From: Moher D, Liberati A, Tetzlaff AJ, Altman DG
The PRISMA Group (2009)
https://doi.org/10.1371/journal.pmed.1000097

Figure 14 - PRISMA diagram showing search of literature dated 2011–2020

NS in Vietnam

A number of publications on NS in Vietnam appeared after 2010. The researcher and health professionals from Vietnam and Australia co-authored several presentations at international paediatric nephrology conferences [3, 9-11] with the oral presentation at IPNA in 2013 awarded best oral presentation (and USD$500 in prize monies) [3]. (See Appendices 2 and 3.)

Other publications on NS from Vietnam related mostly to advancements in the field of genetics [191-193], although one health professional did complete a thesis on quality of life for children with idiopathic NS in Vietnam [194], and another looked at outcomes for 75 children hospitalised at NHP in Hanoi between January 2015 and December 2015 with SRNS and treated with Cyclosporine A [8]. Although acknowledged mortality rates were high (10.7%) in this descriptive prospective study, it was encouraging to learn 69.3% of the patients with SRNS achieved full remission after 6 months of cyclosporine A treatment.

Translation of findings from NS to Lupus in Vietnam

The researcher was pleased to note the HNA template developed in this research project (see Study One) to survey parents of children living with NS in Vietnam was adapted by local health professionals for use in a consultation with parents of children living with Systemic Lupus Erythematosus (SLE) at NHP in 2013, and an article on Lupus Disease Activity by the same team was published in 2020 [195]. Insights from the broader work of CLAN and NHP in Vietnam relating to CAH was also published in 2020 [38]. Beyond NS and Lupus, publications relating to health inequities for children in Vietnam (notably children from ethnic minority backgrounds) called for specific actions to support disadvantaged populations [196, 197].

NS updates internationally

NS and other renal conditions were consistently noted as contributing a significant burden on the health of children in resource-poor settings in recent international publications. A broad range of challenges and burdens preventing these children from enjoying equitable health outcomes were identified, including late presentations, poor socio-economic conditions, use of traditional medicines, inequitable access to qualified health professionals (in rural areas particularly), lack of health insurance, limited diagnostic facilities and unaffordable access to renal replacement therapy [198-213]. The need for better quality data and registers, particularly for the early stages of CKD, has been specifically noted [214] and information relating to international coalitions, registers and research initiatives that may be of benefit for international collaboration have been disseminated in the peer reviewed literature [215].

In 2011 a cross-sectional study with particular relevance to this thesis was published in India [216] that examined the impact of NS on families by comparing mental health and socio-economic status of 50 NS families with a control group of 50 randomly selected families with children presenting to the same hospital for management of minor acute illnesses. Families of children with NS were significantly more likely to be adversely impacted psychologically and financially (10% were forced into debt, all were spending between 30–60% of their monthly income on NS management compared with 6.9% of their monthly income by the control group). The authors recommended families of children with severe forms of NS should be eligible for disability benefits and subsidised for travel and medical care. The establishment of support groups and supportive care at local levels were also recommended.

A series of papers from Nigeria identified paediatric renal disease and NS as significant contributors to the burden of hospital admissions [203, 207, 217]. A four-year retrospective review of paediatric kidney disease (2013–2016) from Abuja found that NS accounted for 12% of all kidney disease [207]; a three-year review of all paediatric admissions (2011–2013) at Abakaliki, Ebonyi found that renal conditions accounted for 4.4% of all admissions, with NS causing 32.9% of these [210]; an eight-year review of 53 children with ESKD (2005–2012) in Ibadan identified NS as the cause in 12 (23%) of cases [217]; and a four-year review (2008–2011) of admissions from an unidentified centre in South-Western Nigeria showed renal conditions accounted for 18.3% of paediatric ward admissions (320/3594), with NS diagnosed in 22.8% of cases [203] and the overall mortality for all renal admissions calculated at 14.4% [203].

A retrospective review of first presentations of Idiopathic NS (INS) in Taiwan (4,083 children aged 6 months to 18 years from 1996 to 2008, identified through the national database, where the national population is 23 million) provided some interesting insights. The male to female ratio was 1.91:1, with an average age at diagnosis of 8.06 years. The annual incidence of INS decreased from 9.91 to 3.36 (average 5.66) per 100,000 children over the 13 years (p=0.002, linear-by-linear association) and was attributed to socio-economic and environmental sanitation improvements achieved in Taiwan during that time. Most patients had 1 or 2 relapses and 50–70% were relapse free at 5 years and 59–90% were relapse-free at 18 years of age; 49% were re-admitted at least once and about 15% were admitted more than three times (the average total number of annual admissions in the first, second and third years was 0.83, 0.32 and 0.19 respectively). Of those with a histological diagnosis, 93% with MCD responded to prednisone. Where age at diagnosis was less than 5 years, the diagnosis was more likely to be MCD (>90% of cases) [218].

A retrospective review of 62 NS cases in the Congo (from 1983 to 2008) suggested a mortality rate of 10% and noted the inequitable health outcomes compared with high income countries [211]. A retrospective review of 4785 children admitted to hospital in Iraq between 2009 and 2012 found that 52/281 (18.5%) of those diagnosed with a renal disease had NS [213]. Another study of kidney disease in Syrian refugee children also indicated NS accounted for 18.5% of all renal disease [219].

New treatment guidelines for NS in 2013 and CKD in 2012 provided clarity for treating health professionals internationally [132, 133, 220, 221]. A gradual increase in focus on quality of life for children with NS and other chronic health conditions was also noted in the literature post-2010 [222-224], with authors sharing insights on the significant impact of NS, CKD and ESKD on children and their parents [21, 204, 211, 217, 225-238], and the relevance of therapeutic, economic, cultural and social factors to health outcomes noted. The importance of reducing the frequency and severity of relapses was emphasised [227, 239, 240] and the links between steroid treatment, relapses, quality of life and behavioural disturbances was affirmed [230, 241, 242]. Again, there was no evidence to suggest bone density was adversely affected by steroid treatment for NS [243].

An emerging appreciation of childhood NCDs

Following the UNHLM on NCDs in September 2011, there was increasing focus in the literature on the burden of non-infectious chronic health conditions generally [244-252] and recognition of NCDs as not just the leading cause of death globally, but inequitably affecting those living in LMICs [253]. CLAN was active in engaging internationally with like-minded organisations to advocate for children and adolescents within the global NCD discourse [9, 49] and NCD Child continues to drive advocacy with and for youth [254].

Whilst the focus in the literature relating to children and NCDs tends to be on a life-course approach to prevention (for instance, epigenetics, pregnancy care, reducing uptake of smoking) and the double burden of disease (for instance with the increase in childhood obesity) [255-257], the specific challenges of children living with NCDs in both low- and high-income settings and rising awareness of the impact of adverse childhood events (ACES) received increasing focus after 2010 [46, 258-264]. Access to diagnostics, essential medicines [265], equipment and quality care [266-269] – including palliative care [270, 271] – were identified as key priorities for all. Other recommendations shared regarding the best ways to support children and young people living with NCDs and other chronic health conditions included:

- support groups [272-275];
- empowerment of parents as carers [276, 277];
- empowerment of young people living with chronic conditions [278-282] with specific appreciation of the need to understand felt needs [283];
- training for health professionals [260];
- reducing social stigma, isolation and discrimination [284-286];
- addressing financial, ethnic and social inequities [287-295];
- provision of culturally safe psychological [223, 296-300] support.

Parental wellbeing, coping and empowerment were consistent themes in the literature [301-303], and single parents have consistently been acknowledged to face especial challenges in caring for children with chronic health conditions [304]. Research indicated the benefits of consulting children with chronic conditions [305], and global advocates have called for youth voices to be promoted and valued [53]. The direct link between chronic conditions - specifically the severity and duration of the condition – and poverty was well documented [306-309], and the need to prioritise action for those living in the most vulnerable circumstances (especially children) increasingly evident [310-312].

Child health equity more broadly

In reality however, very few authors and papers focused on the specific actions needed to redress inequities associated with chronic health conditions of childhood, nor addressed the challenges, burdens and recommendations needed to achieve better health outcomes for affected children in resource-poor settings [38]. The United Nations' SDGs [313] do not specifically focus on chronic conditions of childhood, and the *WHO Pocket Book of Hospital Care for Children* [314] and the IMCI [315] focus almost exclusively on acute and infectious disease. There is only brief acknowledgement of a limited number of chronic conditions in IMCI (HIV/AIDS, tuberculosis and asthma) and a focus on the acute management of a small number of chronic conditions in the *Pocket Book* (including asthma, HIV/AIDS, TB, rheumatic heart disease and epilepsy). Type 1 diabetes and childhood cancer are not covered in either resource, for instance. Given these documents guide international efforts relating to child health in resource-poor settings, it is reasonable to expect systematic inequities relating to children with chronic health conditions will go unchallenged unless major changes occur.

The UN has supported the *Every Woman Every Child* movement [316] since its launch in 2010, and this has promoted collaborative action by international actors to address the major health challenges facing women, children and adolescents (#EVERYchild) – including CLAN [317] and NCD Child [318]. UNICEF has also collaborated with NCD Child and other stakeholders to explore the inclusion of NCDs within their seminal resource Facts For Life, but to date the only tangible outcome is a program guide that focuses on a life-course approach to the prevention of NCDs [319].

CHAPTER 3 – RESEARCH METHODS

3.1 Introduction

In this chapter, the methods used in this research project are described. It begins with an introduction from the researcher, with transparent sharing of the underlying axiology and ontology that informed the research design and implementation. With these foundations explained, next is an overview of the epistemological foundations informing the overarching design of the research project, then the design of each of the two individual studies that make up this thesis:

- Study One – a Participatory Action Research (PAR) approach to the development of tools and resources necessary to facilitate a Health Needs Assessment (HNA) relevant to Nephrotic Syndrome in Vietnam
- Study Two – a mixed methods approach to consultation with key stakeholders as part of a HNA, using the templates and tools developed in Study One.

More detailed information on the methodology informing these studies will be provided in chapter four.

Information regarding the ethical considerations that informed the overarching development of this research project and the formal submissions to relevant Ethics Committees ahead of the commencement of the research is presented in this chapter. More detailed ethical considerations specific to each study are presented within chapter four.

3.2 Research design

An overview of the design and structure of the research project are shown in Table 1 and Figure 4.

3.2.1 Foundations of the research project

By way of transparency, the researcher shares personal insights and information about the ontology, axiology, epistemology and methodology that underpins this research project. An Indigenous research paradigm [320] informed the researcher's overall approach, and helped the researcher appreciate the deep interconnectedness between the many different way of understanding and knowing, as represented in Figure 15. Whilst Wilson represented the connectedness of the four entities using a circular shape, as a non-Indigenous researcher I have captured information relating to this research project within a square and triangles. Whilst maintaining the circle at the centre, the angular shapes are used in respectful acknowledgement that I am not an Indigenous person, but rather am grateful to have drawn on and benefited from Indigenous wisdom throughout this research project.

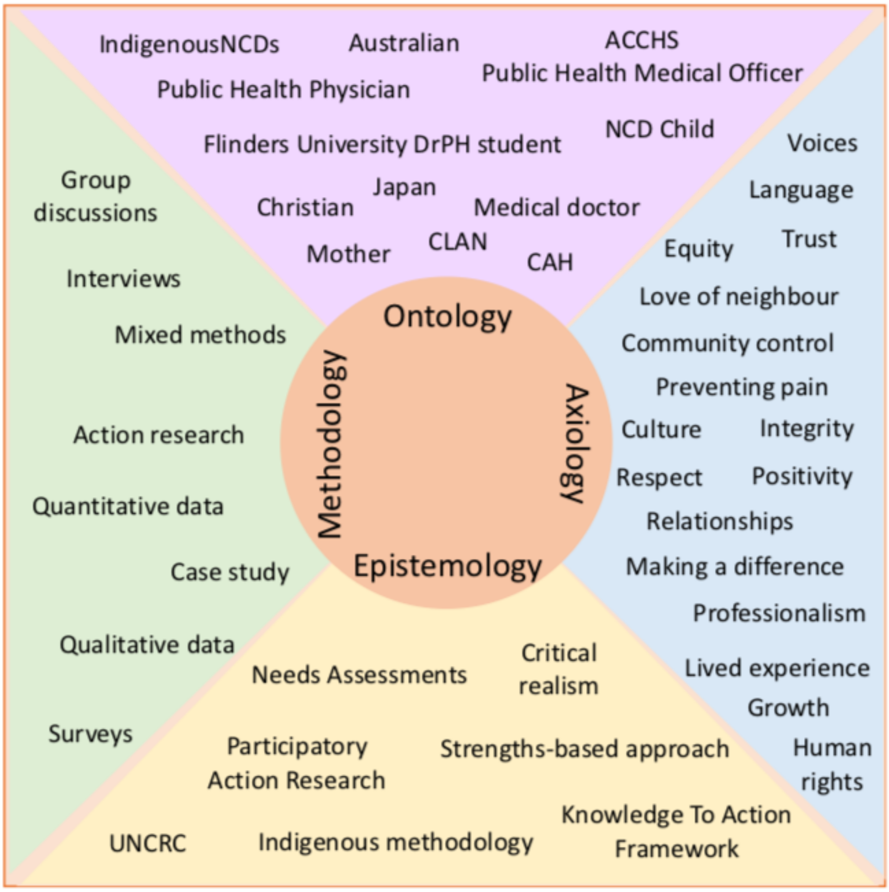


Figure 15 - Foundational ontology, axiology, epistemology and methodology of the research project

3.2.2.1 Ontology

Ontology is the study of being and existence, and as researchers we need to reflect on who we are, and the nature of our existence, so that we can appreciate the impact this might have on the research we do.

<u>Acknowledging the different roles, responsibilities and personal perspectives of the researcher</u>

At least eight different roles and perspectives are noted for transparency.

1. *Flinders University DrPH student*

As a researcher I was mindful of the importance of carefully considering the various roles, responsibilities and perspectives I would bring to my DrPH studies, and ensure the research was conducted with the utmost integrity at all times. Having worked in Aboriginal health for many years I was aware that research could be a “dirty word”; too many researchers had enriched themselves professionally and personally without reciprocal benefit to the Aboriginal communities they did research on, not with. Having worked with communities of children and families living with CAH and other chronic conditions in Vietnam and other countries for many years, I was committed to doing right by the communities at all times and making sure they were the primary beneficiaries of the process. The focus of academics at Flinders University on the Social Determinants of Health (SDOH) was a key factor in my selection of Flinders as a place of study (despite living in NSW), because it aligned strongly with my appreciation of the complex interplay of determinants affecting child health in resource-poor settings.

2. *Mother*

At the personal level, as the mother of a child with a chronic health condition, it was essential that the research was informed by a rights-based, person- and community-centred understanding of the burdens and challenges facing families of children living with NS in Vietnam. Moreover, as a mother and parent I placed great importance on hearing the voices of families and understanding their felt needs, recognising they were the people living with the condition day in, day out, and had invaluable insights to share on the challenges and barriers faced. In my own life I had experienced multiple instances of being more of an “expert” on my child’s chronic condition than the health practitioner we were consulting (for instance, the young doctor assessing our son in the emergency department). This expertise came not as a result of my medical training (I had only ever cared for one child with CAH), but rather my 24/7 role as a carer [321]. In this way, the concept of acknowledging people living with chronic conditions as “experts” was very important to me. Likewise, the imperative of translating research findings into action that would benefit the children in Vietnam in real time was of utmost importance to me.

3. *Australian medical doctor*

As a medical practitioner who had worked as a clinician in Australia (a high-income country) for almost 20 years, I had significant experience caring for children with chronic conditions both as a parent and a doctor with postgraduate qualifications (Diploma of Child Health) and was cognisant of the power of the biomedical model. Caring for patients and seeing them respond to treatments had strongly convinced me of the potential for evidence-based medicine, culturally appropriate care, psychosocial support, education and universal health care (Medicare [322]) to profoundly transform health outcomes. Having completed my Master of Public Health I was mindful that for many colleagues historically, the needs of children living with chronic health conditions in LMICs had been considered “too hard”, “too complex” and as a result “not a realistic priority” (in the context of the apparently overwhelming burden of communicable disease).

4. *President of CLAN*

My experiences to date with CLAN did not support a defeatist approach to chronic conditions of childhood in resource-poor settings. CLAN demonstrated very clearly that relatively simple, low-cost solutions had the capacity to redress current levels of preventable morbidity and mortality for children living with complex chronic health conditions in low-income countries. Moreover, almost without fail, I had seen that parents of chronically sick children in LMICs demonstrated an overwhelming love, passion and motivation to save their children, and virtually all parents, if given the opportunity to help their children, embraced it with alacrity. Encouragingly, there was evidence in the literature (albeit limited to high income countries) to suggest support groups and other group education models were effective and cost effective for improving health outcomes associated with childhood chronic conditions [323-325]. CLAN’s modest budget was a constant encouragement to focus on low-cost, cost effective and sustainable solutions.

5. *NCD Child Chair*

As the inaugural Chair of an increasingly powerful and influential international coalition advocating from a rights-based perspective for children and adolescents within the global NCD, health and development discourse, it was important to me that this research project informed the development of evidence-based recommendations about the best ways to improve quality of life for children living with NS in Vietnam. Being mindful that any recommendations emerging from NS had the potential to offer insights translatable to other chronic conditions of childhood, I was aware that CLAN and NCD Child offered a unique platform for advocacy, with results from this research having the potential to drive change not just for children living with NS in Vietnam, but rather at a global level across a range of childhood NCDs and other chronic health conditions. Development of policy briefs and papers [49] that were launched at key events (such as a panel discussion at the Global Health Council Conference in Washington [326] and a speech by myself at the UN General Assembly Civil Society Hearing in July 2011) were a direct response to this emerging realisation, and NCD Child’s success in strategically influencing language and concepts in the lead up to, and outcomes from, the September 2011 UNHLM on NCDs, were encouraging [52]. Buoyed by achievements so far, and with strong support from a range of powerful stakeholders and partners, CLAN launched NCD Child as an independent coalition following the UNHLM on NCDs in September 2010, and was proud to continue as inaugural Secretariat, with myself as inaugural Executive Secretary.

The inaugural NCD Child Conference was held in Oakland, California, in March 2012, and the Oakland Statement [2] spoke clearly to potential synergies across different childhood NCDs.

The early years of NCD Child [327] were focused on advocating (successfully) for the integration of children, adolescents and a life-course approach within the World Health Organization's Global Action Plan and Global Monitoring Framework on NCDs, with Member States acknowledging for the first time in 2013 at the World Health Assembly that "*Children can die from treatable non-communicable diseases, such as rheumatic heart disease, type 1 diabetes, asthma, and leukaemia, if health promotion, disease prevention, and comprehensive care are not provided*" [328].

In May 2014 CLAN transferred the role of Secretariat of NCD Child to the American Academy of Pediatrics. This was in recognition of the need for an organisation with greater capacity than CLAN to invest in NCD Child to take it to the next level. It was also an opportunity for CLAN to return to our grassroots work helping children living with chronic health conditions in resource-poor communities – and for me to finally complete my DrPH!

6. *Public Health Medical Physician with the Aboriginal Community Controlled Health Service (ACCHS) sector in Australia*

My work with CLAN has always been voluntary. As a day job I have had the privilege of working with the Aboriginal Health & Medical Research Council of New South Wales (AH&MRC) since 2009 (stepping aside briefly in 2013–14 and again in 2017 when NCD Child work and studies have required). Being an employee of an Aboriginal Community Controlled health organisation has been a rich and rewarding opportunity for me professionally and personally. It has allowed me to appreciate at first hand the power and necessity of community control and ensuring community priorities lead public health initiatives. In my role as a public health medical officer with AH&MRC I continually learn from, and have the privilege of working with, true experts in the field of Aboriginal Health. Indigenous wisdom and decolonising research paradigms and methodologies [329] have been introduced to me not just through reviews of the literature, but through active engagement and learning each day. Cultural humility, awareness and growth are constant priorities for me in this role.

In addition to my day-to-day work at AH&MRC, I have also had the privilege of completing my training to be a Public Health Physician through the Australian Faculty of Public Health Medicine (AFPHM), successfully sitting my exams in 2017 and becoming a Fellow of the AFPHM. The rigorous training program and emphasis on the value of established frameworks, quality research and evidence-based approaches aligned completely with my initial rationale for undertaking this DrPH. Since 2018 I have had the great honour of co-chairing IndigenousNCDs [330] with Yorta Yorta woman, Indigenous languages advocate and highly regarded researcher Dr Summer May Finlay, and am passionate about promoting the voices of First Nations persons within the global NCD discourse.

7. *Christian faith*

Whilst I have lived my life identifying as a Christian, in 2004 my husband and I were welcomed into the Catholic Church, and since then Mary, Mother of Jesus, has played a profound role as a muse, mentor and guide for me in my life journey. Each day I wear a Miraculous Medal necklace, and am reminded that Mary is ever present, praying for humanity and capable of helping in miraculous ways as I seek to live my life the way God would have me live it. My faith is very private to me (indeed, when I am in countries like

Vietnam I take great care to be discreet about my faith), but it is a foundational aspect of my work with CLAN. Even CLAN's name (Caring & Living As Neighbours) is inspired by the biblical verse reminding us that love of neighbour is second only importance to love of God.

8. *Japanese exchange student*

As a 17-year-old I had the opportunity to live for six months in Hokkaido, Japan, with a family that I did not know, as a cultural exchange student through a local Council sister-city initiative. I flew to Japan knowing one word of Japanese ("ashi" meaning "leg" – for reasons unknown this word stuck in my head) and knowing my grandfather had almost been killed by the Japanese in Papua New Guinea during World War II, had witnessed many men being killed by the Japanese, and was altogether unimpressed that I was going to Japan.

Over a six-month period, I came to love my host family as my own, and to this day have strong relations with them and we have visited one another several times. I was privileged as a young person to learn at a very deep level that all humans are more similar than they are different. I was also privileged to appreciate the true power of language; I was enrolled to study medicine on my return to Australia, but for much of my time in Japan I functioned at the level of a three-year-old linguistically. Some people saw past this and worked hard to communicate with me. My host mother and I learned how to communicate using hands, facial expressions, mime and dictionaries, and we laughed hysterically most days. I studied hard each day and gradually became socially fluent in Japanese. I learned how language is tied to culture and can help you understand more about others beyond simple grammar and vocabulary.

Acknowledging shifting positionality

With the ontology of the researcher informed by such a broad range of factors, it is important to acknowledge the shift in positionalities that occurred at times. For example, when meeting with families, I was an insider (as the mother of a child with a chronic health condition), but still a clear outsider (NS is different to CAH; I am Australian not Vietnamese; I do not speak Vietnamese; I am a doctor etc). Likewise, when meeting with health professionals I was an insider (as a medical doctor), and yet an outsider, in that I was a public health practitioner and not a paediatric nephrologist. When working with fellow Australians I was an insider (as an Australian), but an outsider to some (for example, as President of CLAN my positionality to other Australians not working with CLAN was different; as the mother of a child with a chronic health condition I shifted – sometimes uncomfortably - between my roles of "parent" and "medical doctor"). Maintaining clear communication at all times and with all stakeholders was an important component of minimising any potential conflict of interest and minimising any missteps with regards positionality.

3.2.2.2 Axiology

Axiology is the study of the nature of value and valuation, and as researchers we need to ask ourselves what is it that we value, and how might this impact on the design of our research? The concept of axiology, and the impact it can have on selection of research methodologies was highlighted for me by Indigenous researchers who not only acknowledge but also celebrate the centrality of relationships and family to their being and work [320]. This caused me to reflect on values and meaning that informed my approach to the research project. Some of these were identified as follows:

- *Equity and human rights*

  Everyone in the world is born equal. It is not acceptable that children in Australia and Vietnam experience diametrically opposite health outcomes simply because of where they are born. The same chronic health conditions have the same impact on human bodies regardless of geography; the differentiating factors are usually tied to the SDOH. Every human being has the right to enjoy health and life to their fullest capacity. Unfortunately, however, human nature is such that equity does not happen without especial effort. We are all responsible to ensure the dignity of every human being is honoured and respected. As someone with the knowledge and capacity to make a difference for children living with CAH and diabetes in Vietnam, I believed that I shared in a collective responsibility to do what I could to protect and promote the rights of children who were inequitably affected by NS in Vietnam.

- *Love of family*

  Although it was only the briefest encounter with the pain of losing a child, I had come close enough to the edge of a cliff to appreciate the inexplicable pain and suffering that is associated with losing a child. I had also experienced the suffering of my own child, seen him scream with pain during medical interventions; seen him waste away to skin and bone and almost die; seen him vomit uncontrollably when he did not have the medicine he needed. More than anything, I wanted to prevent other parents from experiencing such pain. Children are incredibly vulnerable – in their earliest years they are at greatest risk of harm that prevents them from fulfilling their full potential in adulthood. Childhood is called “the golden window” for good reason. It is a unique period when investment in health and wellbeing can pay lifelong dividends. When children’s rights are protected and promoted, they have the best chance possible to be happy, healthy and reach their full potential in life. And whilst this is an ideal – some children have chronic health conditions and special health needs that will affect their wellbeing negatively despite our best efforts - each child should be given the opportunity to reach their own full potential. Where children cannot survive, death should be as humane as possible; we have a collective duty to honour the dignity and humanity of parents and their children and ensure premature child deaths are as painless as possible.

- *Valuing the voices of those who are least often heard*

  Specific efforts must be made to ensure all people are heard equally. The voices of families who have lost children to chronic conditions in resource-poor countries are almost always lost to the world. These families drift away, broken and depressed, and we do not learn from their stories. People with the least power are too often the ones we are least likely to hear from. Specific action is required to ensure we hear the voices of people living with chronic health conditions in resource-poor settings.

- *Love of neighbour*

  The Bible (Matthew 22:36-40) teaches that we should love our neighbour as ourselves:

  > *"Teacher, which is the great commandment in the Law?"*
  >
  > *And he said to him, "You shall love the Lord your God with all your heart and with all your soul and with all your mind. This is the great and first commandment. And a second is like it: You shall love your neighbour as yourself. On these two commandments depend all the Law and the Prophets."*

  When I first heard of the shortages families of children living with CAH in Vietnam were experiencing, it was clear that I had a responsibility to share our family's good fortune with our (global) neighbours' children in Vietnam.

- *Language and culture*

  From my time in Japan, I came to respect the intelligence of children (they understand much more than they can say from a very early age!) and the power of language. Not being able to communicate in Japanese language did not mean I was not intelligent. What I needed to communicate effectively with others was the opportunity to use my own language, or engage with people willing to try and communicate with me in a second language I was not proficient in. In the absence of information and communication, misunderstandings were an inevitable consequence. For instance, once I heard my host family speaking about me and was upset because I assumed incorrectly that they did not want me living with them anymore. In fact, they were plotting how to keep me at their house for longer and stymy existing plans for me to move to another host family. Misbeliefs and myths fill the space of truth and knowledge when language and understanding is limited. The more language I learned, the more I began to appreciate how interconnected language and culture are.

- *Making a difference*

  Having seen real change as a result of CLAN's work for CAH Communities of the Asia Pacific since 2005, I was committed to action and real change for the NS Community of Vietnam. From experience I knew success would depend on strong partnerships, personal relationships, mutual respect and trust. Trust must be earned and can be easily lost, so integrity is essential. Maintaining a positive "can-do" attitude even in the face of seemingly overwhelming challenges is essential to surviving and thriving.

- *Community control and strengths-based approaches*

  My experience working in the ACCHS sector had shown me first-hand the vital importance of a strengths-based approach. My work in the ACCHS sector, and insider positionality within the international CAH Community engendered a strong belief in the importance of Community control, development and empowerment. Community Members are experts about their own Community's needs and priorities and lived experiences of a particular topic or issue enable a profound form of knowledge that needs to be valued on par with (if not above) second-hand knowledge and learning. Language, culture and belonging are central to Community wellbeing, and deep respect is due to Community Leaders and Elders who commit themselves to working hard for the benefit of their Community Members – often at significant personal cost. Within communities the strengths of all members must be harnessed for the good of all, and a strengths-based approach (and humour!) is key to resilience and morale, particularly when circumstances are difficult and challenging.

- *Professionalism*

  As a public health physician, medical doctor and President of CLAN I value professionalism and am committed to doing my best and acting with integrity.

3.2.2.3 Epistemology

Epistemology is the theory of knowledge, and as researchers we need to ask ourselves "how do I know what I claim to know?", and "what knowledge do I consider valid and justified beyond simple belief or opinion?".

Six key knowledge theories, philosophies, paradigms and frameworks informed the design of this research project:

A) Critical realism

B) Bradshaw's Taxonomy of Need

C) The NICE Health Needs Assessment framework and

D) Indigenous methodologies

E) United Nations Convention on the Rights of the Child (UNCRC)

F) Knowledge to Action (KTA) Framework

Within the two studies that comprise this research project there are additional forms of knowledge that played key roles (such as Participatory Action Research and the CLAN strategic framework for action). The details of specific methodologies used in Study One and Study Two will be described in Chapter Four.

A) Critical realism

The social theory of critical realism, as described by Bhaskar [331], greatly strengthened the research project. There was evidence in the literature suggesting critical realism was relevant to a combination of quantitative and qualitative methods, and for case studies [332, 333]. The researcher reflected on three separate ontological realities of critical realism that were relevant to the research:

i) *The empirical* – that which can be experienced directly or indirectly. As the mother of a child, I had directly experienced the trauma that could be associated with CAH and understood at first hand what was required to help a child with a chronic health condition enjoy life to the fullest. The available evidence in 2004 suggested children living with CAH in Vietnam were suffering inequitably, but I wanted to know *why* this was happening.

ii) *The actual* – those that occur but may not be experienced personally. Consulting with families of children living with CAH in Vietnam in 2005 allowed me to understand their felt needs in greater detail, and this informed wider appreciation of the real-life experiences, challenges and burdens they faced daily.

iii) *The real or "deep" structures and mechanisms that are causally connected to the empirical and actual*. Whilst CLAN had spoken with families living with CAH, had some understanding of the challenges and burdens they faced, and could surmise many of the same structures and mechanisms were at play for NS, we could not be certain, and it was important to continue working collaboratively with others to address challenges as they were identified, and explore potential solutions together. By working together, we can establish deeper levels of explanation, understanding and achieve change.

A health needs assessment that facilitated deep consultation with families, health professionals and other stakeholders to better understand the underlying structures and mechanisms contributing to the inequities experienced by the children and families was warranted. By understanding the underlying causes, the world would be in a better position to tackle the barriers and challenges and redress inequities.

More encouraging still, however, critical realism provided strong moral justification not just to understand the underlying challenges, but to take action to address them. Critical realism made the implementation of "quick wins" (arising in real time from recommendations identified by families and health professionals in the interview and data collection process) at low cost by CLAN and other partners at the NS Club meetings in Hanoi and Ho Chi Minh City entirely appropriate. In critical realism, imperfection and the infallibility of knowledge is accepted, along with the ability to adapt and improve over time as new knowledge comes to light [334], as occurs through participatory action research. Just because the research project was not heavily funded did not mean that any actions taken were a waste of time. This realisation was enormously encouraging and reassuring for the researcher. Acceptance of imperfection afforded the researcher freedom to focus on a topic of great "seriousness", yet forgave the many perceived inadequacies faced from poverty, inequity and the overall challenges of conducting research in a LMIC, supported by project management with limited resources. Critical realism allowed all this in the interests of change; discovering a new dialogue that would allow the world to approach NS in LMICs in a new way, such that the basic human rights of every child to health and life might be protected and promoted.

Critical realism also provided a useful lens through which understanding and decisions around recommendations for action could be reviewed, analysed and further developed. For example, it was not until all data were collated and reviewed in detail that an overlying construct, the four planes of agency described by Bhaskar, emerged as the most appropriate framework for understanding data that emerged from Study Two. The four planes described:

i) *Human and material transactions with nature* – the specific impact of NS on the bodies and wellbeing of children was particularly relevant,

ii) *Human to human interpersonal interactions* – in the life of a child with NS these are innumerable, and include relations with family, community, health professionals, society and schools to name but a few,

iii) *Social structures* – for families living with NS these included health systems, health insurance bureaucracies, financial and employment systems and the education system,

iv) *Intra-subjectivity and the stratification of the embodied personality* – children and families living with NS displayed enormous strength and resilience, and in fact, the families consulted represented a survivor cohort, so the researcher was particularly interested in the intrinsic characteristics of those children and families who had survived a diagnosis of NS to better understand the critical actions needed to help future children enjoy the highest quality of life possible.

In reflecting on these different aspects of life with NS, the researcher found the four planes of agency facilitated retroductive analysis and thematic coding of qualitative data, particularly in the context of respecting the many strengths of the NS Community as much as understanding the challenges they faced to inform recommendations for change.

B) <u>Bradshaw's Taxonomy of Social Need</u>

Bradshaw's Taxonomy of Social Need [335] informed the design of the research project through its examination of how to identify social need, and more importantly, how to address it when financial funding mechanisms were not clearly described. Bradshaw acknowledged the complexity of social situations and outlined four different ways of examining a complex social situation:

i) *Normative need* – that which is defined by the "expert" or "professional", who dictates what the "gold standard" might be. In the case of NS in Vietnam, the normative needs of children living with NS in Vietnam would be informed by the published literature and treatment guidelines and the paediatric nephrology experts in Vietnam, all of whom draw upon a strong evidence base to indicate what the most appropriate treatments and approaches to NS might be. Of course, the normative needs vary depending on the cultural and experiential lens of the "experts", and it was important for this reason that the researcher considered not just the published literature, but also early input from local experts to guide the design of the research project.

ii) *Felt need* – reflects the wants of the population in question. In this research project, the felt needs of the community of children and families living with NS were vitally important. Detailed consultation with families (noting ethical considerations that informed the researcher's decision not to consult children) was even more important given the paucity of information available in the public literature relating to their felt needs.

iii) *Expressed need* – results when felt need translates to action. In the case of NS in Vietnam, expressed need was not easily determined because of the paucity of clinical data and patient registers. Overcrowded inpatient and outpatient departments gave some insights into the expressed needs of the NS Community, but the researcher was also mindful some unmet needs were not captured this way (for example, loss to follow-up and mortality outside of the hospital could be easily overlooked through a limited focus on hospital presentations).

iv) *Comparative need* – defines need by studying the characteristics of the population in receipt of a service and comparing it with those who do not receive the service. In this regard, children with NS in Vietnam could be compared with children living in high-income countries, but similarly, the needs of children from families of differing socio-economic backgrounds could be compared.

The interrelation of these four needs is shown in Figure 16 [335], describing and demonstrating how consideration of needs in isolation can lead to misleading insights. For example, health professionals caring for children living with NS in Vietnam frequently spoke of the need for affordable biopsy needles and pathology support to help them diagnose NS, and yet families never once mentioned biopsy needles as an unmet need. This did not mean biopsy needles were not important, but it did speak to the importance of consulting with a range of stakeholders, and in particular families, given the complete absence of data in the literature relating to felt needs of families living with NS in resource-poor settings. Indeed, the absence of evidence in the literature relating to felt needs influenced the design of this research project to prioritise an understanding of felt needs as much as possible.

Figure 16 - Diagrammatic representation of the interrelation of the four social needs (sourced from [335]) – redacted for copyright

C) NICE Health Needs Assessment

Informed by the United Kingdom's National Institute for Health and Clinical Excellence (NICE) [6], a Health Needs Assessment (HNA) was deemed the appropriate framework to facilitate an understanding of the burdens and challenges experienced by families, identify recommendations for change and implement realistic actions in real time wherever possible. The aim of Study One was to develop locally adapted products and tools that could assist with the consultation process (undertaken in Study Two), and thereby enable a systematic method for reviewing the issues and identifying agreed priorities for action (described in Chapter Five) to improve health and reduce inequalities.

The research project followed the five stages of a HNA as described by NICE:

i) Stage One - Getting started

The introductory, literature review and research methods chapters provided a strong foundation for the HNA. Study One (Chapter Four) used a participatory action research approach to facilitate population profiling and clarification of the population being researched; the aims and objectives of the HNA; identification of who needed to be involved; clarification of resources that would be required; and consideration of risks and ethical considerations.

ii) Stage Two - Identifying health priorities

Study Two (Chapter Four) used a mixed methods approach to consult and gather information about the NS Community's felt needs. Systematic and replicable methods were used for gathering data and analysing social needs and guiding consultation to inform an understanding of NS and the underlying structures and mechanisms impacting on health conditions.

iii) Stage Three - Assessing a health priority for action

Analysis of the findings from Studies One and Two (Chapter Four) strengthened an understanding of NS in Vietnam, the causal mechanisms with the most significant size and severity impact, and the most effective and acceptable interventions and actions that could be recommended.

iv) Stage Four - Planning for change

The translation findings (Chapter Five) describe how the Knowledge To Action (KTA) framework was used to identify and implement critical actions in real time to redress inequities and improve health outcomes for children living with NS in Vietnam. The first half of this translation chapter clarifies the problem; aims and objectives; steps taken to adapt knowledge to local context; barriers to knowledge use; and the selection, tailoring and implementation of specific interventions.

v) Stage Five - Moving on / review

The second half of the translation chapter ends the KTA framework, with a focus on how the researcher sought to monitor knowledge use, evaluate outcomes and sustain knowledge use. Whilst a comprehensive, objective evaluation was beyond the scope of this process, the chapter brings together all findings from the HNA and contains recommendations and key learnings that relate not just to NS in Vietnam, but to chronic conditions of childhood in resource-poor settings more broadly. Tangible deliverables, such as the Child Health Equity Action Resources (CHEAR) Toolkit are synthesised and shared as a consequence of the knowledge to action and knowledge creation processes and are intended to assist others seeking to engage in critical action to drive sustainable change.

D) Indigenous methodology

Indigenous methodology consciously and subconsciously informed the design of this research project. Whilst not identifying as an Aboriginal or Torres Strait Islander person myself, as a public health professional working in the Aboriginal Community Controlled Health Service (ACCHS) sector of Australia since 2009, I had the enormous good fortune of constant exposure to the wisdom and strengths of Aboriginal ways of conducting research and managing projects [336]. It is important to acknowledge this on-the-job learning has informed my approach organically and subconsciously not just to this project, but also to CLAN's work more generally over many years.

Specific insights that strengthened this research project and were informed by Indigenous methodologies included appreciation of:

i) The importance of strengths-based approaches – this appreciation ensured I included a focus on enablers as well as barriers when using the KTA framework. Celebration of the NS Community as a cohort of survivors (and not just a disadvantaged Community "in need of saving") influenced the way qualitative data in particular were analysed [329].

ii) Insider versus outsider positionality – as described with regard to ontology, I had to be mindful at all times of my position to the NS Community in particular. I also had to be mindful of stepping back and ensuring Community Members and true insiders had their voices heard (for example with NS Community Members featured in the media and on the NS video that CLAN developed; and Vietnamese health professionals presenting a collaborative abstract on the research project at the IPNA conference in China in 2013).

iii) The impact of axiology, and its interconnectedness to ontology, epistemology and methodology [320].

iv) The centrality of Community, and the importance of person, family and community centred approaches in health care. Community control and leadership throughout all stages of project planning, implementation and monitoring was very important to me, and influenced many outcomes seen in the translation chapter (such as the election of NS Community Executives to guide action). The similarities between Indigenous Communities and Communities of families and children living with NCDs in resource-poor settings was very striking to the researcher. Both groups experience inequitable disadvantage and discrimination; struggle with affordable and culturally safe access to care; and share burdens with other similar communities in other countries (for instance, Indigenous Communities in Australia, Canada and New Zealand share many similarities, as do NS Communities in Vietnam, India and Africa). Struggles relating to self-determination are shared by all these Communities, and there is a power that comes from connecting these Communities with one another locally, nationally and internationally. Communities need opportunities to have their voices heard and their stories shared [329] and where possible this research project sought to facilitate this process for the NS Community of Vietnam.

v) Acknowledging the holistic nature of health and wellbeing [337] and the inter-generational connectedness of many determinants of health was central to understanding and implementing effective and sustainable solutions

vi) The potential for research to harm people and unjustly enrich researchers rather than Communities loomed large and was a constant consideration for the researcher. It was imperative for the researcher that the potential underbelly of this research project be constantly and transparently exposed, examined, discussed and considered, and CLAN's Committee and the researcher's mentors and supervisors assisted with reflections on this risk. It was imperative that the researcher report back to the NS Community on key findings and results from analysis of the stories they shared, and this was achieved in February 2013 when the researcher returned to Vietnam and presented all results to NS Community Members and hospital executives at each of the three participating hospitals (as outlined in the translation chapter).

E) United Nations Convention on the Rights of the Child (UNCRC)

In 2009 the researcher presented CLAN's rights based strategic framework for action at the *International Conference on Realising the Rights to Health and Development for All* in Hanoi, Vietnam [180], and this was an important step in communicating to key stakeholders in Vietnam the nature and underlying epistemology that informs CLAN's work.

Activities emerging from CLAN's five pillars are in accordance with the 54 articles of the UNCRC [338], and Vietnam and Australia are both signatories to the Convention. As part of World Diabetes Day celebrations in 2015, CLAN collaborated with partners to launch Child-Friendly Rights Flyers in several languages (including Vietnamese) to help children and families living with Type 1 diabetes learn more about their rights to health and life. The flyers were then adapted for a range of childhood NCDs (including CAH [339], childhood cancer, rheumatic heart disease and asthma) with a range of stakeholders CLAN engaged with through NCD Child to strengthen the rights-based discourse relating to child health (an NS specific flyer has been included in the CHEAR Toolkit). The researcher also took opportunities at NS Club Meetings to introduce the NS Community of Vietnam to the UNCRC, the work of NCD Child and the broader NCD discourse.

F) Knowledge to Action (KTA) Framework

The knowledge to action framework published by Graham *et al* in 2006 [340] (Figure 17) has been acknowledged by WHO as a useful tool for addressing complex health problems, and is especially relevant to the PAR approach taken by the researcher. Whilst the KTA emphasises assessment of barriers to knowledge use, this research project also sought to understand the strengths within the NS Community and broader cultural factors that influence knowledge use and have the potential to augment efforts to implement change.

Figure 17 - Knowledge To Action (KTA) Framework (sourced from [340]) – redacted for copyright

The KTA Framework is relevant to the implementation of CLAN's Strategic Framework for Action, and the interplay of these two frameworks has been explored by CLAN in some detail [38] (Figure 18). As mentioned above, the KTA Framework is used throughout Stages Four and Five of the HNA to describe the interplay between knowledge, action and the development of tools and resources that occurred throughout the research project that are shared in the CHEAR Toolkit (Appendix 1).

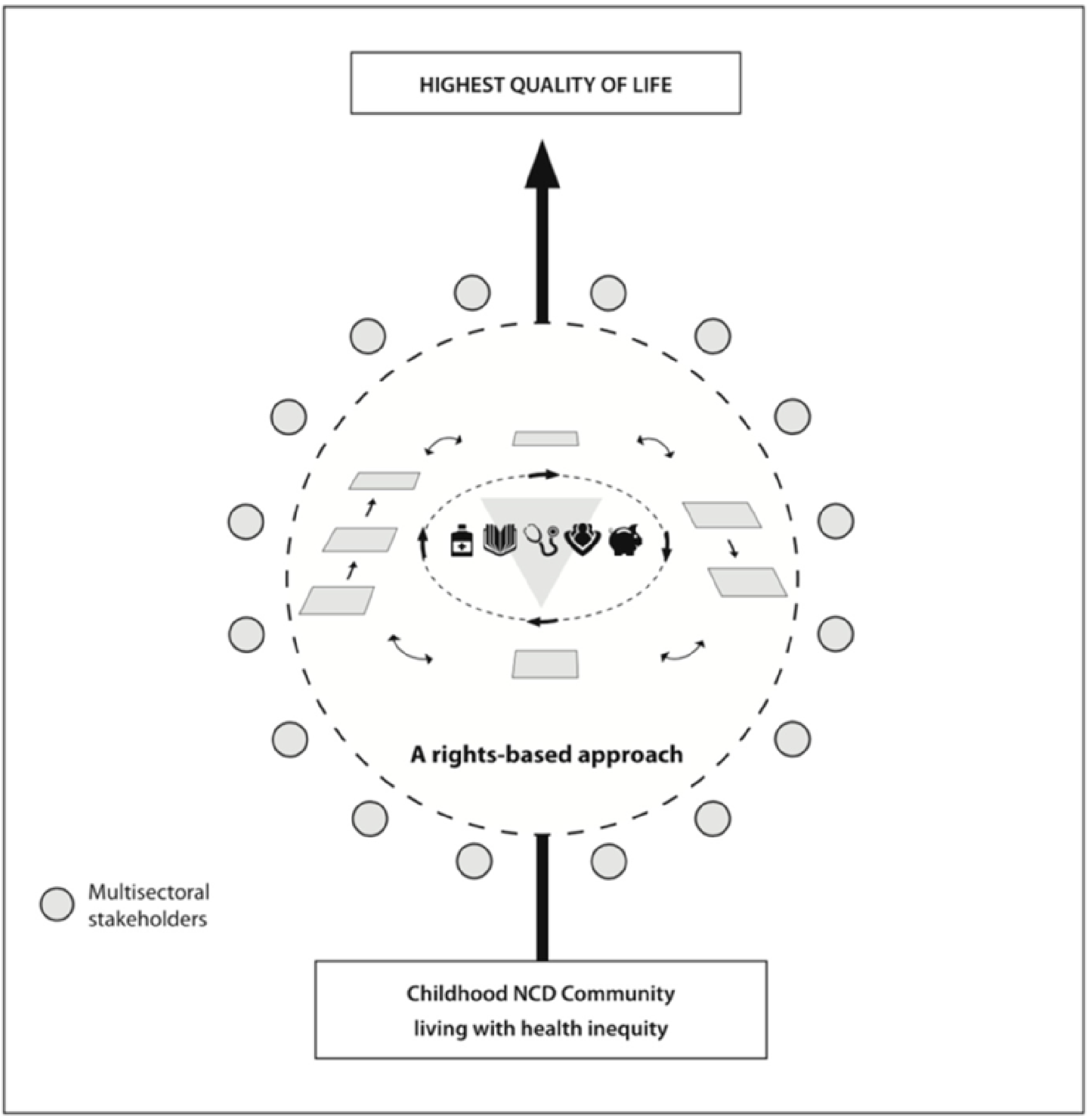


Figure 18 - The interplay between the KTA Framework and CLAN's Strategic Framework for Action

3.3 Research ethics

3.3.1 Ethical considerations

3.3.1.1 Ethics Committee applications in Australia

To ensure all steps of the development and implementation of the research project complied with best practice, an application to the Flinders University Social and Behavioural Research Ethics Committee was submitted and granted (Project 5071). The submission was developed following face-to-face meetings with colleagues in Vietnam in September 2010, and email correspondence with three hospitals before submission in December 2010.

3.3.1.2 Ethics Committee applications in Vietnam

In addition to the Flinders application, documentation was developed in consultation with hospital executives and senior paediatric nephrology staff at each of the three participating children's hospitals in Vietnam and submitted following face-to-face meetings and final discussions in February 2011. It was agreed the Ethics Committee at the National Hospital of Pediatrics in Hanoi would take the overall responsibility for approving the project, although each hospital had to review the submission internally to ensure the project could proceed. The Directorate of each hospital was consulted regularly at all stages of the research project and data collection processes, and results were communicated back to NS community members (with oral presentations at the annual NS Club Meetings at all three hospitals in 2013), health professionals and hospital executives according to an agreed timeline.

3.3.1.3 Ensuring the research project benefits the NS Community of Vietnam

In addition to addressing routine ethical considerations, the research project was further informed by insights arising from CLAN's Community Development approach, which has much in common with decolonising methodologies and guiding principles outlined by the Ethics Committees controlled by the Aboriginal Community Controlled Health Service (ACCHS) sector of Australia. In this regard, the following questions were addressed in the research design and planning phases to ensure the NS Community of Vietnam would benefit from the project and not be harmed [329, 341]:

i) **Whose research is it?**

Whilst the research was undertaken as part of a DrPH through Flinders University, collaboration with the NS Community of Vietnam, local hospitals and health professionals and CLAN was integral to success. To facilitate collaborative action, the NS Community of Vietnam was maintained as the central visual hub at all times. All stakeholders shared a commitment to ensuring the research would guide meaningful and real-time action to improve quality of life and health outcomes for the NS Community of Vietnam. To achieve this, results were communicated to the Community and local health professionals and executives in timely and meaningful ways, and insights regarding actions that could be taken to improve quality of life were taken by CLAN and other stakeholders wherever practical and possible (see Chapter five for more details on this).

ii) Who owns it? Is there community control of the research?

The lead researcher (KA) took responsibility for conducting the research but was always cognisant and respectful that Vietnam is a Communist country, local hospital executives would need to approve all aspects of the research for the project and collaborative action to continue. Whilst the hospital executive always had full control, there was a shared commitment to ensuring the NS Community of Vietnam would be empowered to engage, inform and guide the project. Hospital executives were familiar with CLAN's model, which prioritises person-and family-centred and community development approaches. CLAN's commitment to community development and maintenance of the NS Community of Vietnam as the visual hub and primary beneficiary of the research findings assisted with transparency, reporting and dissemination of information. NS Club Executive Leaders were identified, consulted, involved and engaged at all stages of the project.

iii) Whose interest does it serve? Who will benefit from it? Will the Community benefit? Considerations of beneficence

The project was conducted in such a way that all stakeholders stood to gain. The NS Community of Vietnam would have existing inequities, challenges and burdens redressed to the greatest extent possible. Hospital Executives would see changes in expressed need (reduced inpatient and outpatient numbers). Health professionals would see reductions in comparative need, with better health outcomes for their patients, reduced workloads, and opportunities for professional development. The researcher would complete their DrPH. CLAN had the opportunity to review and refine its strategic framework for action.

The PAR approach taken in Study One was informed by a shared view that it was not ethical simply to learn more about the problem. All stakeholders must act on insights in real time to their fullest capacity to improve health outcomes and reduce health inequities for the children (critical realism). Processes were established to ensure insights were translated to priority actions wherever possible (for instance, CLAN's Action Plan for NS Vietnam captured key actions needed, and identified which stakeholders were responsible – see chapter five and the CHEAR Toolkit).

iv) Who has designed its questions and framed its scope? Is there cultural sensitivity?

The focus of the DrPH and research questions to be addressed were determined through consultation involving the researcher and hospital executives, and in response to shared understanding of normative, comparative and expressed need. The specific questions asked of families were developed through a PAR approach, and informed by a review of available evidence, consultation with local health professionals and hospital executives, and NS Community members. To strengthen cultural sensitivity, a well-respected and experienced psychologist, Dr Hao, was appointed by NHP to assist the researcher and ensure cultural safety and competence were prioritised. CLAN's extensive experience doing similar work in Vietnam had reassured local authorities that activities would be conducted in a culturally safe way, but Dr Hao's experience and expertise provided invaluable guidance throughout.

It was agreed ethical considerations ruled out consultation with children living with NS, so only parents were involved in survey and interview processes. Some parents were identified as potential NS Club leaders, and they were consulted throughout the project in this capacity also.

v) **Who will carry it out?**

The lead researcher (KA) took responsibility for completing the research. All stages of the project were approved by the relevant authorities.

vi) **Who will write it up?**

The lead researcher (KA) took responsibility for writing up the research. Local health professionals assisted with preparing presentations of results at relevant conferences and to the NS Community at NS Club Meetings in 2013.

vii) **How will its results be disseminated?**

There was a commitment to regular sharing of results and insights with health care professionals and hospital executives. De-identified data from the project were reported back to each hospital so they could use it however they felt appropriate. Results were reported to the NS Community at Club meetings so they had full visibility over the project and could monitor outcomes and voice their satisfaction – or dissatisfaction – with same.

At all times during consultations, clear communication with NS Community members was prioritised to ensure families were aware of confidentiality; were supported to give informed consent; felt confident there would be no negative impact if they chose not to participate; and were aware that CLAN and other stakeholders had a commitment to realistic action in response to input. This approach sought to provide participants with hope and optimism for the future, whilst ensuring expectations were not unduly raised.

In all situations, where recommendations for action to address health determinants of any significant size, severity or degree of preventability could be enacted at low cost and with reasonable ease, the researcher committed to collaborate with other stakeholders in real time and with them, attempt to enact potential solutions as fully as possible. In determining the resources needed to undertake actions in real time, considerations of time, materials, skills and funding were considered carefully and discussed at length with the researcher's supervisors and Executive of CLAN. Potential risks and barriers were explored in regular meetings and debriefs.

Presentations on key findings were shared at relevant conferences. Future publications are a goal, with the final DrPH thesis hopefully supporting peer review publications in future.

viii) **How will participants be reimbursed?**

CLAN raised funds so that no families would be out of pocket for participating in the project. The pilot interviews conducted in Study One were held on the grounds of the participating hospitals, and only families who were attending the hospital were invited to participate. Participation in the pilot interviews was voluntary, and in fact families lined up to participate, presumably because the consultation offered a rare opportunity to consult with a local doctor and visiting international NS specialist and ask detailed questions about their child's care.

The supporting psychologist and cultural broker (Dr Hao) was paid for his time and expertise at an agreed rate. Local hospital staff time was contributed in-kind. The lead researcher (KA) and supervisor (EH) were not paid, and each covered their own travel costs. Health professionals conducting parent interviews at each hospital were all paid at agreed rates for their time, which included completion of a brief survey after each interview.

ix) How will this enhance Community skills and knowledge?

Participating local health professionals, NS Community Executives and NS Community members had the opportunity to ask detailed medical questions of the visiting supervisor (a highly regarded paediatric nephrologist from Australia) and participating psychologist.

The shared learnings regarding the HNA and consultation process helped strengthen the capacity of local partners to replicate efforts with other conditions in future. Of note, templates developed in this research project were subsequently translated to facilitate consultation with the Lupus Community of Vietnam.

The translation of seminal educational resources on NS into Vietnamese language and training sessions provided over many years to Vietnamese health professionals by visiting international NS experts contributed to the skills and knowledge of the NS Community of Vietnam.

x) Will participants be safe?

"Above all do no harm (nor cause discomfort or inconvenience)" was an overarching maxim that guided the researcher, and specific care was taken to consider the health and wellbeing of all participants at all times. The three health professionals contracted to assist with parent interviews were specifically selected for their capacity to conduct interviews in a competent and compassionate manner. Where families raised specific medical queries or concerns during interviews that the interviewer could not answer, the families were referred to their treating doctors immediately following the interview for clarification.

Acknowledgement of the United Nations Convention on the Rights of the Child (UNCRC) and a rights-based approach was routinely communicated as foundational aspects of CLAN's strategic framework for action. Respect for all human beings, the rights of all children to live their lives to their fullest capacity, and the responsibility of all stakeholders to protect and promote these lives underpinned the work of CLAN and the lead researcher.

xi) How will research merit and integrity be safeguarded?

Commitment to strong, quality research underpinning CLAN's work was the rationale behind doing this DrPH. The thesis will be made available on the Flinders University website and publicly available for review.

xii) How will informed consent be secured?

Consent was at all times voluntary and informed, with clear communication to families at Club meetings that withholding consent or declining participation would have no adverse consequences on care received, and that results of participation would be communicated back to participants in a planned manner. Information sheets in Vietnamese language were given to all families participating in parent interviews, and a checklist on the survey template reminded interviewers of key information to share with participants at the start of each interview.

xiii) Is there any conflict of interest? If so, how will it be managed?

As mentioned previously, management of potential conflict of interest was carefully considered by the researcher. Separation of roles (ie that of researcher and that of President of CLAN) was enhanced by open and transparent communication with families, health professionals, and the university at all times. Formal ethics submission processes helped identify potential risks and specific steps to safeguard families and children. The researcher reported to the CLAN Committee at CLAN Association meetings, and gave regular updates to research supervisors as planning, data collection and implementation of critical actions progressed.

xiv) How will data be managed and stored?

A commitment was made by the researcher that all completed templates and data would be stored securely for a minimum of 7 years (until 2020) or until completion of the project, in line with requirements of Flinders University’s ethics committee. De-identified data were shared with participants in a planned manner.

3.3.2 Risk assessment

One benefit of using the NICE HNA framework was the opportunity to conduct a robust initial risk assessment through consideration of the risks already acknowledged in the literature as associated with a HNA [6]. Examples of potential risks and solutions that were identified are shown in Table 3 - Risk assessment based on known risks associated with HNAs, and these informed the planning and implementation of the research project.

Table 3 - Risk assessment based on known risks associated with HNAs

Potential risks	Proposed solutions
Challenges working across professional boundaries that prevent power or information sharing	- Regular discussions with hospital executives (who had requested the focus on NS) - Person and community centred approach, which maintained a collective focus on felt needs and the priorities of the NS Community - Ethics application process strengthened methodology and transparency
Failure to develop a shared language between sectors	- Research proposal shared with all stakeholders - CLAN Action Plan for NS in Vietnam shared with all stakeholders - Regular consultation with Dr Hao (Vietnamese psychologist and cultural mentor) to identify potential problems early
Failure to obtain commitment from the most senior powerbrokers	- Ethics applications at all three participating hospitals - Co-supervision by Vietnamese hospital executive
Failure to access relevant data	- Agreement from all hospital executives prior to data collection on suitability of information collection tools - Club meetings facilitated data collection and were a proven method - Translation of data by expert, qualified translators, with minor editing for local dialect - Skilled and trained interviewers
Failure to access the target population	- Local HCPs engaged, supporting and committed to the success of the project - Approval given by hospital executives
Failure to maintain team impetus and commitment	- Regular communication with all stakeholders - Face-to-face meetings scheduled regularly - Timeline shared - NS Club meetings held annually
Failure to translate findings into effective action	- CLAN action plan shared with all stakeholders and monitored regularly - Fundraising to support critical action - Regular reporting on achievements (newsletters, reports)

In addition to specific risks previously identified by NICE, consideration was also given during meetings with local stakeholders and CLAN's Committee to the strengths, resources and capacity constraints underpinning the research project. Strengths included:

- CLAN and the researcher's previous experience working with the CAH Community of Vietnam
- Translation of CLAN's model to other health conditions and countries
- Flinders University's academic support
- The generous sharing of expertise by Dr Elisabeth Hodson and Dr Alison Tong relating to the field of paediatric nephrology, clinical management and research
- Commitment by hospital executives and health professionals in Vietnam who were caring for children living with NS in Vietnam to the project. Request to researcher to focus on this topic indicated it was a priority to local champions.
- Dr Hao's role as cultural mentor
- Dr Yen Thanh Mac and other members of CLAN's team provided invaluable support.

Balancing these strengths, consideration of potential resource constraints facing the project highlighted the following concerns:

- Travel – was an essential component of the project but brought additional expense and limits to flexibility. It was important to carefully plan each trip and maximise activities undertaken each time.
- Limited financial resources – careful budgeting and fundraising would be a priority for CLAN and the researcher. Identification of potential partners and other stakeholders would be important, as would commitment by the Vietnamese government, children's hospitals and Ministry of Health to invest in the wellbeing of the NS Community of Vietnam. An example of this occurred in August 2011 when the Vietnamese government announced it would include all NS essential drugs on the national insurance list for the first time.
- Tight timeline – Club meetings and travel dates represented relatively fixed events that had to be planned around (for example, hundreds of families were predicted to attend meetings in November 2011 and February 2012), so ethics deadlines and PAR cycles had to be completed according to inflexible scheduling restrictions.
- Rules and regulations – there was an absolute need for the researcher to defer to hospital executives, cultural norms and governing requirements at all times, and demonstrate total (and very genuine) respect for and awareness of the Communist system that the project was operating under.

3.3.3 Risk management strategies

The following mitigating strategies were adopted:

- Inclusive approach – at all times, the broader NS Community of Vietnam was maintained as the visual hub of the project, and wherever possible, an inclusive approach informed decision making so that the greatest number of children would benefit.

- Locally adapted solutions wherever possible – advice from local stakeholders was always sought and prioritised.

- Cultural humility was a guiding principle, and the guidance of Dr Hao was consistently sought to ensure culturally appropriate processes.

- Voluntary engagement acknowledged and appreciated – acknowledgement of the commitment of many, in a voluntary capacity, to the success of this project informed approaches in which gratitude, consultation and respect were prioritised. Regular communication with key participants ensured clear understanding of roles and responsibilities at all times.

- Payment of consultants – where voluntary contributions were not fair or appropriate (as agreed at the start of the project and relating to persons such as expert translators and interviewers) predetermined payments at accepted local rates were made to compensate people for their time and expertise.

- Data management – a realistic approach to data management was taken, using approaches that facilitated timely, scaled outcomes without compromising quality. Use of Excel, Nvivo, Word, EndNote and online library and data resources (accessed through Flinders University) assisted the researcher.

- Quality translations – appropriately qualified and endorsed translators were used at all stages of the project.

- Standardised approaches – implementation of templates and conduct of the HNA was strengthened through the provision of training and guidance to interviewers and regular review and checks on progress. Risks of bias (such as information bias, selection bias and confounding) were routinely considered and efforts made to redress appropriately. Triangulation of insights (from families, health professionals, other stakeholders and existing literature and evidence) strengthened identification and prioritising of critical issues for urgent action.

- Monitoring and evaluation – regular checking with key stakeholders and authorities allowed the researcher to ensure the project was tracking satisfactorily for all concerned. The CLAN Action Plan facilitated the identification of key indicators to support ongoing monitoring and evaluation. Monitoring clinical health outcomes was beyond the scope of the researcher, but anecdotal reports on expressed needs and subsequent publications by local health professionals provided a useful gauge over the longer term of the project impact and outcomes.

- Strong program management – CLAN’s Action Plan, Program Logic Framework and project timeline informed planning, communication and implementation at all stages, and consideration of internal and external risks associated with the research project. The researcher was able to meet with CLAN’s Committee and other stakeholders to discuss potential risks, consider how best to prepare for and prevent such risks, and mitigate them if they occurred.

CHAPTER 4 – STUDY ONE & STUDY TWO (HNA STAGES 1–3)

STAGE ONE OF THE HNA – Getting Started (STUDY ONE)

4.1 Introduction to Study One

Study One is the first study presented in Chapter 4. It was conducted between September 2010 and July 2011 and comprises Stage One ("Getting Started") of five stages in the Health Needs Analysis (HNA), with a focus on establishing firm foundations for the overall research project (see Table 1 below). It is a descriptive case study and documents the Participatory Action Research (PAR) approach used across three cycles to achieve three specific objectives:

- To establish firm governance foundations for the HNA,
- To develop the templates to support information gathering processes in the HNA,
- To identify critical actions to improve health outcomes and redress inequities.

The documentation of Study One presents three PAR cycles as distinct, separate processes contributing to achieving these objectives in specific ways during specific timelines (each cycle associated with a separate trip by the researcher to Vietnam). The reality is that all three cycles helped to achieve the three objectives, and the reporting simplifies what was a complex, comprehensive and continuous process of active collaboration over a 12-month period. For example, the identification of critical actions that could be taken to benefit the NS Community of Vietnam throughout the HNA were identified and actioned across all three cycles. Likewise, the process of securing ethics approval in Australia and Vietnam spanned PAR cycles one and two. Such flexibility and continuous cycling is well documented as an essential component of PAR [342], and any key concerns or risks identified by the researcher as associated with such flexibility are explicitly documented in the case study. A timeline for the whole study is shown in Table 4 at the end of this section.

<table>
<tr><th colspan="5">Table 1. Overview of DrPH Thesis structure</th></tr>
<tr><th>Chapter Number</th><th colspan="3">Structure of thesis</th><th>Stages of the Health Needs Assessment</th></tr>
<tr><td>1</td><td colspan="3">Introduction</td><td>Introduction to the HNA</td></tr>
<tr><td>2</td><td colspan="3">Literature review and initial consultations</td><td>Background context - NS and other chronic conditions of childhood in Vietnam and other resource-poor settings</td></tr>
<tr><td>3</td><td colspan="3">Research methods</td><td>Underlying axiology, ontology and epistemology</td></tr>
<tr><td rowspan="5">4</td><td colspan="4">Study One and Study Two (HNA Stages 1-3)</td></tr>
<tr><td colspan="3">Study 1
Participatory Action Research (PAR) approach to the development of project foundations and information gathering templates to facilitate consultation with key stakeholders to strengthen understanding of challenges and burdens facing children and families living with NS, recommendations for change and identification of critical actions that could be taken within this HNA.</td><td>Stage 1 – Getting started
- Identify the population (who, where, why?)
- Aims and objectives
- Who was included in the project team?
- Who was included in the stakeholder group?
- What resources were required?</td></tr>
<tr><td colspan="3">Study 2
Implementation of HNA templates</td><td rowspan="2">Stage 2 – Identify health priorities
- How was a profile of the population developed?
- What data were available on the health of the population?
- How was information gathered about the population's and the service providers' perceptions of needs?
- What barriers were encountered?
- How were these barriers overcome?
- What were the key issues for the population?
- What priorities were chosen and why, in terms of impact and changeability?
- What evidence informed your decision?</td></tr>
<tr><td>Part A – Parent surveys</td><td>Part B – Parent interviews</td><td>Part C - Health professional survey</td></tr>
<tr><td colspan="3">Summary of Study 1 and 2</td><td>Stage 3 – Assess priorities for action
- What interventions were considered most effective and acceptable?
- How were resource needs met?</td></tr>
<tr><td rowspan="2">5</td><td colspan="3" rowspan="2">Translation Findings
- Translation of insights from consultation into critical action to improve health and reduce inequalities
- What did we learn?
- Recommendations for NS in other countries / for other chronic conditions of childhood</td><td>Stage 4 – Planning for change
- Summary of the action planning process</td></tr>
<tr><td>Stage 5 – Moving on / Project review
- How well was the action plan implemented?
- What was achieved by the project?
- How did it contribute to reducing inequalities?
- What was learned through the project's successes and challenges?
- What needs to happen next?
- What new priority was chosen for the population?
- What main message from the last HNA will you take forward to the next?</td></tr>
<tr><td>6</td><td colspan="4">Conclusion</td></tr>
<tr><td></td><td colspan="4">References</td></tr>
<tr><td></td><td colspan="4">Appendices</td></tr>
</table>

A summary of the three PAR cycles is presented below.

1) **Cycle One (Setting the Foundations)** – this PAR cycle sought to establish the foundations of the HNA, with specific focus on clarifying the approach that would be taken to consult with the NS Community of Vietnam, formalising a project plan and timeline, identifying and engaging the stakeholders and partners who needed to be involved, securing the necessary resources, securing ethics approval and analysing potential risks to the project (Figure 19).

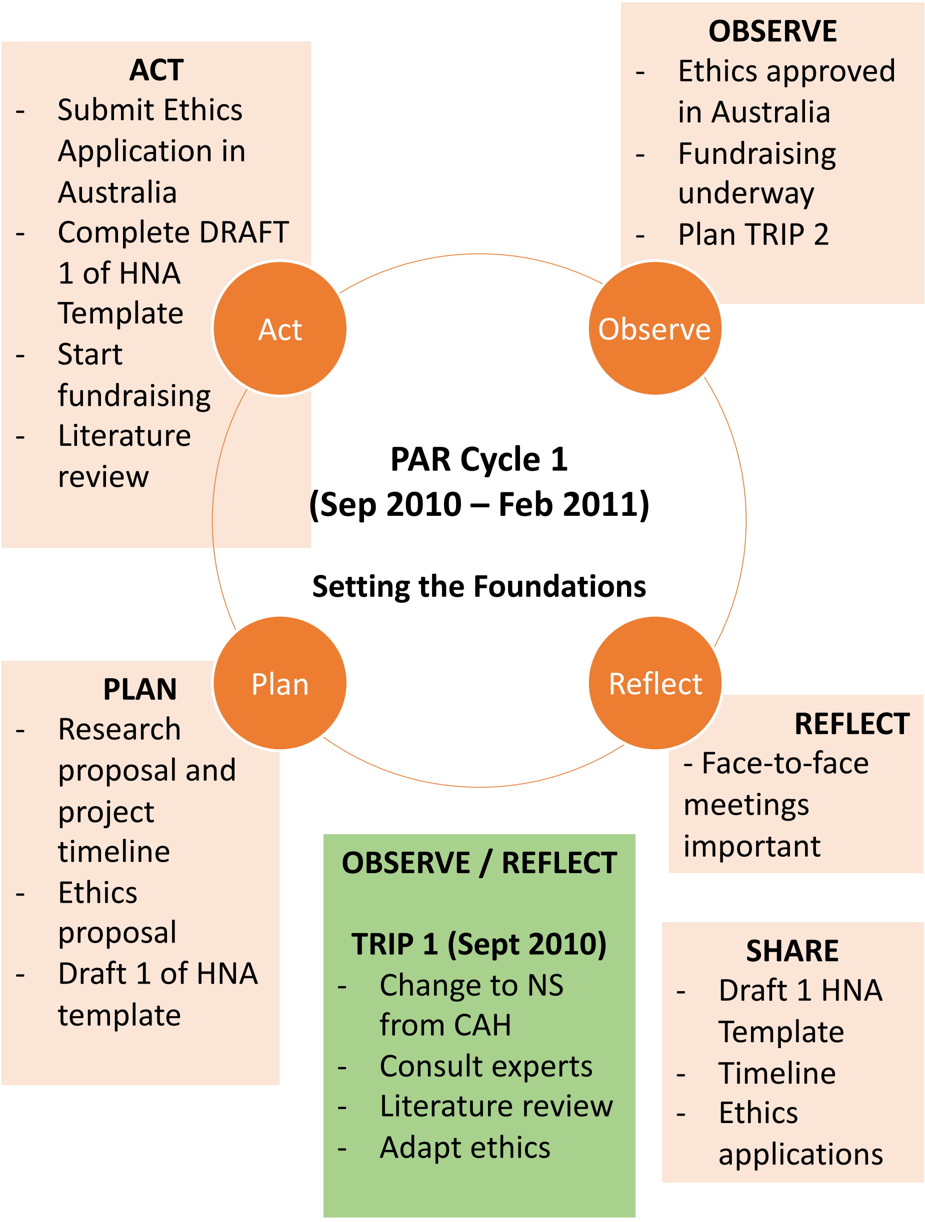


Figure 19 - PAR Cycle 1 - Setting the Foundations

2) **Cycle Two (HNA Template Refinement)** – The second PAR cycle (Figure 20) sought to refine information gathering tools required to facilitate consultation with relevant stakeholders in Vietnam in the HNA, ensure all ethics approval processes were in place, and support planning processes for the NS Club Meetings (and implementation of critical actions at these public spheres to benefit the children and families) planned for November 2011 and February 2012.

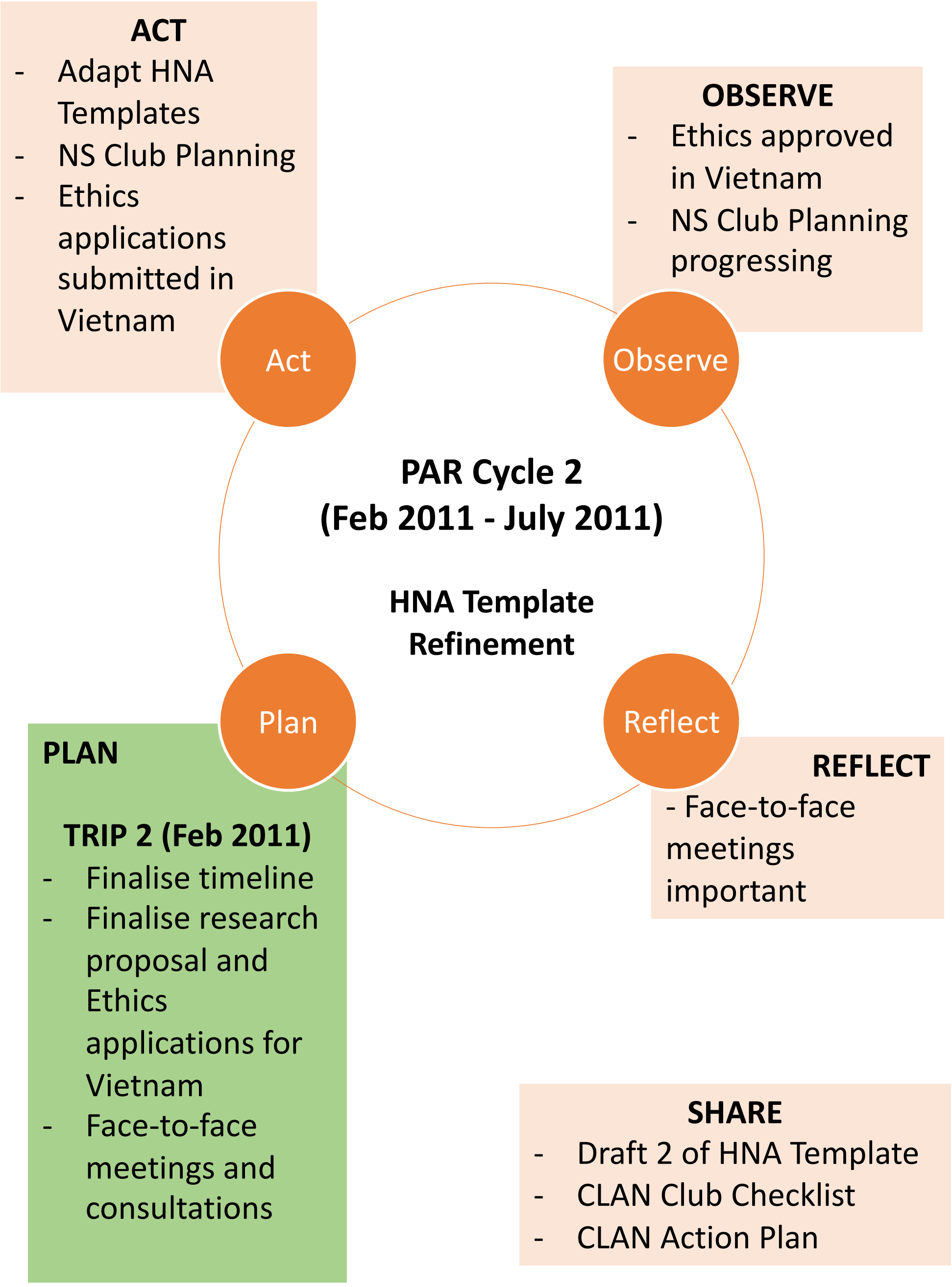


Figure 20 - PAR Cycle 2 - HNA Template Refinement

3) **Cycle Three (Pilot Interviews)** – The third PAR cycle (Figure 21) sought to finalise templates for use in the HNA and further facilitate early identification of realistic and critical actions that could be taken in real time ahead of the inaugural NS Club Meetings and throughout the life of this research project to improve health outcomes and redress inequities experienced by children and families living with NS in Vietnam.

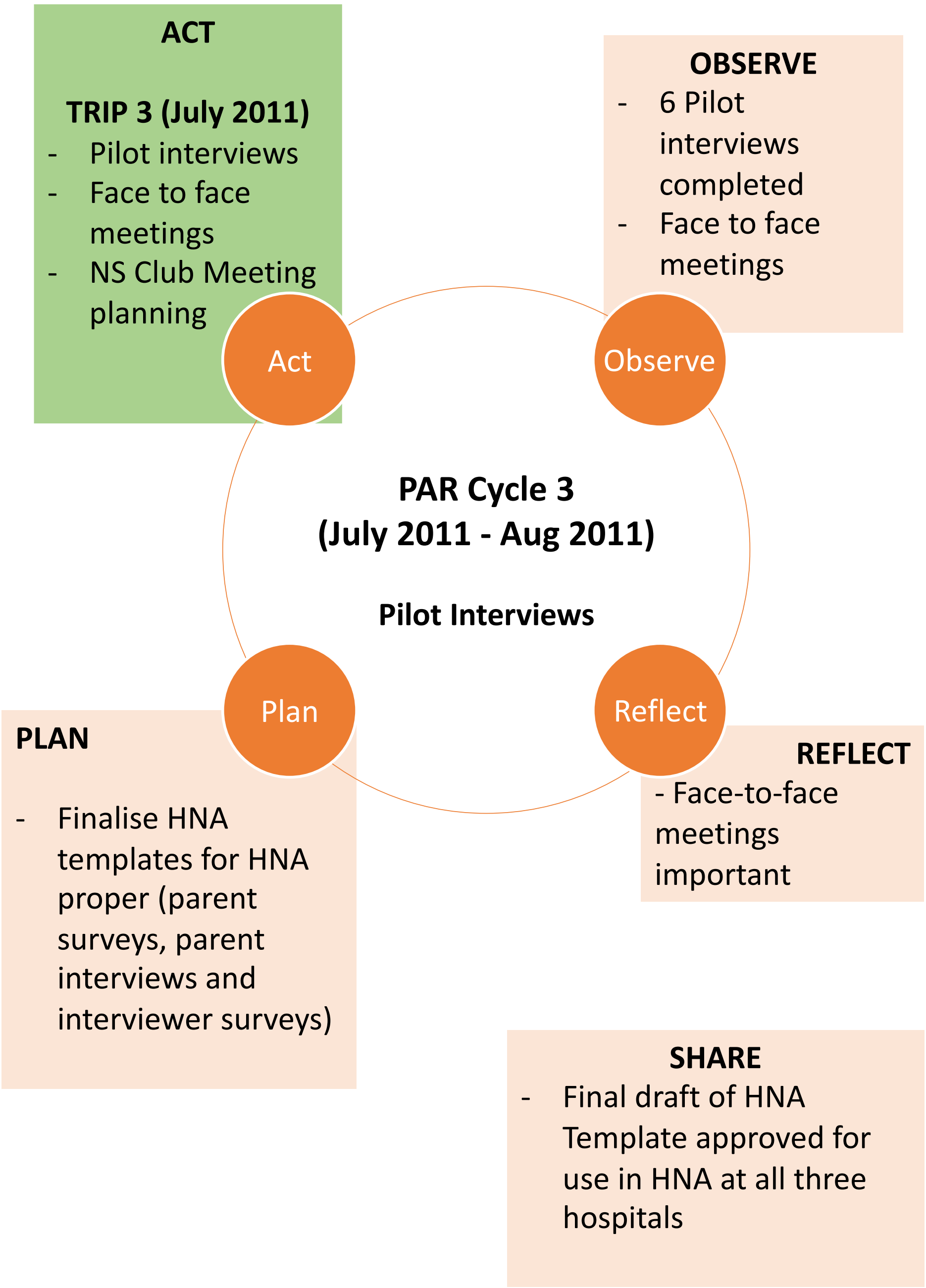


Figure 21 - PAR Cycle 3 - Pilot Interviews

Table 4 - Timeline for the DrPH and Health Needs Assessment (HNA)

DrPH Thesis Timeline & HNA Stages	Sept 2010	Oct 2010	Nov 2010	Dec 2010	Jan 2011	Feb 2011	Mar 2011	Apr 2011	May 2011	Jun 2011	Jul 2011	Aug 2011	Sept 2011	Oct 2011	Nov 2011	Dec 2011	Jan 2012	Feb 2012	Mar+ 2012	2013	2014	2015	2016
Travel to Vietnam	Change from CAH to NS					Initial NS specific visit					Ethics approved Pilot interviews				NS Clubs in HCMC			HCP lectures NS Club in Hanoi		Data collection complete Mar 2013	CLAN	CLAN	CLAN
Key milestones				Ethics application submitted to Flinders University. 1st draft of HNA templates		Ethics application process in Vietnam commenced					NHP Ethics application approved; 2nd draft of templates approved for pilot use	Essential NS medicines added to national insurance list; final HNA templates approved						NS Club Video	NCD Child	NS Club (Feb) & reporting back on results; NS Clubs IPNA	NephCure NCD Child		Australian Ambassador attended NS Club Meeting
HNA Stage One (Getting started): Study One – Developing tools and resources to facilitate a HNA of Nephrotic Syndrome in Vietnam																							
Cycle 1	Setting the foundations – Draft One																						
Cycle 2						HNA template refinement – Draft Two																	
Cycle 3											Pilot interviews – Draft Three												
HNA Stage Two (Identify health priorities): Study Two - Implementation of the HNA templates / Consultation with stakeholders																							
Parent interviews													Started September 2011, completed May 2012										
Parent surveys																							
Health professional interviews																							
HNA Stage Three (Assess priorities for action) – Summary of Study One and Study Two HNA Stage Four (Planning for change) - Translational activities conducted within the scope of the HNA – Critical action to improve quality of life and health outcomes for children living with NS in Vietnam																							
HNA Stage Five (Moving on / Project Review)																							
Fundraising																							
NS Club Meetings																					NS Club	NS Club	NS Club

4.2 Methods

The ontology, axiology and epistemology informing the development of this research project were presented in Chapter Three.

4.2.1 Methodology

Rationale for a descriptive case study

Case studies are generally accepted as well suited to "*how and why questions which can be explanatory in nature*" and are valued for their ability to bring transparency to a range of complexities that have occurred over a period. Case research has been defined as "*a research method that involves investigating one or a small number of social entities or situations about which data are collected using multiple sources of data and developing a holistic description through an iterative research process*" [333], and has therefore been proven a useful methodology for documenting PAR initiatives [343]. A descriptive case study was believed to be well suited to exploring causal mechanisms in accordance with a critical realist epistemology.

Rationale for Participatory Action Research (PAR) approach

A critical realist approach to case research constantly seeks causal mechanisms, and as such, becomes one of "*continuous cycles of research and reflection. The final result is the identification of one or more mechanisms that can be regarded as having caused the events*" [333]. In this regard, PAR and case study research were considered useful and complementary methodologies to support the identification and / or development of information gathering tools that could support the conduct of a HNA relating to NS in Vietnam.

Early consultation with experts and review of the literature suggested there were no pre-existing information gathering tools to support a HNA relating to NS in Vietnam. The researcher was keen to bring academic rigour to the development of information gathering tools developed *de novo* and used in the HNA, so that future communities, health professionals and researchers could rapidly and confidently take up where this researcher left off, and use / adapt the tools knowing the process underpinning their development was robust and valid.

By its nature, a PAR approach had the capacity to support a collaborative approach to the development of templates to facilitate consultation with key stakeholders in Vietnam to learn more about the challenges, burdens and recommendations that families of children living with NS had to share, and this was considered essential to success. Whilst the researcher took responsibility for overall leadership and facilitation, engagement with a range of experts throughout the project was essential, and a PAR approach strengthened this aspect of the project.

PAR guiding principles

There are six key characteristics of quality PAR that the researcher sought to integrate in Study One [342]:

- Cyclical
  - Participatory
  - Systematic
  - Dynamic
  - Developmental
  - Critical

These characteristics informed the design and conduct of the research project:

i) **Cyclical**

Three PAR cycles are reported in Study One. Each followed the same overarching and systematic format of Plan, Act, Observe, Reflect and Share (although the "observe" and reflect" phase were repeated at the start of the first cycle to provide context and meaning). The key goals and planned deliverables of each cycle are described below:

PAR Cycle One – Setting the foundations (Draft One of the information gathering tools)

In Cycle One, the researcher collaborated with a range of key stakeholders to establish strong governance structures and foundations for the HNA, with focus on the development of initial draft versions of high quality, robust, valid information gathering tools that would be used to facilitate consultation with families and other key stakeholders to learn more about NS in Vietnam, so they could be submitted to the relevant Ethics Committees in Australia and Vietnam.

Cycle One started with an extended approach that allowed the researcher to:

- Observe – what was happening
- Reflect – on the context and research questions, as well as the next steps needed. Governance processes, ethics applications and project planning were key objectives identified early on.
- Plan – develop a clear strategy to inform the development of the HNA tools (in particular, an initial draft to submit to Ethics Committees in Australia and Vietnam for approval)
- Act – implement the strategy
- Observe – describe what happened
- Reflect – analyse / develop "theory" / insights on key findings; check with others / seek feedback
- Share – ensure all hear and engage with the process and story

PAR Cycle Two – Refinement of the information gathering tools (Draft Two)

Informed by ongoing consultation with local experts and the literature, initial draft versions of the information gathering tools submitted to Ethics Committees were further refined ready for formal review by the relevant participating hospitals in Vietnam ahead of their use in the conduct of Pilot Interviews in July 2011. This consultation period also informed planning for the inaugural NS Club Meetings.

PAR Cycle 3 – Pilot interviews – final tools ready for use in the HNA (Draft Three)

Using the information gathering tools in formal pilot interviews enabled the researcher to consult broadly and further refine the tools, such that they were ready for final sign off by the participating hospitals for use in the HNA proper. Moreover, one-hour consultations with six families during the pilot interview process gave the researcher excellent insights into the challenges, burdens, strengths and recommendations for action that families had to share, and these informed ongoing planning and action with CLAN and other stakeholders in real time to ensure optimal use of the NS Club Meetings for the benefit of children and families living with NS in Vietnam (described in full in Chapter Five).

ii) **Participatory**

The following key stakeholders were identified early in discussions and review of the literature as critical to the project's success:

- Hospital executives
- Parents and other caregivers of children living with NS in Vietnam
- Health professionals caring for children living with NS in Vietnam
- Other stakeholders identified throughout the research project, predicted to include Ministry of Health officials, Insurance agency representatives, specialists in the field of NS in high income countries and other NGOs (beyond CLAN).

There was acknowledgement of the critical role public spheres would play in enabling effective consultation and participation. Examples of public spheres that the researcher planned to use in Study One included email correspondence, face-to-face meetings, NS Club Meetings, and visits to the inpatient and outpatient departments of the participating hospitals. Participation of members from the NS Community Vietnam (through face-to-face meetings and NS Club Meetings) was prioritised, and processes of engagement refined to enhance social inclusion and social justice. For example, the nature of the research project was carefully explained to families, and their input sought on the appropriate conduct of NS Club Meetings; NS Club Executives were elected by the Community to represent Community views most effectively and strengthen engagement and communication with all; poorer and remote area families were reimbursed for travel and other costs associated with attending Club meetings; and interviews with families were limited to families already at the hospital to reduce any burden on families of participating. Participants were engaged and involved throughout the project to build a shared understanding and commitment to contribute to change.

iii) **Systematic**

Processes needed to be logical and clearly communicated to all. Research proposals, action plans, timelines and other project management tools were key to achieving this. Progress and processes were recorded, and regular updates shared with supervisors, mentors and participants.

In Cycle One, attention was given to establishing clear systems and processes that would set up the overall research project for success. These included documenting the timeline, processes and systems established to promote strong governance structures and safeguard ethical considerations, with regular reporting and consultation to relevant authorities in place so that hospital executive were informed of the project at all stages and always felt able to influence actions and activities as required.

iv) **Dynamic**

Working in Vietnam since 2004 had shown the researcher the vital importance of flexible, dynamic, respectful and culturally safe approaches. The three PAR cycles allowed for change, adaptation, and flexibility in real time. For instance, initial plans were adapted as needed: what started as a single template for families and a detailed template for health professionals were adapted into detailed survey and interview templates for parents and a simpler template to guide less structured discussions with other stakeholders. Working internationally, across language and cultural barriers with a modest budget and volunteer human resources made dynamic and flexible approaches essential at all times.

v) **Developmental**

Multiple small steps were taken throughout the research project to gradually shape the entire picture. Realistic timelines were set at the start of the project (Table 4, above) and these were largely adhered to (with completion of data collection by 2013). Some translational activities (such as the work of NCD Child) were more successful than expected, so final formal write up of the project as a DrPH thesis was necessarily delayed. Importantly however, reporting back to participants (including families and hospital executives) was not delayed, and occurred on time and as planned in February 2013.

vi) **Critical**

Limited budgets and resources necessitated strategic action, with endorsement by CLAN's Committee when decisions regarding spending of limited finances had to be adjusted or changed because of recommendations from stakeholders during the consultation processes.

Cultural humility was essential, and Dr Hao as cultural broker, guide and mentor was invaluable, as were the contributions of subject matter experts from Australia (Dr Elisabeth Hodson and Dr Allison Tong) and long-term members of CLAN's team such as Dr Yen Thanh Mac. Regular reflection by the researcher enabled considerations of power, privilege, participation, ethical action, community control, racial and ethnic discrimination to occur [344]. CLAN Committee meetings and updates to supervisors facilitated this process.

CLAN’s commitment to timely action and belief in the “golden window” of childhood to reducing preventable morbidity and mortality brought urgency to the need for rapid identification of critical actions that could be taken to benefit children and families living with NS in Vietnam. This approach aligned well with the project’s critical realist epistemology.

4.2.2 Materials

More detail is reported in each specific PAR cycle, but considerations included:

- Data management
    - Endnote (version X9, Clarivate Analytics, Philadelphia, USA) – for collation of literature identified during the literature review
    - Secure storage – for handwritten notes and computer files in locked facilities
- Internet access
    - Online library database access - for review of publicly available literature
    - Internet access for grey literature search
    - Skype and email access
- Travel and accommodation
    - For face-to-face consultation with experts and conduct of pilot interviews
    - For reporting back to Community Members
- Office supplies and administrative support – to assist with:
    - Ethics application
    - Research proposal
    - Project timeline
    - Development of CLAN Action Plan for NS in Vietnam
    - Printing of tools (circulated via email and as paper versions to key stakeholders – costs supported by CLAN)
- Translation support
    - Information gathering tools – translated into Vietnamese once finalised
    - Translation of educational resources, Club Newsletters, Informed Consent and introductory documentation (costs supported by CLAN)

- Cultural brokerage
    - Services of Dr Hao – funded by researcher
- Fundraising / financial support
    - The researcher successfully applied for a grant of AUD$5,000 from Flinders University to assist with the costs associated with the project.
    - CLAN held major fundraising events for efforts to support the NS Community of Vietnam from 2010 to 2012 [1], and these events helped cover the cost of critical actions outlined in Chapter Five.

4.2.3 Ethical considerations specific to Study One

Development of the information gathering tools that would be used to conduct the HNA was undertaken with the goal of promoting:

- Community involvement and direction – whilst acknowledging the NS Community was already heavily burdened and struggling, the researcher sought to balance efforts to avoid additional requests to the NS Community Members with a strong commitment to promoting active Community involvement, empowerment and engagement at all times. The identification of an NS Community President early in the project was vital to promoting Community control and leadership, and involvement of the hospital executive in this process ensured the process occurred in culturally appropriate ways.

- Financial responsibility and accountability – the researcher was accountable to CLAN's Committee for the expenditure of funds raised during CLAN fundraisers between 2010 and 2012. In addition, CLAN's finances were audited externally and reported in publicly available annual reports to safeguard all processes.

- Transparent communication with relevant authorities – CLAN's Action Plan for NS in Vietnam and the documentation submitted to all participating hospitals' Ethics Committees in Vietnam assisted with accountability and communication processes. Respecting processes within Vietnam (a Communist country with different requirements to Australia) was essential, and the researcher had to ensure the project had ongoing permission from appropriate authorities to allow it to progress to fruition.

- Equity and access - the overall design of the consultation process (timing, location, language, structure, approach) took into account the extreme poverty and disadvantage members of the NS Community were facing and sought always to minimise additional burdens of participation for families and children. The researcher sought to ensure the benefits for the families and children of participation would always outweigh the costs (for example: payment of stipends for participation; using skilled health professionals in the interview processes who could answer families' questions in real time; providing educational resources, free urinary dipsticks, food and other positive resources for families at the NS Club Meetings).

It was important to the researcher that NS Community members benefited from their participation in Study One, so specific efforts were made to benefit families. For instance, time was dedicated during all pilot interviews to address any specific concerns or queries that families may have and share as much information with them as possible about NS. Active involvement of the NS Club Executive in planning and implementing critical actions identified during and emerging from Study One was another attempt at this – for instance with the NS Club video that was developed, the Executive were involved in the planning and implementation and given key speaking roles. Club Executive also took a lead role in planning and running the NS Club meetings.

4.3 Results

In this section more detail is given about three PAR Cycles completed during Study One, as part of Stage One of the HNA. Each cycle involved a trip to Vietnam by the researcher to optimise participation of all key stakeholders.

4.3.1 Cycle 1 – Setting the foundations

- Trip 1 – September 2010
- Shared deliverables: timeline; budget; HNA Templates Draft One; Ethics applications

4.3.2 Cycle 2 – HNA template refinement

- Trip 2 – February 2011
- Shared deliverables: HNA Templates Draft Two; CLAN Action Plan for NS in Vietnam; NS Club Checklist

4.3.3 Cycle 3 – Pilot interviews

- Trip 3 – August 2011
- Shared deliverables: HNA Templates Draft Three

4.3.1 Cycle 1 – Setting the foundations

Introduction

Cycle One of Study One focused on establishing a firm foundation for the HNA and a PAR approach to the development of the tools and resources considered necessary to facilitate consultation with key stakeholders and inform a better understanding of the challenges and burdens facing children and families living with NS in Vietnam. One urgent priority of Cycle One was to prepare a draft of the information gathering templates needed to conduct the HNA for submission to Ethics Committees in Australia and Vietnam for review and consideration. Other key priorities for Cycle One were:

- Clarifying how the NS Community would be consulted (identifying “the population” for the HNA)
- Agreeing aims and objectives

- Engaging appropriate stakeholders
- Identifying existing resources and gaps
- Establishing appropriate governance processes
- Formalising a project plan / timeline that was acceptable to all

An extended PAR cycle was used in Cycle One, with additional “observe” and “reflect” phases setting the scene, describing the context, and showcasing the foundational insights that informed the development of the tools and resources needed to facilitate consultation with key stakeholders. To this end, Cycle One was composed of the following phases:

PAR 1a) Observe – what is happening? Clarify the current context (eg what tools and resources already exist / what does the literature say?)

PAR 1b) Reflect – what needs to happen next? Who needs to be involved? And how?

PAR 1c) Plan – working with others to agree key methods of how the draft templates were to be developed for the Ethics Committees in the first instance, but beyond that, how the templates would be refined over time so that they would be high quality and effective tools for identifying challenges, burdens and recommendations (the what, who, how, when, where of actions required)

PAR 1d) Act – carry out agreed action plans and document results

PAR 1e) Observe – discuss what happened

PAR 1f) Reflect – identify key insights and recommendations for next steps

PAR 1g) Share – disseminate outcomes and deliverables (notably, Draft One for the Ethics Committees).

PAR 1a) Observe – recap of current context

Context of the research project

The researcher’s trip to Vietnam in September 2010 confirmed local authorities’ preference for a focus on NS and the researcher was respectful of specific considerations that are required when working in a Communist country. CLAN had had the privilege of working in Vietnam since 2004 and enjoyed long and positive collaborative relationships focused on improving health outcomes and quality of life for children living with CAH, so the researcher was familiar with cultural and procedural considerations that were to inform the project. The paramount consideration was to ensure the hospital executive at each of the three participating hospitals was informed of and able to influence activities at all times and ensure there was agreement such actions were appropriate.

Acknowledging the researcher did not have a lived experience with NS, and to systematise the HNA information gathering processes, initial plans included the development of templates to facilitate consultation with three key groups of stakeholders:

- Parents of children living with NS in Vietnam
- Health professionals caring for children living with NS in Vietnam and
- Other key stakeholders (such as Ministry of Health and Insurance Company representatives).

Consideration of epistemology and methodology

Discussions with stakeholders in September 2010 confirmed the NS Community of Vietnam was experiencing significant unmet social needs, as reflected in the:

- *Expressed needs* – the high burden of disease was evident from the crowded hospital inpatient and outpatient departments and anecdotal reports of preventable morbidity and mortality.
- *Normative and comparative needs* – early consultation with experts from Vietnam and Australia and review of the literature highlighted not just the preventable morbidity and mortality associated with NS in Vietnam, but also the potential for some relatively simple and affordable action to effect dramatic change for the Community. There were clear and extreme health inequities compared with experiences and health outcomes achieved for and by NS Communities in high-income countries.
- *Felt needs* – whilst there was limited evidence in the literature, conversations with families and visits to hospital wards showed that children and families alike were experiencing very poor quality of life with NS. Felt needs included affordable access to essential medicines and locally available quality care, and a desire to end their extreme poverty and suffering.

Reflection on existing tools, resources and experiences

Consultations with parents of children living with CAH in Vietnam in 2005 had demonstrated to CLAN the importance of listening to families, understanding felt needs and planning critical actions around the insights they provided. Whilst CLAN's five pillars provided a starting point for critical action to support the NS Community of Vietnam, there was acknowledgement that tools used to facilitate the CAH Community consultation process were not necessarily relevant to NS, and so it was essential to consider what tools were necessary to facilitate consultation as part of a HNA relating to NS in Vietnam.

Guided by these insights, the researcher prioritised the identification and / or development of tools and processes in Study One that would support a mixed methods approach in Study Two. Consultation processes and tools suitable for sampling large numbers of families would be important, so quantitative data could inform insights relevant to the experiences of the broader NS Community through deductive reasoning. Semi-structured parent interviews (according to structured sampling guidelines) were likewise considered important, because qualitative data gathered thereby were likely to reveal rich insights through inductive reasoning. The researcher's preference for a critical realism approach to the identification of recommendations for critical action through abductive and retroductive reasoning (in Studies Two and Three) placed value on both quantitative and qualitative data, and informed reflections on the capacity of CLAN's model to guide planning in advance of detailed community consultation insights being available [332].

Rapid review of the literature and consultation with experts to identify other existing tools and resources

In preparation of Draft One (for submission to Ethics Committees in Australia and Vietnam), the researcher undertook a rapid review of the literature and consultation with experts to identify additional existing tools and resources that could assist with the HNA. Sources of information used to research this question included the published literature and expert opinions. Search terms used when reviewing the literature to answer this question included:

- nephrotic syndrome OR renal OR kidney
- quality of life OR health OR wellbeing
- morbidity OR mortality OR burdens OR challenges OR barriers OR fears OR burden of illness OR impact OR problem
- child OR adolescen* OR pediatric OR paediatric OR teen
- Vietnam
- Chronic OR chronic disease OR non-communicable disease OR chronic health condition
- Guidelines OR survey OR health needs assessment OR tool OR interview OR consultation

Existing tools and resources that were identified included:

- Surveys used to date in Vietnam

CLAN had been working in the field of CAH, DM and ASD in Vietnam. Questionnaire tools developed *de novo* by CLAN and used in Vietnam to survey families of children living with CAH were later adapted for use with families of children living with type 1 diabetes [33, 43], but no official manuals or protocols had been established to allow others to undertake this work easily and effectively. Review of the literature indicated there had been similar consultations with communities of Vietnamese families living with other chronic health conditions (notably epilepsy and HIV or AIDS) using tools developed *de novo* and adapted appropriately. Although these tools were not directly relevant to NS, they nonetheless provided useful starting points in terms of identifying indicators that should be included in the HNA tools for this research project [81, 83, 84, 86, 95, 345-352].

- The Rapid Assessment Protocol of Insulin Access (RAPIA) Tool

Developed by the International Insulin Foundation, the Rapid Assessment Protocol of Insulin Access (RAPIA) questionnaire [353] was an example of an internationally recognised tool initially developed to conduct health needs assessments relating to diabetes and later translated to strengthen an understanding of CAH in Vietnam. As such, the RAPIA provided a useful platform for adapting a rapid needs assessment to inform recommendations for effecting change for a community of children with a serious chronic health condition such as NS. In particular, the RAPIA offered an example of a tool that supported collection of data in a rapid manner, and could be adapted to help strengthen an understanding of:

- the current burden of illness of a chronic condition in Vietnam
- key recommendations of main stakeholders on steps needed to effect change to improve health outcomes, and
- challenges and recommendations from the micro, macro and meso levels.

- Other Health Needs Assessment (HNA) frameworks

The 2009 Population and Housing Census provided a useful template [54] against which national Vietnamese baseline datasets could be compared, particularly for data relating to the demographic profile of the NS Community of Vietnam.

The National Institute of Clinical Excellence's Health Needs Assessment (NICE HNA) framework [6] offered a useful guide to practical steps that should be undertaken to complete a HNA.

Other tools had been developed to assist with monitoring the impact of projects and programs relevant to health [96, 354-356] and assist with planning and implementation of critical action to drive change.

- Quality of life measures

A number of tools were available to measure quality of life for children and adults affected by chronic health conditions in Vietnam and other countries, with especial focus on parental stress resulting from caring for children with chronic conditions [81, 87, 88, 128, 349, 357-362]. Unfortunately, no existing templates were suitable for the specific objectives of this research project in Vietnam, although aspects of several informed the development of the final tools used. One study from Egypt was particularly helpful, and described the development of a questionnaire to guide parental interviews used to evaluate the quality of care delivered to children with chronic conditions, as prescribed in treatment guidelines available to all clinicians, and analyse the impact of this healthcare on quality of life [159]. This study was not directly translatable to the research project primarily because no accepted treatment guidelines were available, but the different questions asked were reviewed and adapted where relevant.

Key learnings from the Egyptian study were integrated into the HNA process of this project. For instance, clinicians used medical records to capture some data (for instance details of drug prescription) and each interview took approximately 30 minutes to complete. There was 100% agreement from parents (approached in a random sequence) to participate, and researchers noted:

> *The high response rate was attributable to the fact that these children are managed in crowded public hospitals where their caretakers (primarily the mothers) were usually not given enough time to talk about their children's conditions. Therefore, through these interviews, mothers were given an opportunity to discuss their problems and difficulties with their sick children*.

The survey tool from Egypt was developed *de novo* and included background questions relating to:

- demographic variables
- diagnostic procedures
- drugs taken by patients routinely and in emergency situations
- mode of administration of drugs given and intervals between doses
- specific questions relating to each chronic condition under study

Impact of illness on children was assessed using seven indicators:

- dependence on parents in domestic activities
- level of activity compared with peers
- mood compared with peers
- level of socialising
- degree of discomfort attributable to illness
- level of physical disadvantage and
- urinary incontinence

Other questions related to parental satisfaction with care, information on school attendance and scholastic achievement were included.

- Other factors considered in the context of *de novo* development of tools

Place of residence, ethnicity, gender, age, education, family background, socio-economic status, cohesion, social capital and engagement consistently emerged as relevant equity considerations in a large number of studies [62, 75, 76, 94, 97, 98, 363-366], and informed the development of questions around demographics, family size and social supports and structures. Questions relating to the impact of sociocultural factors on hospitalisation and admissions were informed by research from Japan, which spoke to the association noted there between family dynamics and length of stay for children with NS [367].

Studies looking at the psychosocial adjustment of children with kidney disease were of interest [368-370], although an early decision not to interview or survey children or young people made some findings less relevant. Input from teachers had also been used by some researchers, as had input from families where high levels of understanding facilitated consultation [128]. Neither of these scenarios was entirely applicable to this research project, although insights helped inform tool development.

Research relating to power and positionality – in particular, how the researcher can be aware of these and minimise their impact – was reviewed and informed discussions with the research project's cultural mentor particularly during the planning phase [371]. Insights from the literature around funding and insurance structures (notably barriers and challenges) and self-medication informed the development of questions around health insurance and use of traditional medicines [58, 59, 372].

There were limited qualitative studies into the needs and priorities expressed first hand by children, families and communities living with NS or other chronic health conditions of childhood. These highlighted the novel nature of such insights when compared with those emerging from clinicians and quantitative studies, thereby emphasising the need for more patient and family perspectives [33, 60, 83, 86, 97, 343, 350, 354, 373-375].

Preparing Ethics Committee applications

The researcher was mindful that applications would have to be submitted to Ethics Committees in Australia and Vietnam. In Vietnam, the Ethics Committee deadlines were more flexible – the submissions were submitted to the participating hospitals' executive staff, who would then liaise with the appropriate authorities as required.

In Australia, the researcher had to submit an application to the Flinders University Ethics Committee by December 2010 for the project to commence in February 2011 (which was the date the researcher was invited to return to progress the project). As part of this application, it was necessary to provide draft versions of the information gathering tools that would be used in the HNA process, so that the Committee could understand consultation processes that would be taken with families and ensure ethical considerations were appropriately addressed.

Given the initial review of literature and consultation with experts in Australia and Vietnam confirmed there were no pre-existing tools that could be used in a HNA with the NS Community of Vietnam, it was clear all tools and products would need to be developed *de novo*, albeit it with the following resources guiding the development process:

- The 2009 Vietnamese government population census template
- CLAN's 2005 survey template used to consult parents of children with CAH in Vietnam
- The International Insulin Foundation's RAPIA template used for diabetes and CAH in Vietnam (with micro, macro and mesa consultation templates)
- The PROGRESS-Plus [366] equity indicators (place of residence; race / ethnicity; occupation; gender; religion; education; socio-economic status; social capital; age; disability and sexual orientation)
- International quality of life (QOL) research relating to NS (acknowledging these templates were less useful, because this research project was not focused primarily on QOL, but rather the identification of challenges, burdens and recommendations for change).

PAR 1b) Reflect – what needs to happen next?

Having confirmed the information gathering tools would need to be developed *de novo, s*pecific considerations considered essential to this were identified as follows:

- Tools must be of highest quality possible for them to facilitate a systematic approach to capturing quality data, and should be trialled in advance if possible

- Tools would ideally have potential to be adapted for use with other chronic health conditions of childhood and other countries / cultures

It was agreed timing and project management would be critical. In particular:

- A timeline was needed to outline steps taken so that deadlines could be met, particularly time-bound activities such as travel (which had to be planned well in advance) and preparation for Club Meetings (early discussions suggested this would be an appropriate public sphere for consultation, as had happened with the CAH Consultation). Based on past experience by CLAN, quality meetings for large numbers of children generally took around six months to organise, and meetings for 2013 (to facilitate reporting results back to Community) had to be planned at an early stage

- Conduct of a research project internationally with limited resources would require detailed planning to optimise use of each visit to Vietnam. Budgets were key to accountability and transparency for CLAN's Committee and served as guides for fundraising goals.

- Governance and ethical considerations would be very important. Conduct of the project in a Communist country meant transparent approaches, careful consultation and permission seeking would be paramount. Children and families living with NS were a vulnerable group, so ethical considerations had to be considered with great care and detail so that no NS Community Members would be worse off as a result of participating in any facet of the project.

- Potential for conflict of interest between role of researcher and President of CLAN had to be considered, and full transparency and declaration through clear communication and reporting was necessary to protect all parties from potentially unethical actions.

- Research findings must translate to critical action in a timely way, so that EVERY opportunity to benefit the children in real time would be optimised. The researcher was committed not to undertake research for the sake of research, but rather to optimise quality of life for the NS Community.

The literature and early consultations clearly identified a need for information gathering tools that were developed to facilitate an understanding of potential health determinants and indicators of the impact of NS on health functioning (as per the health triangle [6], see Figure 24). Categories identified during the initial rapid review and consultation process included:

- Demographic and epidemiological factors
  - Burden of NS (prevalence, incidence, morbidity, mortality)
  - Social determinants (such as education, ethnicity, income, employment, rural versus urban living)
  - Family structures and support – have major influence on health outcomes and wellbeing of parents and children alike
- School and social life
  - Impact of NS on schooling, noting the potential for generational poverty if education is forfeited
  - Impact of NS on social life and wellbeing of children and families
- Physical considerations
  - Height and weight
  - Vaccination status – given infections are associated with relapses
  - Type of NS - whilst the majority (90%+) of children could expect positive health outcomes, some types of NS would always be associated with poorer health outcomes
  - Time since diagnosis – has large bearing on health outcomes
  - Expressed needs – frequency of hospitalisation
  - Wellbeing scores
  - Measures of complications / relapses
- Access to quality health care (comparative and normative needs)
  - Type of medicines used
  - Access to essential medicines
  - Access to qualified health professionals in local areas
  - Use of traditional medicines
  - Management of NS (including ESKD)
- Financial impact of NS
  - Health insurance
  - Cost of care
- Health literacy (of families and health professionals)
  - Understanding of NS
  - Educational resources used

  - Self-management of NS

- NS specific felt needs
  - Burdens and challenges
  - Measures of the health functioning impact of NS on children and families.

Figure 22 - The Health Triangle (adapted from the NICE HNA guide [6]) – redacted for copyright

The information gathering tools also needed to facilitate the identification of recommendations for future action. Moreover, the process of capturing recommendations had to occur in such a way that it allowed the researcher to identify rapidly realistic actions that could be undertaken in the short- to medium-term and at low cost to drive improvements in quality of life and health outcomes as soon as possible. In particular, there was a golden opportunity to enact critical actions before and at the inaugural NS Club meetings, so it was essential the researcher systematically communicated new findings to all stakeholders in a timely way.

PAR 1c) Plan

The researcher considered the following in the planning process:

- What is needed?
- Who is needed?
- When will it be completed?

- Where will it be completed?

What is needed?

Priorities identified in the planning process included the need to finalise:

i) Governance processes

  - Clear governance processes had to be established with hospital executives and health professionals in Vietnam. Email correspondence was the most appropriate method to arrange face-to-face meetings at all three children's hospitals in Vietnam (planned for February 2011) to ratify all plans with all stakeholders.

ii) Submission of ethics applications

  - Ethics applications must be prepared and submitted in Australia and Vietnam
  - December 2010 was the deadline for Australia
  - The applications for Vietnam must be submitted following the visit to Vietnam in February, with plenty of time allowed for review of final HNA templates and discussion of NS Club plans with local authorities ahead of the next proposed visit in July 2011.

iii) Development strategy for the HNA information gathering tools

  - Discussion with stakeholders in Vietnam in September 2010 led to agreement on possible project timelines and dates the researcher could potentially visit Vietnam in 2011
  - Initial drafts would need to be developed collaboratively and *de novo* and submitted in December 2010 as part of Ethics applications (based on review of the literature and consultation with experts)
  - Further development and refinement of tools and products to occur in a PAR style with key stakeholders as part of HNA during February visit and ahead of July pilot interviews.
  - Finalisation of drafts to occur through pilot process once ethics was approved, ready for use from August 2011 (interviews) and November 2011 / early 2012 (NS Club meetings for surveys).

iv) Funds / resources

  - Application to Flinders University for funding to assist with costs of research
  - Fund-raising by CLAN to ensure realistic recommendations could be translated to critical actions in real time.

v) Project plan

- Strong project management was critical – including program logic and CLAN action plan
- Clear timeline
- Communication with all stakeholders (particularly during meetings in person in Vietnam in February 2011) so that all key stakeholders agree with the approach

Who is needed?

Based on CLAN's experiences working to support the CAH Community in Vietnam, it was clear a broad number of stakeholders would need to be involved, but the following were prioritised for consideration for conduct of the HNA:

i) Hospital executives and health professionals in Vietnam

NS is a complex chronic health condition of childhood, and anecdotally families prefer to take their children to tertiary referral centres where they believe their children will get the best care and will be seen by specialist health professionals who are most expert in the management of NS in Vietnam.

Expressions of interest were received from all three major children's hospitals in Vietnam to be involved in the consultation process:

- National Hospital of Pediatrics (NHP) in Hanoi
- Children's Hospital One (CH1) in Ho Chi Minh City (HCMC)
- Children's Hospital Two (CH2) in HCMC

To receive appropriate permissions to conduct research and project work in Vietnam and operate in a culturally appropriate way in a Communist setting, it was imperative that hospital executive and senior health professionals be consulted and integrally involved at all stages. Approval would have to be sought in advance on appropriate ways to engage and progress the study. It was not considered necessary to develop a specific "template" to facilitate consultation with these stakeholders, but rather ensure strong governance processes were established from the start of the project. Regular email and face-to-face meetings were planned to ensure the necessary stakeholders were consulted and updated in such a way that transparency and approval processes could be maintained appropriately.

There was acknowledgement that critical action in response to emerging insights and recommendations for change arising from the research would require resources beyond the scope of the researcher. It was agreed that CLAN would provide in-kind and financial support, and NHP would serve as the main conduit to communication with the Vietnamese Ministry of Health. The specific details relating to ethics would be discussed in person with the executive of each hospital during face-to-face meetings in February 2011. Hospital executives would select appropriate staff to support the project (including translators, cultural mentors and specialist paediatric nephrology support).

ii) NS Community Members

A decision was made early to prioritise the voices of people living with NS, and ensure information gathering tools had capacity to capture experiences and insights from as many children and families living with NS in Vietnam as possible (quantitative data) but also offer in-depth insights (qualitative data). Whilst the researcher was initially open to the concept of interviewing young people living with NS (and included this in the ethics application), there was general early agreement that this should be avoided given the potential vulnerability of young people, the risk of causing harm and potential sampling challenges (for instance, younger children generally had milder and more common forms of NS but would likely be less able to provide useful information in an interview or survey. Older children were more able to participate in surveys and interviews but were more likely to represent a smaller, less representative cohort of young people with more severe forms of NS).

iii) International NS experts

Colleagues in Vietnam requested Dr Elisabeth Hodson (EH), a highly regarded specialist paediatric nephrologist from Australia be involved. EH generously agreed to support the project, provide supervision as an expert in the field, and facilitate additional networking as needed.

Alison Tong (AT) was recommended by EH as a skilled researcher in the paediatric nephrology field, and the researcher was very grateful when AT generously agreed to support the project and travel to Vietnam with KA and EH in November 2011.

NephCure was another notable stakeholder internationally working in the field of NS, and CLAN identified reaching out to this organisation as a priority within its general preparation processes for upcoming NS Club Meetings.

iv) Cultural mentor

Dr Hao, a well-regarded psychologist in Hanoi, was appointed by NHP as a resource to the lead researcher. Dr Hao would provide expertise in translation, supporting families appropriately during interviews, conduct of interviews and adaptation of HNA templates so they were culturally safe and appropriate. Dr Hao was reimbursed at an agreed hourly rate.

v) Translators

The appropriate hospital doctors were nominated by hospital executives to support the project as needed. This included translation of tools and resources into Vietnamese and support with interviews and surveys. Where additional work was needed, CLAN paid for translator support (e.g. booklets on NS; conduct of formal interviews with families).

vi) CLAN (Caring & Living As Neighbours)

CLAN's Committee and Executive teams of CLAN supported engagement with this project and committed funding and in-kind resources to facilitate realistic actions to improve quality of life for children living with NS in Vietnam identified throughout the research project. There was acknowledgement this support of the project would require additional fund-raising, so this was commenced in February 2011 and involved bushwalks and social events.

vii) Other key stakeholders

It was agreed between KA, EH, Hospital Executives, and local health professionals that there may be a need to consult with additional stakeholders during the project (such as Ministry of Health / Insurance agency) and these would be discussed and agreed as the project progressed. A template was drafted for the Ethics Application process to support this process.

When will it be completed?

The timeline for the project was approximately three years (September 2010 to March 2013), with efforts conducted part-time to equate to one year full-time equivalent. The three-year timeline reflected the need to conduct the research in a part-time manner because of:

- limited resources and funding
- the nature of the research (challenges of consulting unique stakeholders)
- the need for travel overseas and between the three hospitals in Vietnam
- the importance of full participation of and engagement with all stakeholders.

To conduct initial consultations with families at NS Club Meetings and other forums at three children's hospitals in late 2011 / early 2012, ethics approval and template development needed to be completed by mid-2011. There was acknowledgement tools and resources would have to be developed rapidly (less than six months part-time). The researcher prioritised reporting results back to all stakeholders in Vietnam (particularly members of the NS Community), so travel back to Vietnam in 2013 for reporting was to be included in the overall planning process and timeline. The complexity of the project required a detailed timeline and project plan to be finalised and shared with stakeholders, so everyone could be appropriately briefed and engaged, with shared expectations and plenty of opportunity for input to influence the outcome at all times.

Where will it be conducted?

The researcher was delighted all three children's hospitals wanted to be involved and made every effort to ensure they had the opportunity to participate equally. This was achieved by always making the collective NS Community of Vietnam the focus. As a result, NS Club Meetings were conducted at all three hospitals, and resources were shared amongst the participating hospitals according to the size of their respective NS Communities.

Consultation with families was to occur exclusively at the hospitals, to minimise additional or unnecessary travel expenses / loss of income and other financial burdens for families. Where families were asked to travel for events outside their normal visits to the hospital (such as the NS Club meetings), the researcher (with support from CLAN – as had been usual practice for CAH Club Meetings) committed to reimbursing their travel costs with stipends to cover food and travel expenses, with allocation made according to need (those from the poorest families and those living furthest from the hospitals were given the highest priority).

It was identified early in proceedings that development of tools and resources must occur in such a manner as to respect and value local differences (notably dialects, vocabulary), and so it was essential the drafting process of the HNA templates involved stakeholders from both HCMC and Hanoi equally and at all stages.

PAR 1d) Act

i) Governance processes established

Face-to-face meetings were held with executive at all three children's hospitals in Vietnam in September 2010 (KA), and requirements for the project were discussed. Plans were made for visits to Vietnam (in February and August of 2011), with the February meetings to focus on finalisation of the necessary ethics application processes in Vietnam; endorsement of an overarching research proposal by all hospitals; approval of consultation processes; and agreement on an overall project timeline.

Between visits to Vietnam, it was agreed regular email correspondence would be used for communication between the researcher and other stakeholders. It was agreed face-to-face meetings with each hospital's executive would occur during each subsequent visit, to check progress was according to plan. Specific requirements of each hospital were identified and met, for example face-to-face meetings to be held throughout the project with separate hospital executives to discuss specifics, invitation of Prof. Nguyen Thanh Liem (Director of NHP) to join the project as a Co-Supervisor, a detailed research proposal to be submitted to each hospital outlining specific operating procedures for the project and proposed governance processes (as was shared with all hospitals in January 2011).

ii) Ethics applications submitted

A formal ethics application was submitted to Flinders University on 15 November 2010. The application submitted to Flinders in Australia was simultaneously shared with colleagues in Vietnam via email (ahead of the face-to-face meetings planned to discuss any additional ethics considerations during the visit to hospitals in Vietnam planned for February 2011). Final ethics approval was given by Flinders University in December 2010.

iii) Completion of Draft One of the information gathering tools

Review of the literature and consultation with relevant experts guided the development of the first draft template. Three initial templates were developed for submission with the ethics applications:

1) A questionnaire for families of children living with NS. This first draft included nine sections:

- Demographic details
- Health markers
- Diagnosis of NS
- Medicines used to manage NS
- Your child’s health in the last 12 months
- Understanding of NS
- Burdens and challenges
- Financial considerations
- Recommendations for change

2) A questionnaire for health care professionals that covered:

- General information – details of participant
- Epidemiology of NS
- Profile of children at your hospital
- Access to medicines / equipment / resources for NS
- Burdens and challenges
- Financial considerations
- Recommendations for change

3) A questionnaire for policy makers and other organisations that addressed:

- Epidemiological insights
- Burdens and challenges
- Recommendations for change

Draft One is provided in Appendix 5.

iv) Overall project plan / timeline endorsed by key stakeholders

Project planning was critical to the success of the research. A timeline was developed to guide finalisation of the HNA templates (see Table 3) and key dates were agreed by all stakeholders as follows:

- **Sept 2010 – February 2011 (Cycle 1)** – setting the foundations
    - To result in the following outcomes and deliverables:
        - Preliminary review of the literature and available evidence and consultation with experts
        - First draft of the HNA templates
        - Submission of ethics applications in Australia (with copy to Vietnam)
        - Project management tools (timeline, budget)
- **February 2011 – July 2011 (Cycle Two)** – refining the HNA templates and ongoing planning for the inaugural NS Club meetings
    - To result in the following outcomes and deliverables:
        - Finalisation of ethics approval processes for Vietnam
        - Second draft of the HNA templates (ready for approval by each hospital for use in pilot interviews in Cycle Three)
        - CLAN Action Plan for NS in Vietnam
        - Club Checklist
- **Cycle Three (July 2011 – August 2011)**
    - To result in the following outcomes and deliverables:
        - Pilot interviews to guide the final refinement of HNA templates
        - Third and final draft of HNA templates (translated into Vietnamese ready for use in HNA)
        - Key insights regarding challenges, burdens and recommendations continue to inform CLAN's NS Action Plan and NS Club Meeting planning processes

Implementation of the HNA templates (reported in Study Two) was planned to occur as follows:

- Interviews (from September 2011 to May 2012) – with parents and other stakeholders to occur in HCMC and Hanoi once templates approved
- Parent surveys and focus group discussions – at inaugural NS Club Meetings (planned for Nov 2011 in HCMC and Feb 2012 in Hanoi)

Feedback to participants was planned to occur once all data were collated, analysed, and approved by hospital authorities for reporting back to families (estimated to be ready by early 2013)

It was agreed the following principles would guide consultation processes with key stakeholders (see Table 3):

1) Families (in Vietnam)

- Consultations to take place in the hospitals, recognising these as the geographic hubs for families who travel from all provinces nationally to attend these three hospitals for care.

- Information gathering tool templates would be adapted as needed to ensure they were as culturally appropriate, valid and effective as possible. The first draft of the HNA templates submitted to ethics in December 2010 assumed a single consultation process with families (i.e. suitable for use in either interview or survey settings). However, this approach was refined after the face-to-face meetings with local stakeholders in Vietnam in February 2011, where it was agreed that it would be more appropriate to have two styles of consultation with families:

    - *Interviews* – it was estimated that 15 interviews would be necessary at each hospital (45 in total); to be held in inpatient or outpatient departments, depending on selection requirements and location of families, to minimise additional burden of travel for families.

    - *Surveys* – to be conducted at NS Club Meetings to be held in November 2011 and February 2012 at each of the three hospitals, jointly run by CLAN and the hospitals. It was agreed families would be offered individual support from nurses / doctors at Club meetings to complete surveys (to account for any literacy challenges). Questions asked by families at Club Meetings during Q&A sessions could further inform insights, understandings and actions.

- NS Club Meetings were agreed as the most appropriate public sphere for large scale consultation because they allowed consultation with large numbers of families through surveys, and were suitable for implementation of key activities in real time to improve health outcomes and drive change (necessary components of a HNA). To consult with members of the NS Community about the best ways to run NS Club Meetings, it was agreed questions would be included:

    - In the interview templates, to support planning of the NS Club meetings, and

    - In the surveys, to enable evaluation of the Club Meetings.

2) Health professionals (in Vietnam and Australia)

- *Ad hoc* consultation in an ongoing basis would guide all aspects of the project
- Formal consultation as needed. The template was formalised and submitted with ethics applications and a minimalist approach was needed (given focus on felt needs and burden on health professionals already significant, so efforts should be made to minimise further burdens)

3) Other stakeholders

- *Ad hoc* consultation – as identified throughout the project. At this stage Ministry of Health and Insurance agency representatives were identified as likely to be important.
- Formal consultation - draft template was submitted with ethics application.

v) Critical action in real time to improve health outcomes and redress inequities

Continuous critical actions to improve quality of life for the NS Community (September 2010 to 2013) were prioritised and documented in Chapter Five (translational findings). Contributions to critical actions taken during this HNA in response to insights emerging from Cycle One included:

- Draft development of CLAN's Action Plan for NS in Vietnam (for detailed discussion during February 2011 trip) and fundraising targets and strategies set. Constant feedback of key insights from the consultation processes to all stakeholders (including CLAN) by the researcher ensured critical actions informed the strategic plans.
- Development of consultation templates to facilitate timely and systematic capture of key recommendations from families, health professionals and other stakeholders. For instance, specific questions relating to the conduct of NS Clubs and recommendations for change were structured such that the researcher could access insights readily and arrange translation quickly and cheaply to ensure voices of stakeholders informed action in a timely manner wherever possible.

PAR 1e) Observe

What went well?

An overarching project timeline was developed and agreed by all stakeholders. The ethics application was approved by Flinders University in 2010. Research proposal and ethics application documents were shared with all three hospitals, ahead of face-to-face meetings in February 2011 to address specific concerns each hospital's internal ethics committees may have.

Planning commenced early for NS Club Meetings (ideally these take about six months to prepare for), allowing plenty of time for critical action around the five pillars (for example, translation of educational resources into Vietnamese; planning for the production of a video of the NS Club meetings; development of an NS Club Newsletter to provide quality, evidence-based information targeted at information gaps identified during early consultations).

CLAN's Committee provided invaluable fundraising support for the inaugural NS Club Meetings and translation of educational resources on NS into Vietnamese language [1]. CLAN was fortunate that Australian experts (EH and AT) generously volunteered their time and expertise and contributed to their own travel expenses. Dr Hao was nominated by NHP to provide cultural support and expertise, and he expertly guided the development of the information gathering tools and consultation processes with families.

The systems established to enable key recommendations and insights regarding critical actions to be identified in real time proved effective (with the researcher reporting back to CLAN's team and other stakeholders using the CLAN Action Plan for NS in Vietnam), and this greatly contributed to planning for NS Club meetings.

What could have gone better?

Funding is always a challenge, and whilst it would have been ideal for CLAN to cover all expenses of volunteers and other stakeholders, the in-kind contributions of Dr Hodson, Prof. Tong, the Vietnamese health system, hospital executives, Ministry of Health and NS Community Members would never have been within the scope of CLAN's budget and must be acknowledged as true enablers of the entire project.

Likewise, the voluntary contributions of CLAN's team and the researcher were enabling factors, and this reliance on the altruistic contributions of others is both a strength of and risk to the ongoing sustainability of CLAN's work.

Whilst existing information gathering tools and educational resources in Vietnamese were not available for this project, the researcher hopes the tools created can be shared with others, negating the need to reinvent any wheels in future, thereby making it simpler for them to drive critical action to redress health inequities associated with other chronic conditions of childhood in resource-poor settings.

PAR 1f) Reflect

What could be done differently next time?

In the spirit of "see one, do one, teach one", future projects can budget for their activities based on the financial accounting of this project. Costs should be captured as accurately as possible to help CLAN and others budget and fundraise more effectively.

It took a broad range of stakeholders to achieve the outcomes from Cycle One (for instance: Dr Hao, a psychologist; EH, a paediatric nephrologist from Australia; SM, a police officer from Australia who helped fundraise; passionate health professionals in Vietnam) and all provided invaluable support. Future initiatives could consider other stakeholders who might also get involved and support critical action. For instance, the Australian government's aid program or private sector representatives may have an interest or opportunity to support child health initiatives in our region.

What should the next steps be?

The tools developed in Cycle One were developed with the idea in mind that they could be used to support Communities of children living with conditions other than CAH and NS. Vietnamese colleagues expressed interest in the idea of using the templates to better understand challenges for the Lupus Community of Vietnam.

PAR 1g) Share

The HNA Templates (Draft One) as submitted for ethics approval processes in Australia and Vietnam are not included in this thesis but are available on request. They formed the foundation of the final templates used in the HNA proper, which are shared in the CHEAR Toolkit (Appendix 1). The timeline is provided in Table 3. The financial reports are publicly available in CLAN's Annual Reports [2, 51].

4.3.2 Cycle 2 – HNA Template refinement

Introduction

Cycle One established a firm foundation for this next stage of the project, Cycle Two, which preceded formal the pilot testing planned for August 2011 (Cycle Three) prior to their official use in the HNA (Study Two). The trip to Vietnam in February 2011 aimed to support action around the key priorities for Cycle Two, which were to:

- Review Draft One templates according to:
    - Insights arising from ongoing review of available evidence
    - Consultation with expert stakeholders in Vietnam in February 2011
    - Local, cultural and language considerations and
    - Practical requirements (informed by a critical realist approach)
- Finalise Draft Two of the templates ready for submission to all participating hospitals for formal approval prior to use in the pilot testing phase in July 2011
- Continue to capture recommendations identified by stakeholders during Cycle Two so they can be translated to critical action in real-time.

In reporting Cycle Two the following phases are described:

PAR 2a) Plan – working with others to agree key methods of how the aim will be achieved (the what, who, how, when, where of actions required)

PAR 2b) Act – carry out agreed action plans and document results

PAR 2c) Observe – discuss what happened. A comparison of Draft One (from Cycle One) and Draft Two (the draft developed in Cycle Two) are compared, to demonstrate changes that were made as a result of the steps taken in the Act phase.

PAR 2d) Reflect – identify key insights and recommendations for next steps

PAR 2e) Share – disseminate outcomes and deliverables

PAR 2a) Plan

What is needed?

PAR Cycle One had determined the timeline for the development and refinement of the HNA templates as follows:

- *Draft One* – developed in Cycle One and submitted as part of the Ethics Applications (November 2010 in Australia and February 2011 in Vietnam)
- *Draft Two* – refined in Cycle Two as a result of face-to-face consultation in Vietnam in February 2011.
- *Draft Three (see CHEAR Toolkit)* – final changes informed by Pilot Testing in July 2011; formally approved by all hospital executives prior to implementation from September 2011 to May 2012.

Face-to-face meetings, ward visits and other interactions at all three children's hospitals in Vietnam with local stakeholders in February 2011 were critical to PAR Cycle Two. It was important that any insights gleaned during the consultative processes of Cycle Two (February to August 2011) also inform collaborative action in real time for the NS Community (see Chapter Five). To this end, the researcher kept handwritten records in dedicated notebooks when on site in Vietnam to capture all feedback received. Key insights were then shared via email and teleconference calls with CLAN's Committee and other relevant stakeholders to strengthen action planning, with a specific focus on the upcoming NS Club Meetings in 2011 and 2012. New insights were added to the CLAN Plan for NS in Vietnam work plan, and this document was used for sharing information with key stakeholders in an ongoing basis as well as introducing potential new stakeholders to the overall strategic plan.

Who is needed?

A participatory action approach to drafting and refining the templates required involvement of the following stakeholders:

- Health professionals – from Vietnam and Australia; engagement occurred through email, teleconference, Skype and face-to-face meetings

- NS Community Members – informal discussions with families in Vietnam (discussions with three families at CH1 in February 2011 and visits to renal wards at all hospitals; all with treating doctors present as translators to minimise stress and potential confusion for families)

- CLAN – regular communication with CLAN's Committee occurred during regular meetings and email correspondence.

- Hospital executives – engagement occurred during face-to-face meetings when researcher was in Vietnam, as well as via email correspondence. Executive approval was required prior to new actions, and each of the three draft versions had to be submitted ready for final approval to be considered at each stage of the project.

How will it be achieved?

There were three key activities planned for PAR Cycle Two:

1. Review of the literature – there were few additions to the templates emerging from the literature at this stage; most literature insights were gleaned prior to the Ethics application being submitted in December 2010.

2. Consultation with subject matter experts – email and paper circulation of HNA template drafts and face-to-face meetings in Vietnam to finalise ethics applications were the primary public spheres for consultation. Such processes informed the majority of edits and development of Draft Two of the HNA templates as well as final edits of the documents submitted to each of the participating hospitals in Vietnam for Ethics Committee review.

3. Consideration of other tools that would be needed for the HNA beyond the information gathering templates.

When will it be completed?

Table 3 captures the timeline that was followed. The February 2011 visit to Vietnam focused on face-to-face discussions with key stakeholders to finalise ethics applications and research proposal in Vietnam and fine-tune Draft One templates ready for the pilot interviews planned for August 2011.

Where will it be conducted?

The activities of Cycle Two occurred in the following public spheres: Flinders Online platforms (for review of the literature); via email (for regular consultation with subject matter experts); and during face-to-face meetings in Vietnam in February 2011 (with hospital executives and local health professionals in both Hanoi and Ho Chi Minh City).

PAR 2b) Act

Action 1. Review of the literature and evidence

Comprehensive literature review findings are reported in Stage One of the thesis and informed the refinement of Draft One templates that were submitted for Ethics.

There was limited additional evidence or clinical data available relating to children and families (paper files; data not available to researcher; no rapid analysis possible) living with NS in Vietnam that was identified between February 2011 and August 2011 and influenced the development of the HNA templates.

Action 2. Consultation with subject matter experts to guide refinements to the draft

Face-to-face meetings with key stakeholders (hospital executives, health professionals and families) in February 2011 provided rich insights into ways the first draft templates could be strengthened and were essential to the overall governance of the project. The researcher prioritised meeting with all hospital executives individually and addressing any specific queries or concerns a particular hospital may have. Permission was granted to progress with the project (and meet with families and health professionals whilst in Vietnam in February), with final adjusted templates shared with all hospitals in March 2011.

Agreement was reached with all three Hospitals on general governance approaches:

- No comparisons to be made by individual hospitals
- All results to remain de-identified by hospital, but each hospital to have access to its own data so as to allow optimal local responses to insights
- Hospital executive to have oversight and control at all times
- Consultation with individual tertiary referral centres on most appropriate approach to ethics approval process in Vietnam.
- Director of NHP to be a Co-Supervisor of researcher
- Shared goal was to understand situation for families of all children living with NS in Vietnam and work collaboratively within capacity to improve health outcomes and quality of life.

Key changes needed to the Draft One parent consultation template identified during PAR Cycle Two included:

- Removal of redundant questions that did not strengthen understanding of challenges or recommendations for change, such as:
    - “Is your child present with you today?”

- Deletion of questions where quality of data collected was likely to be of a poor quality; risked unduly upsetting families in the collection process; or raised concerns relating to privacy or confidentiality. The following questions were deleted for these reasons:
    - “What type of NS does your child have?” (very few families knew this, so it was only worth asking this question if health professionals who knew the child were in attendance)
    - “Has a child passed away in your family” (the rationale was to understand if other children had been affected, but it was agreed that it would be better just to ask about a family history of NS instead of a child’s passing)
    - Address / Phone number – these data would not be used, so there was no point collecting. Families’ names were collected so that health professionals could follow up with families if urgent issues were raised in the consultation (and staff already had all contact details).
    - “Who does child live with?” (this was quickly identified as superfluous)
- Inclusion of more insights relating to schooling was considered important (especially why children were missing school), so this section was strengthened.
- Early appreciation of the fact very few families had an understanding of the type of NS their child had (i.e. SSNS or SRNS) had an impact on research design. For example, early discussions revealed very few families understood which medicines their child was using now or had ever used. It appeared there would be little value to be gained in asking families about the medicines their children used for NS unless a health professional was present. Discussions with hospital executives determined the best approach would be for any clinically related questions to be limited to interviews, with clinical questions separated and answered by health professionals in parallel. This approach required separate templates for interviews and surveys, so it was agreed the development of separate templates for interviews and surveys would emerge from the pilot interviews in August 2011.
- Inclusion of questions on traditional medicines was important, as these appeared to be used extensively. Additional questions were developed to enable the researcher to learn more about the use - and cost - of these.
- Early acknowledgement that very few families had an understanding of the pathophysiology of NS influenced the design of the interview and survey templates. There were useful qualitative data insights to be gained from asking about these things in interviews, but perhaps less value for surveys of large numbers of families. These insights were explored further in the pilot interviews in July.
- Quantitative approaches to eliciting confidence levels appeared useful and well accepted by families. Questions regarding local health professionals were strengthened, to allow stronger insights into distances families were having to travel to consult health professionals they trusted. Distance was rapidly emerging as a significant burden, so was important to understand in more detail.

- Grandparents featured strongly in early discussions with families, and a detailed understanding of the demographic profile of families seemed important, so additional questions were added to reflect this support role extended family appeared to play.
- The financial burdens of NS were clearly enormous for families, and lists of potential expenses were created to help prompt families' recollections of expenses (including unexpected expenses, such as pagoda fees (a cultural practice of offering monies for spiritual blessings)
- Families and health professionals responded very positively to questions about possible NS Club meetings. Additional questions were added to the interview templates to better understand what families wanted, identify barriers to engagement and support Club planning.

Changes to the health professional consultation template

There was emerging recognition that the health professional template was of less value than the parent template. There was early saturation of insights due to extensive preliminary consultation with health professionals prior to February 2011, and whilst the process of finalising the health professional template was worthwhile in that it ensured the researcher had captured all key insights and learnings from health professionals in a systematic manner to date (and thereby created a robust tool for future use), there did not seem to be much value to be gained from formally consulting with health professionals any further in this particular research project.

Noting the considerable burdens on staff already, a more practical alternative was identified: specific questions were instead added to the end of the parent interview template so they could be completed in real time by the health professional conducting the parent interview (which was estimated to take about one hour). This approach allowed the interviewer to capture information in real time, and as it turned out, this format worked well and resulted in invaluable insights from trained professionals who had just spent an hour listening intently to families discuss their challenges and burdens. These interviewers were perfectly placed to rapidly document key ideas / insights that came to them through this process. This approach aligned very well with the researcher's commitment to privileging the voices of people living with NS and balance out the strong participation to date by health professionals versus families.

Changes to the "other stakeholders" consultation template

No changes were made to this very brief template. It was agreed that interviews with the Ministry of Health and Insurance Company representatives would be important to secure if possible.

On return from Vietnam in February 2011 Draft Two templates were finalised by the researcher and submitted to the Director of NHP for approval for use in pilot testing in July 2011. Draft Two is provided in Appendix A.

Action 3. Additional tools developed ahead of the NS Club Meetings

These tools and deliverables are discussed in more detail in Chapter Five, but included:

- Tools to support conduct of Club Meeting (such as NS Club Meeting planning checklists; meeting agendas and evaluation surveys; budgets; CLAN's Action Plan to capture agreed priority actions; and reporting templates)
- Education resources – with stakeholder consultation suggested the following resources needed to be developed:
    - Electronic slide sets ("Powerpoints") – for education of families and health professionals
    - Club Newsletter – FAQs; myth busting information for families (and health professionals)
    - Translated educational resources – NS booklets for families (and health professionals)

The researcher worked with a range of stakeholders to coordinate finalisation of these tools and resources ahead of the inaugural NS Club Meetings.

PAR 2c) Observe

What changed?

Draft One (developed during Cycle One) and Draft Two (adapted during Cycle Two) are compared in Table 5.**Error! Reference source not found.** Most of the changes related to the template for families.

Table 5 - Changes to HNA information gathering tools as a result of PAR Cycle Two

Changes to the HNA Templates	**Draft One**	**Draft Two**
Template structure	Single template for families	Agreement on the need to shift to separate templates: - One for interviews (to allow capture of more detailed health insights and qualitative data) - One for surveys (to allow consultation with large number of families) Exact details to be determined during pilot interviews
Template content	- Minor focus on topics that emerged as significant and needing more detailed information and insights	Questions added on: - Schooling - Health insurance - Health - relapses, hospitalisations etc - Vaccination (identified potential missed opportunity to improve health) - Traditional medicines use (a potential drain on limited family resources)
Template implementation processes	- Emerging recognition that families had very limited insights regarding the cause or management of NS; any technical questions would need to be answered by health professionals	- Inclusion of a section for HCPs to complete (e.g. Type of NS) in interview template - removal of questions checking parental understanding from surveys (interviews only)
HCP template		No changes
Other stakeholder template		No changes

What went well?

The final draft information gathering tool templates which were submitted with the ethics application and research proposal were submitted to all Ethics Committees in Vietnam by March 2011. This was undertaken with clear communication that edits to the templates would be made based on refinement processes informed by consultation with local stakeholders (PAR Cycle Two) and again following pilot testing once formal ethics approval was given in both Australia and Vietnam (PAR Cycle Three), with approval obtained from the relevant hospital executives at every stage, prior to next steps being taken. Final ethics approval was given for the project by Vietnamese officials in July 2011, just prior to the pilot interviews that same month (with interim approval to participate in all proposed meetings between September 2010 and February 2011 to assist with project planning).

Given the limited time, resources and consultation opportunities, this phase of the project went very well. Commitment by Vietnamese stakeholders to the success of this project was fundamental to its success and the researcher could not have asked for more support than was given.

The face-to-face meetings in February, visits to hospital wards and informal conversations with health professionals proved invaluable in refining the HNA templates and guiding next steps of Study One. Preliminary discussions with families in Ho Chi Minh City and Hanoi in February 2011 provided particularly important insights into some of the changes needed to improve the templates and reinforced the importance of conducting some more formal pilot interviews in July, prior to starting interviews in September, and the Club Meetings starting in November 2011.

There were emerging concerns the template for health professionals would not be that useful, and that formal consultation might unnecessarily burden health professionals who a) had already spoken at length with the researcher during the early consultation phase and b) were already over-stretched, so the researcher explored options with other stakeholders for alternative consultation strategies. The addition of dedicated questions in a survey style for interviewers to complete after doing the parent interviews was considered and would be explored further in Cycle Three.

This decision was easy to make not just because an alternative strategy that allowed data to be collated and analysed in an efficient way, but also because the researcher had come to realise that despite best intentions of local stakeholders, some of the data that would have been ideal (such as incidence, prevalence, health outcomes and quality of life data) was beyond the scope of this research project. Paper files, with details recorded in Vietnamese, located variously between overcrowded inpatient and outpatient clinics, not centrally located in registers and available only to already over-burdened health professionals did not hold any promise. Reassuringly, a focus on felt needs was also appropriate given the large gap in knowledge in the existing literature.

The cyclical, dynamic nature of the PAR approach to finalizing the templates proved invaluable in the face of a rapidly shifting landscape. In August 2011, the Ministry of Health unexpectedly made an announcement that essential medicines required by families for management of NS would be included on the national insurance list and therefore would now be affordably available to families. This news was met with great celebration, joy and gratitude by all stakeholders, and meant that many of the template questions (and advocacy goals) relating to access to medicines had to be revised completely. This was a nice problem to have!

Inclusion of questions around recommendations for change, and suggestions for upcoming NS Club meetings were vitally important to action planning, and there was a strong commitment amongst all stakeholders to incorporate new insights into meaningful action in a timely way at all times. Examples of how this was achieved are detailed in Chapter Five (translational findings), but activities included: development of fact sheets; translation of educational resources on NS into Vietnamese language; and approval arranged in advance for a video of the NS Club Meeting in February 2012 to assist with advocacy and awareness efforts.

What could have gone better?

The delay in writing the final DrPH Thesis would undoubtedly have been overcome by an increase in available resources (human and financial); a digital approach to data collection and analysis (not achievable given digital accessibility and literacy for families in Vietnam at the time); and capacity of the researcher to dedicate more hours to detailed documentation in real time. Unfortunately, the realities of life as a mother to three young children, President of an NGO, Founder of an emerging movement (NCD Child), and paid employment as a Public Health Physician all limited the capacity of the researcher to achieve this.

Fortunately, strong systems and commitment to capturing all evidence in secure ways has meant documentation could be delayed without impacting adversely on the research findings themselves. In fact, it could be said the researcher is better placed now to provide more insightful analysis than would previously have been possible (having since completed formal Fellowship training with the Australian Faculty of Public Health Physicians). Of critical importance, reporting back to Community Members and Hospital Executives was not delayed, and occurred, as planned, in 2013.

PAR 2d) Reflect

Recommendations for next steps included:

- Plan for pilot testing in August 2011 - the changes made to the template (Draft Two emerged from Cycle Two) were numerous, and yet there was acknowledgement of the important role that pilot testing in Cycle Three would play in refining the drafts even further – in particular separating questions that should be in the survey versus interview templates for families. The researcher focused on preliminary planning on the separate templates ahead of the July visit and Cycle Three, so that that six pilot interviews could be used optimally.

- Continue NS Club Meeting planning - insights informing critical action to benefit the children and families were fed into planning in a continuous manner and are described in more detail in Chapter Five.

- Toolkit development for sustainability - whilst the templates developed for guiding consultation with health professionals and other stakeholders were not used extensively in formal consultation processes in this research project, they are still included in the final CHEAR Toolkit emerging from this project, in hopes they may prove useful to others as a starting point for discussions. The general and somewhat simplistic template to guide discussions with “other stakeholders” was almost universally useful and did not change much throughout the project. Additional tools and resources developed ahead of the NS Club Meeting are also included in the Toolkit (e.g. NS Booklets and Club Checklist).

PAR 2e) Share

The following resources are available in the CHEAR Toolkit:

- CLAN Action Plan for NS in Vietnam
- CLAN Club Checklist
- NS Club resources (such as the FAQ Factsheet; NS Booklets and health professional training samples).

4.3.3 Cycle 3 – Pilot interviews and finalisation of templates

Introduction

In Cycle Three of Study One a series of pilot interviews was used to:

- Assist with fine-tuning the templates / tools / resources developed in Cycle Two (Draft Two) to ensure they were optimally suited to facilitate consultation with key stakeholders during the HNA and inform an understanding of the challenges and burdens faced and recommendations for change.
- Clarify emerging insights with stakeholders in a timely way, to identify critical actions that could be undertaken urgently ahead of the upcoming NS Club Meetings to address challenges and burdens, improve health outcomes and redress inequities.

In reporting Cycle Three the following phases were addressed:

PAR 3a) Plan – working with others to agree key methods of how the pilot interviews would be completed (the what, who, how, when, where of actions required)

PAR 3b) Act – carry out agreed action plans and document results

PAR 3c) Observe – discuss what happened. In particular, compare the changes between Drafts Two and Three templates.

PAR 3d) Reflect – identify key insights and recommendations for next steps

PAR 3e) Share – disseminate outcomes and deliverables – notably Draft Three final templates ready for approval and use at the NS Club Meetings and parent interviews.

PAR 3a) Plan

What

Discussions were conducted in February and via email regarding the best way to progress with pilot testing and who should be involved. It was agreed:

- Pilot testing with six families in Hanoi should be sufficient to trial the parent templates (noting earlier consultation process with families had been conducted in HCMC) and finalise the survey and interview templates

- Dr Hao, KA and EH would conduct the pilot interviews. This would allow for:
  - Culturally safe / appropriate approach
  - Accurate translations
  - Paediatric nephrology expertise
  - CLAN Experience

Formal consultation interviews would be conducted by the researcher during the August trip with several nurses (acknowledging the bulk of consultation to date had been with doctors). Saturation of insights from medical professionals meant no other interviews with medical doctors were planned for at this stage.

The aim of the six pilot interviews with families (to be conducted in Hanoi) was to:

- Refine the Draft Two templates, ready for submission of a final Draft Three to all participating hospital executives for formal approval ahead of the HNA (with interviews in September 2011 and surveys at Club meetings in November 2011).

- Trial implementation processes and checklists so that the final HNA would be as effective and streamlined as possible. Pilot interviews were an opportunity to reflect on process considerations / principles that should guide the HNA proper.

- Identify any processes or systems that needed strengthening ahead of the HNA, such as:
  - Documentation and rapid understanding of key challenges, burdens and recommendations, identification of emerging insights and gaps
  - Check for resonance of process with families and interviewers, and estimate likely duration of interviews, to assist with budgeting and planning
  - Reassure the researcher and others involved in interviews that proposed processes would align with overarching principles – and in particular “above all do no harm” to families
  - Planning for NS Club meetings
  - Training requirements for interviewers / researchers so there would be a standardised approach to interviews at all locations

- Capture of early recommendations for critical action prior to NS Clubs

- Agreement on the number of interviews needed to achieve saturation (it was proposed 15 interviews at each hospital would allow saturation of insights, but the pilot process would allow the researcher to reconsider this estimate).

Who

It was determined that pilot interviews should be conducted with:

- Health professionals – as per findings in Cycle Two, a decision was made not to focus extensively on these interviews. However, formal interviews with two nurses from the hospitals in Vietnam were considered important to check for saturation and balance voices of nursing staff with those of medical doctors, families and cultural mentors

- Families – it was agreed six pilot interviews would likely be sufficient to ensure saturation and key insights were achieved

- Other stakeholders – At least one representative from the Ministry of Health and another from an Insurance Company, with appropriate persons determined by hospital executives.

How

All pilot interviews were to be conducted by the lead researcher, Dr Hao (Psychologist) and EH, with the involvement of local paediatric nephrologists if needed for clarification.

Process recommendations established for each pilot interview with families included:

- No more than three interviewers present at any one time, to minimise intimidation of families (although overwhelming impression was that families really appreciated attention and opportunity to speak with people interested in their child's health).

- Regular consideration of power structures, with doctors asked not to interview their own regular patients where possible, so that families felt free to respond honestly.

- Agreed methods of capturing insights during the interviews established and shared with all interviewers during training; need for standardised approach to interviews consistently emphasised

- Oversight by Dr Hao (Psychologist) to ensure culturally safe approach

- Involvement of researcher in all pilot interviews so that emerging insights could inform future planning

- Involvement of EH or a local paediatric nephrologist in all pilot interviews to provide medical expertise and responses to medical questions families posed. There was acknowledgement that the researcher had a duty to families to respond in a timely, accurate, expert way to questions raised, and the researcher did not have sufficient knowledge of NS to guarantee this (despite being a medical practitioner), hence the need for paediatric nephrologists to join.

- Pilot interviews with health professionals and other stakeholders were to be conducted by the lead researcher and EH (unless these stakeholders did not speak English, in which case Dr Hao would be asked to assist with translation).

When

Pilot interviews were completed during the researcher's visit to Vietnam in August 2011, in time to start HNA proper in September (interviews of families) and inform planning ahead of Club Meetings in November 2011 and February 2012 where possible.

Where

Pilot interviews with families were conducted at NHP in Hanoi, and with other stakeholders (such as Ministry of Health and health professionals) at locations convenient to them.

PAR 3b) Act

All pilot interviews were completed as planned:

i. Families - six interviews with families of children living with NS;

ii. Health professionals - two interviews with nurses were completed, and an additional opportunistic interview with a paediatric nephrologist was completed

iii. Other stakeholders - one interview with Ministry of Health and another with Insurance Company representatives were completed.

<u>Recording processes</u>

A decision was made jointly early on by all that the pilot interviews would not be voice recorded as originally planned. It was felt this may make some families anxious. Instead, handwritten records of the pilot interviews were made by the researcher on printed copies of the templates and later transcribed to Word documents. This method worked very well during the pilot interviews.

Process insights emerging from the interviews with families included:

- It was agreed 15 interviews at each hospital was an appropriate number,
- On average, each interview lasted 60 minutes or less,

- Because most interviews would be completed before the first NS Clubs in November 2011, it was a good opportunity to elicit direct insights and advice from families about best ways to run Club Meetings.

A detailed analysis of the changes to the HNA templates following the pilot interviews is summarised below:

- Insights and changes relating to the interview template for families:
    - Distance - more questions were added to capture (quantitative) data regarding distance of homes from hospital; rural / urban living; and mode of travel
    - The experience of having a child diagnosed with NS was clearly a traumatic experience for many families; questions were included in the interviews to strengthen understanding of this, what helped to reduce stress, what made things worse, and how processes could be improved in future
    - Insurance was clearly a major challenge for families – questions were strengthened around this to allow for better understanding of the issues
    - Questions were added around testing of urine at home, once it became clear very few families were doing this basic action that had major consequences for health outcomes and quality of life.
    - Questions were added to better understand the impact of NS on the social and emotional wellbeing of parents
    - An additional question invited families to ask any questions / share any comments, and this strengthened the capacity of the tool to draw comments and insights from families
    - A separate technical section was added for health professionals to complete ahead of the interviews (relating to clinical and health specific details) and for interviewers to complete at the end (given they had just spent an hour with the families, the interviewers were ideally placed to share insights. This would also reduce any additional burden on other health professionals to spend time being interviewed). Each participating hospital generously committed the time of health professionals to support completion of the clinical section of the interview templates.
    - Questions were added about access to the internet
    - Insights were sought about Club meetings to assist with planning, with strong indications that families would like to attend if invited
    - Some structural changes were made (eg responses listed left (negative) to right (positive); scaling options from 1–10 that were offered)

- Insights and changes relating to the survey template for families:
    - Ideal tools would open the consultation process up to all families of children living with NS in Vietnam. Therefore, the final template would be as practical as possible and maximise closed / quantitative responses
    - To optimise the likelihood of families completing the survey independently, efforts were made to limit technical and clinical questions. Interviews demonstrated that families had little information about this
    - Evaluation questions were added to provide feedback on the best ways to run NS Clubs in the future
    - There was opportunity to strengthen understanding of access to internet / ability to speak English and actions needed to support families, and strengthen advocacy and access to existing educational resources for the Community
- Several insights and changes emerged on ways to improve the overall consultation processes for families. Some general principles that were identified were:
    - Include more questions to strengthen understanding / fill gaps in knowledge relating to challenges and recommendations for change
    - Work with interviewers to ensure sensitive topics were not discussed in front of children
    - Agreement on the average time for each interview (approx. one hour) so the researcher could budget accordingly and notify families in advance of the time they would be contributing.
- Specific insights relating to interview processes included:
    - It was useful to capture qualitative (rather than quantitative) data as much as possible in the interviews rather than the surveys
    - The order of questions was adjusted to allow interviewers the chance to establish rapport / gain trust / help interviewee feel relaxed with non-confrontational questions and topics at the start
    - Completion of the technical / medical section by HCPs on the ward prior to interview (with family members' permission) reduced the burden / stress for interviewees and increased the accuracy of data
    - Interviewers were encouraged to offer opportunities for families to ask questions and share comments
    - Inclusion of survey questions for interviewers at the end of each interview helped capture key insights / comments that arose for them, especially given they had just spent an hour with the family

    - It was clear that families were desperate for information on NS. Interviews were an opportunity to share information and answer questions, but also to form an understanding of the Community's baseline level of knowledge and use this to plan the type of information / educational resources that would most help families in future. The insights also allowed the researcher to remove questions (for instance, questions on pathophysiology were removed when it became clear families had very basic level of understanding)

- Specific insights relating to survey processes included:
    - A question on ethnic group was included to get larger scale picture of representation
    - Surveys were designed to capture quantitative data as much as possible, so fewer open questions (e.g. around experiences at time of diagnosis) and more closed questions were used
    - Questions were streamlined to simplify response process (e.g. use of scaling and yes–no responses)
    - Families had limited understanding of NS, so the more technical / complex questions about NS were removed from the surveys
    - Questions were removed where there was early saturation of insights as a result of pilot interviews and other interviews
        - For example, questions about understanding of the cause of NS were changed from qualitative to scale questions
        - Use of prednisolone (redundant – everyone used it)

Summary of key insights that emerged

The brief survey for interviewers was deemed very effective. The researcher had already reached saturation with consultation of health professionals using the more detailed template used in the early consultation stages of planning (Chapter Two and PAR Cycles One and Two), so did not plan to conduct any further interviews using this template. The parent survey and interview templates were edited to account for all feedback received regarding the best questions to ask about health determinants (Figure 23) to best deliver an understanding of the impact of NS on health functioning. The template for policy makers and other stakeholders worked very well in the pilot interviews and was not further modified.

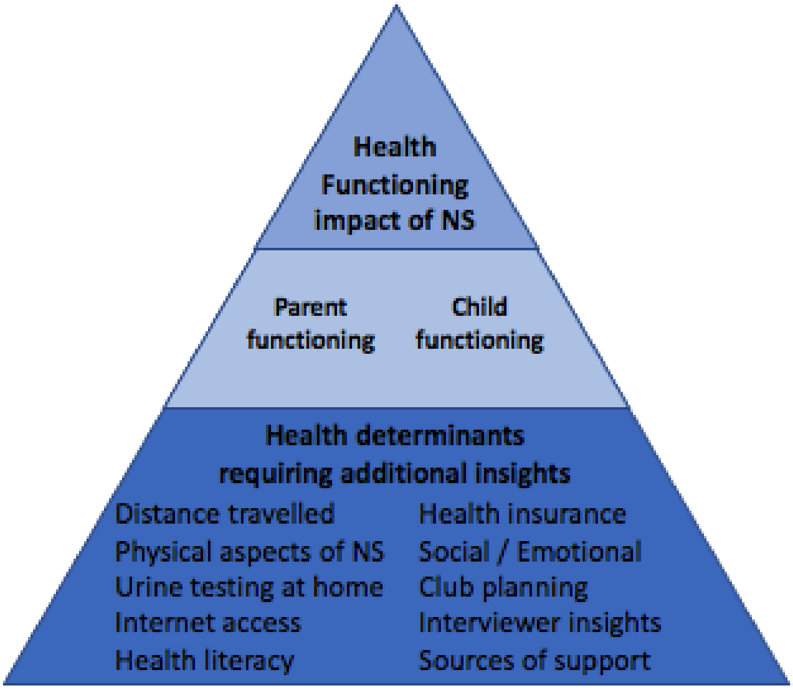


Figure 23 - Health Triangle insights from PAR Cycles One and Two of Study One

Translation processes

The HNA interview and survey templates for families had to be translated from English into Vietnamese. Templates for health professionals and other stakeholders were not translated because most of these stakeholders spoke English. Once finalised, parent templates were translated by nominated and qualified / certified translators by all hospital executives before their approval for use in the HNA:

- *Interview template for families (with HCP questions)* – (English and Vietnamese)
- *Survey template for families* – (English and Vietnamese)
- *Interview / Survey template for HCPs* – (English)
- *Interview / Survey template for other stakeholders* – (English)

Minor changes were required to translated versions to adjust for local dialect differences between Hanoi and HCMC, and care was taken to ensure these minimal changes did not affect meaning. Training requirements for interviewers in Study Two were informed by the insights arising from Cycle Three. Having interviewers located and trained at all three hospitals by the researcher assisted with promoting standardised approaches.

PAR 3c) Observe

What went well?

Key insights were identified that informed planning for the HNA. In particular, templates were adapted and refined during pilot interviews to strengthen engagement with families in the following ways:

- *Parent interview template* – improvements strengthened processes. For instance:
    - Systematic approaches established to strengthen ethical considerations (e.g. checklist shared with interviewers to communicate clearly that research is voluntary / no consequences of non-engagement / confidential)
    - Interviewer training encouraged commitment to a relaxed, safe atmosphere through structure of questions / nature of enquiry
    - High quality information collated (translation by skilled health professionals – medical doctors / psychologists)
    - Standardised approach throughout
    - Detailed consultation with smaller number of families gave the researcher excellent insights to start planning NS Club Meetings
    - Sampling criteria developed that would allow insights from representative spectrum of NS Community
    - Translated versions of final templates were checked by all stakeholders, with minor changes made to account for dialects in north and south of Vietnam
    - Final version approved by all hospital executives
    - Regular Skype and check in by interviewers to researcher meant that fresh insights were shared in real time.
- *Parents survey template* improvements sought to facilitate strong process:
    - Systems established to ensure ethical considerations were clearly communicated (e.g. clearly stated participation is voluntary / no consequences of non-engagement / confidential)
    - Order of questions promoted relaxed, safe atmosphere and cultural safety and nature of enquiry was prioritised
    - Standardised approach to deliver (at NS Clubs) at all three locations

In Table 6, recommendations for change that were identified and included in the CLAN Action Plan (see the CHEAR Toolkit) as a result of the pilot interviews are outlined.

Table 6 - PAR Cycle 3 - Key insights emerging form the pilot interviews informing critical action using CLAN's five pillars

Key challenges	**Health determinants**	**Key recommendations**	**Proposed actions (and pillars)**
Lack of information / limited NS information in Vietnamese language	Access to information Health literacy Language barriers	Need more resources Families request deeper level of knowledge and understanding	Pillar 2 – Translation of educational resources into Vietnamese; conduct of educational talks at NS Club meetings for families; conduct of training sessions before NS Club Meetings for health professionals
Poverty / financial stress / lack of strong support from insurance system	Income Health insurance	Help us escape poverty Loss of work very hard for farming families	Pillar 1 – give dipsticks to families so they can test urine at home Pillar 2 – education on use of dipsticks; education on early management of relapses by families; advocacy to ensure medicines affordably available and on insurance scheme Pillar 3 – review treatment guidelines to reduce number of hospital visits needed Pillar 4 – support families financially to attend NS Club Meetings, with especial focus on very poor and remote / rural families (e.g. stipend; travel fund) Pillar 5 – promote health insurance; encourage school attendance
Distance a challenge – especially for rural / remote families	Location of home Time Access to transport		Pillar 2 – educational sessions for health professionals from all areas to better understand NS and improve local access to quality care Pillar 3 – explore hotline for families Pillar 4 – travel stipends for families to attend Club Meetings
Parents worried about children's schooling	Attendance at school		Pillar 2 – educational resources to dispel myths regarding broken bones, need to avoid play and special diet Pillar 4 – encourage school attendance
HCPs need more training / awareness of NS	Access to quality health care delivered by qualified professionals	More training Local doctors better trained	Pillar 2 – educational sessions on NS; translation of booklets that include management prompts; give educational resources to health professionals as well as families Pillar 3 – promote links with international experts (ANZPNA; IPNA); support to access international journals and best treatment guidelines
Isolation / no network / feel alone	Social factors (acceptance,	Club meeting useful	Pillar 2 – NS Club video to raise awareness of NS; advocacy to promote social inclusion and reduce stigma

Table 6 - PAR Cycle 3 - Key insights emerging form the pilot interviews informing critical action using CLAN's five pillars			
Key challenges	**Health determinants**	**Key recommendations**	**Proposed actions (and pillars)**
	inclusion, discrimination)	Community to nominate Club Presidents Connect families via Facebook / SMS	Pillar 4 – Conduct of NS Club Meetings; explore development of social media platform for families to use to connect
Parents not confident in management / want to know how to best care for children / want to prevent relapses	Parent education levels Sex preference Parental capacity Parental health literacy	Lectures for families Training on how to test urine and diagnose relapse early Families WANT to be independent	Pillar 1 – share free dipsticks with families so they can be empowered with management of NS Pillar 2 – educational resources and training sessions for families Pillar 3 – education for families on how to use dipsticks and manage relapses at home Pillar 4 – encourage engagement
Myths created in absence of information	Cultural determinants Access to information Access to quality healthcare	Families want help to care for their children the best way	Pillar 2 – development of educational resources to dispel myths
Want greater awareness / advocacy	Advocacy / power / voice / agency	Create video of Club meeting Invite media Invite powerful people Share Club Meeting reports	Pillar 2 – advocacy to raise awareness of NS and the challenges families face; reports of NS Club Meetings to hospital executives; meet with Ministry of Health; develop a video; engage celebrities / Ambassadors to enhance profile of NS; social media; conferences presentations and publications
Change system	Multisectoral engagement and commitment	Meetings with Hospital executives Families only get 2-3 mins with HCPs in OPD – how can this time be used better?	Pillar 2 – advocacy; train nurses on renal ward in patient education and empowerment; share printed educational resources with staff so all newly diagnosed families receive Pillar 3 – share detailed results of consultations and international treatment guidelines with hospital staff and executives so they can consider options to adjust OPD processes (e.g. reduce number of follow-up visits; reduce admission stays)
Opportunity to translate activities to Lupus Community of Vietnam	Strong health systems	Completion of one interview with parents of child with Lupus.	Pillar 4 - Permission given to participating hospitals to use information gathering tools and adapt to benefit other NCD Communities

What could have gone better?

Overall, the pilot interviews worked very well, and no specific challenges were identified. Strong involvement of, and support from, local health professionals was invaluable.

PAR 3d) Reflect

The final versions of Draft Three were submitted to the hospital executives of all participating hospitals, and permission granted to use templates in the HNA. Planning for the parent interviews and Club Meetings continued according to the original timeline and plan, with no major concerns or problems arising.

PAR 3e) Share

The Final Draft of the HNA interview and survey templates as approved for use by all hospital executives is included in the CHEAR toolkit:

- *Interview template for families (with HCP questions)*
- *Survey template for families*
- *Interview / Survey template for HCPs*
- *Interview / Survey template for other stakeholders*

4.4 Stage One Conclusion

Table 7 - Stage One Conclusions

Case study notes: Stage One of the HNA (Study One) – Getting Started	
Identify the population (who, where, why?)	The population focused on in this HNA was the Nephrotic Syndrome Community of Vietnam. For the purpose of this HNA, the NS Community was defined as all children under the age of 18 years living with NS in Vietnam.
Aims and objectives	The aim of the HNA was to better understand the challenges and burdens facing families, as well as key recommendations for change, with a view to enacting critical action in real time to improve health outcomes and redress inequalities for children living with NS in Vietnam.
Who was included in the project team?	A participatory action research approach informed the development of the information gathering tools and resources used in this HNA, and included the following groups: - Health professionals, executives and executive members of the NS Clubs from the three largest children's hospitals in Vietnam - Members of the NS Community of Vietnam (represented by families of children attending the children's hospitals in Vietnam) - NS experts from Australia - Australian NGO - CLAN (Caring & Living As Neighbours)
Who was included in the stakeholder group?	Other stakeholders as indicated (NephCure; Ministry of Health officials; Insurance agency representatives etc)
What resources were required?	Access to: - Internet / phone / Skype - Experts (travel / consultancy fees / stipends as indicated): - Health professionals (local and international) - Hospital Executives - Families - Other stakeholders - Other resources: computer, email, phone, paper, pens - Ethics application process costs (time / administration) - Travel costs - NS Club Meetings (including meals for families / travel stipends) - Translation of educational resources - Printing costs - Video production - Gifts / toys for children - Consultancy fees for interviewers - In-kind donations
What tools and resources were developed?	Project management tools (timeline, Action Plan, Program Logic, ethics application documents) HNA templates Club planning checklist

STAGE TWO OF THE HNA – Identifying Health Priorities (STUDY TWO)

4.5 Introduction to Study Two

Study Two is the second study presented in Chapter 4. It was conducted between September 2011 and May 2012 and comprises Stage Two ("Identifying health priorities") of the five stages of the HNA. It was designed to gather data to better understand the profile and situation of the NS Community of Vietnam and inform an analysis of the underlying determinants contributing to the health inequities experienced.

Study Two was a cross-sectional, mixed methods study that used the information gathering tools and products developed in Study One to facilitate consultation with parents, guardians and health professionals caring for children living with NS Vietnam through surveys (Parts A and C) and interviews (Part B). The aim of the consultation was to:

> *- inform an understanding of the situation, challenges and burdens experienced by children and families living with NS in Vietnam, and*
>
> *- identify practical, realistic recommendations for action that could be taken to improve health outcomes and redress inequities.*

Five information gathering tools were developed in Study One to assist with Stage Two of the HNA. These are contained in the CHEAR Toolkit, Appendix 1:

A. Survey template to consult with of parents / guardians of children and young people living with NS in Vietnam

B. Semi-structured interview template to guide consultation with parents / guardians of children and young people living with NS in Vietnam

C. Survey template for health professionals who interviewed families

D. Interview / survey template to facilitate consultation with health professionals caring for children living with NS in Vietnam

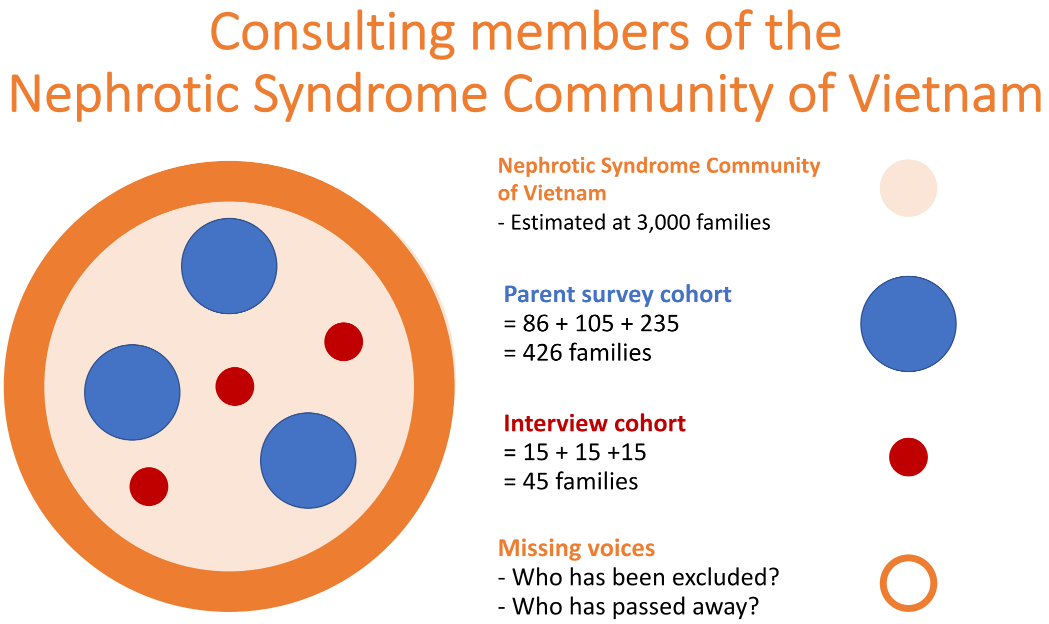
E. Interview / survey template to facilitate consultation with other key stakeholders relevant to redressing inequities for children living with NS in Vietnam

The use of templates A, B and C is reported in Study Two. As previously explained, the use of templates D and E informed broader consultation and planning processes and was reported in Chapter Two.

<table>
<tr><th colspan="5">Table 1. Overview of DrPH Thesis structure</th></tr>
<tr><th>Chapter Number</th><th colspan="3">Structure of thesis</th><th>Stages of the Health Needs Assessment</th></tr>
<tr><td>1</td><td colspan="3">**Introduction**</td><td>Introduction to the HNA</td></tr>
<tr><td>2</td><td colspan="3">**Literature review and initial consultations**</td><td>Background context - NS and other chronic conditions of childhood in Vietnam and other resource-poor settings</td></tr>
<tr><td>3</td><td colspan="3">**Research methods**</td><td>Underlying axiology, ontology and epistemology</td></tr>
<tr><td rowspan="5">4</td><td colspan="4">**Study One and Study Two (HNA Stages 1-3)**</td></tr>
<tr><td colspan="3">**Study 1**
Participatory Action Research (PAR) approach to the development of project foundations and information gathering templates to facilitate consultation with key stakeholders to strengthen understanding of challenges and burdens facing children and families living with NS, recommendations for change and identification of critical actions that could be taken within this HNA.</td><td>**Stage 1 – Getting started**
- Identify the population (who, where, why?)
- Aims and objectives
- Who was included in the project team?
- Who was included in the stakeholder group?
- What resources were required?</td></tr>
<tr><td colspan="3">**Study 2**
Implementation of HNA templates</td><td rowspan="2">**Stage 2 – Identify health priorities**
- How was a profile of the population developed?
- What data were available on the health of the population?
- How was information gathered about the population’s and the service providers’ perceptions of needs?
- What barriers were encountered?
- How were these barriers overcome?
- What were the key issues for the population?
- What priorities were chosen and why, in terms of impact and changeability?
- What evidence informed your decision?</td></tr>
<tr><td>Part A – Parent surveys</td><td>Part B – Parent interviews</td><td>Part C - Health professional survey</td></tr>
<tr><td colspan="3">**Summary of Study 1 and 2**</td><td>**Stage 3 – Assess priorities for action**
- What interventions were considered most effective and acceptable?
- How were resource needs met?</td></tr>
<tr><td rowspan="2">5</td><td colspan="3" rowspan="2">**Translation Findings**
- Translation of insights from consultation into critical action to improve health and reduce inequalities
- What did we learn?
- Recommendations for NS in other countries / for other chronic conditions of childhood</td><td>**Stage 4 – Planning for change**
- Summary of the action planning process</td></tr>
<tr><td>**Stage 5 – Moving on / Project review**
- How well was the action plan implemented?
- What was achieved by the project?
- How did it contribute to reducing inequalities?
- What was learned through the project’s successes and challenges?
- What needs to happen next?
- What new priority was chosen for the population?
- What main message from the last HNA will you take forward to the next?</td></tr>
<tr><td>6</td><td colspan="4">**Conclusion**</td></tr>
<tr><td></td><td colspan="4">**References**</td></tr>
<tr><td></td><td colspan="4">**Appendices**</td></tr>
</table>

Whose voices are missing?

The approaches to sampling used in Study Two are described in more detail in Parts A, B and C of this methods section, but the overall goal of the research was to ensure a representative sample of the NS Community was consulted (Figure 24). Despite this, the researcher acknowledges significant sub-sections of the NS Community of Vietnam were not included in the research. These included families of children who had already died from NS, families lost to follow-up because of extreme poverty or inability to travel, families with literacy challenges who felt uncomfortable asking for support to complete the surveys at the Club meetings, and other children and families living with NS in the most vulnerable circumstances did not have their priorities or voices captured through this HNA.



Consulting members of the
Nephrotic Syndrome Community of Vietnam

Nephrotic Syndrome Community of Vietnam
- Estimated at 3,000 families

Parent survey cohort
= 86 + 105 + 235
= 426 families

Interview cohort
= 15 + 15 +15
= 45 families

Missing voices
- Who has been excluded?
- Who has passed away?

Figure 24 - Approach to sampling members of the Nephrotic Syndrome Community of Vietnam for this research project

4.6 Part A - Survey of parents and carers of children living with NS in Vietnam

Aim - Conduct of a written survey of families of children with NS at three of the major children's hospitals in Vietnam to better understand the challenges and burdens they face, as well as their key recommendations for change.

4.6.1 Part A Methods

4.6.1.1 Context and purpose

4.6.1.2 Selection of participants

4.6.1.3 Materials

4.6.1.4 Data collection

4.6.1.5 Data analysis

4.6.1.6 Ethical considerations

4.6.1.1 Context and purpose of the parent surveys at Club meetings

Anecdotally, Nephrotic Syndrome places enormous burdens on families and the paediatric health system in Vietnam. Smaller peripheral and regional hospitals routinely referred children with NS to the tertiary and quaternary children's hospitals, so it was considered reasonable to assume the majority (but not all) children diagnosed with NS in Vietnam at the time were known to the three children's hospitals involved in this research project. Each paediatric centre involved in this research project indicated they had between 400 and 1,500 children with NS attending for care, although with no official registers (and some estimates including old as well as current patients) the numbers were difficult to assess accurately. The researcher estimated there were at least 3,000 children living with NS in Vietnam at the time of this research project, with at least 600 children newly diagnosed with NS each year.

Experiences in the past with CAH and Type 1 diabetes Club Meetings sponsored by CLAN in Vietnam had demonstrated that using the Clubs as public spheres was appropriate for engaging with large numbers of families of children with the same chronic health condition. Although there had not previously been any NS Club Meetings held in Vietnam, and the concept of the "NS Community of Vietnam" was new to all children's hospitals involved, it was agreed early that NS Club meetings would offer the greatest opportunity to consult with the largest numbers of families and more accurately understand the challenges families faced and their recommendations for change, without unnecessarily burdening health staff. The Club Meeting forums had been proven to be culturally safe, acceptable and appropriate for families and health professionals alike, with up to 360 CAH families having attended Club Meetings supported by CLAN on any one day.

Whilst the survey of CAH parents facilitated by the researcher in 2005 had only 54 participants [33], there was confidence a similar approach could be used to consult a larger number of NS families if necessary. Just as a version of the CAH survey was now being used to support a HNA relating to NS, one objective of the research was to determine if the HNA tools and resources developed and used in this project could potentially be translated for use in other settings to drive change for children living with other chronic health conditions.

The descriptive, cross-sectional analysis of the NS Community of Vietnam undertaken in this project used a survey template to guide consultation with parents that included closed and open questions (85 in total), providing quantitative and qualitative data (Table 8). Key topics the survey sought to cover were:

i. Demographics (19 questions)

ii. Schooling (12)

iii. Life with NS (20)

iv. Management of NS (19)

v. Financial impact of NS (10)

vi. Burdens and challenges (3)

vii. Recommendations for change (2)

In designing this mixed methods approach preference was given to quantitative / closed questions in the survey wherever possible. The researcher sought a comprehensive understanding of families' experiences, recommendations and feedback, whilst keeping the process as simple as possible (fast, easy, self-explanatory). Although there was confidence that families would enthusiastically participate in the surveys (at that time NS families in Vietnam had been consulted very infrequently – if at all - on their child's health and were keen to tell their stories), large quantities of qualitative data would require much work with coding / analysis, so surveys of large numbers of families with quantitative data collection were preferred to inform an overall picture of the NS Community of Vietnam. Qualitative data from interviews could help the researcher explore challenges, burdens and recommendations in more detail.

The researcher considered adding evaluation questions to the survey template to assist with formal evaluation of the NS Club Meetings, however, after discussion and consideration with other stakeholders a decision was made not to do this. The survey sought to understand the baseline views of families and seek responses that were not biased by any content families were exposed to at Club Meetings. For this reason, it was considered best to ask parents to complete the surveys at the start of the NS Club meetings wherever possible.

Of the 85 questions in the parent survey, 69 (81%) were quantitative and 16 (19%) qualitative. The 16 qualitative questions sought detailed insights regarding:

- Schooling (5)
- Management of NS (3)
- Financial impact of NS (3)
- Burdens and challenges (3)
- Recommendations for change (2)

Table 8 - Topics included in the parent survey information gathering tool

Consultation topics		Parent survey questions		
		Quantitative	Qualitative	Total
1	Demographics	19	0	19
2	Schooling	7	5	12
3	Life with NS	20	0	20
4	Management of NS	16	3	19
5	Financial impact of NS	7	3	10
6	Burdens and challenges	0	3	3
7	Recommendations for change	0	2	5
	Total	69	16	85
	%	81%	19%	100%

4.6.1.2 Selection of participants

It was collectively agreed to aim for the largest possible numbers of families living with NS to attend the Club Meetings. The rationale was threefold. Firstly, surveying large numbers of families at Club Meetings would make it possible to capture large numbers of responses from families in a quick and cost-effective way. The more families that participated, the more confident the researcher could be that the results reflected the experiences of the broader NS Community. The researcher, CLAN and other stakeholders had limited resources available, so any process had to be ethically sound, culturally safe and enable high quality research findings to be achieved. Use of the Club Meetings as a public sphere for consultation and PAR allowed all these requirements to be met.

Secondly, it was important to ensure insights were as representative as possible of the broader NS Community of Vietnam. It was important to avoid systematic exclusion of families and reduce selection bias. Holding Club Meetings in Ho Chi Minh City (at the two largest children's hospitals in HCMC) and Hanoi (at the largest children's hospital in Vietnam) was key to achieving this. The meetings were promoted extensively by health professionals to all families they saw in the preceding weeks and months. Poorer families and those living long distances from the hospitals were informed financial support would be available to cover the costs of travel and food, as well as a modest stipend acknowledging the loss of income associated with time taken to attend.

Finally, there were altruistic reasons for wanting to have as many families as possible attend the meetings. CLAN's experiences with CAH and diabetes had demonstrated that Club meetings offered opportunities to facilitate change and enact practical recommendations to redress health inequities in real time (for instance, through education, sharing of information, dispelling myths, networking and provision of emotional support), and this process of improving health outcomes and reducing inequities was as much a focus of the overall HNA as collecting information. To this end, planning for the conduct of the survey occurred in parallel to planning for other critical actions that could be taken to benefit children and families (see Chapter Five).

Consequently, it was agreed all families of children living with NS and receiving care at each of the three major children's hospitals in Vietnam were eligible to receive an invitation to NS Club meetings held on the following dates:

- 17 November 2011 - Children's Hospital 1 in Ho Chi Minh City (HCMC)
- 18 November 2011 - Children's Hospital 2 HCMC
- 9 February 2012 - National Hospital of Pediatrics (NHP), Hanoi.

There were no specific selection criteria for attending the club meetings, other than a diagnosis of NS not requiring haemodialysis or peritoneal dialysis, and several techniques were employed to raise awareness of the Club meetings and invite families to attend, including:

- Invitations issued opportunistically to families attending outpatients and inpatients at each hospital in the months preceding the Clubs
- Telephone calls to other known patients to let them know about the meeting.

There was no systematic targeted approach or sampling quota used in determining which families were invited to the Club meetings, although serendipitously, one hospital decided to target particularly newly diagnosed families, whilst another focused on inviting families of children with more serious and complicated NS. The decision not to focus on children requiring dialysis was made in the interests of these families. These children required very specific support that was beyond the means of CLAN to provide, and it would have been unfair to expose them to the positive messaging other families could expect to hear (i.e. that 90% of children with NS will grow out of the condition over time, with no long-term impact on their renal health).

4.6.1.3 Materials

The NS Club meetings were financially supported by CLAN (Caring & Living As Neighbours), an Australian-based Non-Government Organisation committed to helping children who are living with chronic health conditions in resource-poor settings enjoy the highest quality of life possible. A small travel allowance was budgeted to support the attendance of very poor families (a routine practice of CLAN at CAH and diabetes Club meetings they had supported over the years), and the existence of this stipend was communicated to NS families when they were invited to attend by the hospital staff. The *CLAN Club Checklist* and *CLAN NS Action Plan* were used to facilitate planning of the Club Meetings (see Chapter Five).

The templates developed in Study 1 were used to guide consultation with families in Study Two. Paper versions of the surveys were printed and given to families when they registered for the Club Meetings on the day. Along with the surveys, families were also given welcome bags at registration containing a range of resources depending on the hospital they visited, but all included booklets on NS (translated into Vietnamese), water to drink, pens to complete the survey, urine testing strips, an NS Club Newsletter (in Vietnamese) with printouts of talks / messages that would be shared at the meeting, and other gifts including small toys for the children. Lunch, travel stipends and other support were given to families as per routine approaches followed at previous CAH Club meetings, with amounts and distribution processes determined in consultation with local health professionals and hospital executives.

4.6.1.4 Data collection

At the start of each Club meeting the researcher and head doctors at the hospitals introduced the survey concept to families, explaining the nature and purpose of the survey and broader HNA research project to the families. Families were informed that participation in the survey was completely voluntary, that their responses would be de-identified and completely anonymous, and that if a family chose not to participate that was completely acceptable and there would be absolutely no negative consequences for them or their child if they declined to participate.

Recognising the potential for literacy barriers, families were discreetly offered support from nurses and doctors to help them complete the survey on a one-on-one basis as needed if desired. Staff knew each family very well, so were able to target those from poorer families and those with lower levels of education to offer support. Families used their free pens to complete the surveys and time was allocated before and during the Club meeting for families to sit and complete the paperwork independently and privately. Health staff were available to answer questions as required. A large box was made available to hold completed surveys at each centre, and staff assisted families in completing and submitting the surveys as needed. The box with completed questionnaires was given to the researcher at the end of the NS Club meetings.

4.6.1.5 Data analysis

All surveys were individually numbered, and this non-identified number was used in Excel spreadsheets and future analysis to identify survey responses. All survey responses were translated into English, and simultaneously entered into an electronic spreadsheet (Excel version 16.43, Microsoft 365 subscription) by an approved and qualified translator (medical doctor involved in the project and the translation processes to date) who was financially compensated at an agreed rate. Data were kept separate for each of the three hospitals to facilitate analysis at two levels. Individual reports were developed for each hospital, so that each hospital had access to their own data (shared by the researcher in person in February 2013), and data from all three hospitals were combined and used to inform the results presented in Study Two of this thesis.

When using the Excel spreadsheet, quantitative responses were analysed and represented visually where possible, to enhance reporting back to Community Members and hospital executive. Because of small sample sizes detailed statistical analysis was not completed. Qualitative data was entered in to NVivo, a qualitative software tool and coded thematically by the researcher, with coding and themes discussed with key stakeholders at various stages throughout the project.

In reporting insights from the Club Meetings, care was taken to ensure no data specific to any one hospital or participant, beyond the numbers of families surveyed, was included in the thesis. All hospital level data and de-identified survey reports were shared with executives at each hospital in February 2013.

4.6.1.6 Ethical considerations

The translated Vietnamese version of the final parent survey template (developed in Study One) was approved by each hospital prior to use at Club meetings. Ethics approval for completion of these surveys at the NS Club meetings was gained from Flinders University in Australia, and from each hospital in Vietnam. Data were stored safely for a minimum seven years or until the end of the project, in line with requirements of Flinders University's ethics committee.

Although Club Meetings offered opportunities for group discussions, the researcher decided these forums would not be used for additional structured information gathering in Study Two but would be reported in Chapter Five as part of the overall approach to translating knowledge to action. Questions families asked were collated by the researcher and used to inform future critical action and additional practical interventions (such as resource development, education and training) that might benefit families (see Chapter Five). The rationale for this was the belief that the interviews and surveys would achieve sufficient saturation. It was also decided that it was more appropriate to use the Club Meetings for giving back to families (for instance, responding to questions that had already been elicited during the pilot interviews and detailed consultations already completed; facilitating the identification of NS Community leaders; and using the time with so many families in one place at one time to optimise educational and information sharing).

In this context, the informal, relaxed and open "Question and Answer sessions" at Club Meetings usually lasted for about an hour and were ideal opportunities for families to raise questions and interact with national and international experts in the field of NS. The group setting allowed large numbers of families to receive accurate information at the same time and minimised the need for duplication of messaging. The rationale for not inviting parents of children currently receiving dialysis was affirmed, given these sessions were used to convey overwhelmingly positive messages to families about their children's prognosis and prospects with the right management, and this would have been at odds with the situation of children with ESKD. Such mismatch would potentially cause emotional trauma for the families of children receiving dialysis and was to be avoided.

As acknowledged previously, the researcher was mindful of the risk that very poor, illiterate families who lived a long way from the hospital may not have been able to attend Club Meetings. Health professionals tried to publicise for many months before the meeting that stipends and travel support would be available to help cover costs associated with attending, but it is reasonable to assume the barriers to attendance were too great for some. It was not considered ethical to have a control group that was not offered any support, information and education that the Club Meeting could provide, particularly when exceptional shifts in health outcomes and prognosis could be expected based on previous experiences with the CAH Community of Vietnam.

4.6.2 Part A Results

4.6.2.1 Process insights – Implementation and response

Response rates

There were 428 questionnaire-based written surveys completed by 426 of the 488 (87%) families of children with NS who registered their attendance at the inaugural NS Club Meetings. In two families, both parents completed a survey form for the same child (as determined by date of birth, address and name of the child on the survey forms), so the responses of both parents were merged into a single response and only 426 of the 428 responses were included in the final analyses.

Of the 426 families surveyed at the NS Club Meetings, responses were received from:

- 86 families at Children’s Hospital 1 in Ho Chi Minh City (17 November 2011)
- 105 families at Children’s Hospital 2 HCMC (18 November 2011)
- 235 families at the National Hospital of Pediatrics (NHP), Hanoi, Vietnam (9 February 2012).

Response rates were not reported by individual hospitals. There were no details available for the 62 (13%; 62/488) families from the three hospitals who did not respond, nor their reasons for choosing not to respond. In general, families who responded were very thorough in completing the surveys. Response rates for individual questions are included in the results for transparency and are shown in tables at the start of each section.

4.6.2.2 Findings from the parent surveys

4.6.2.2.1 Demographics

There were 19 quantitative questions used to describe the demographic profile of the cohort of parents of children living with NS in Vietnam consulted at the NS Club Meetings, to better understand the "*who*", "*where*" and "*how*" of their lives (Table 9).

Table 9 - Questions relating to demographic profile included in the parent survey

Topics	Quantitative questions	Qualitative questions	Survey questions – Demographic profile	Response rate
Who?	1		Respondent profile	87%
	1		Child's age (years)	99%
	1		Sex	95%
	1		Ethnicity	99%
	1		Household size	91%
Where?	1		Rural: Urban	73%
	1		Province	70%
	1		Av. distance of home from hospital (km)	91%
	1		Av. distance of home from hospital (hours)	94%
How?	1		Av. Monthly family income (million VND)	76%
	1		Source of family income	86%
	2		Parental education	92%
	2		Parental career	92%
	1		Primary caregiver	94%
	1		Mode of transport	85%
	1		Internet access	95%
	1		English speaking	90%
Total	**19**	**0**	**19**	

Who?

Respondent profile

The person completing the questionnaire was asked their relationship to the child with Nephrotic Syndrome they were representing (Figure 25). The response rate to this question was 88% (374/426). The survey was completed by a mix of mothers (43.4%; 185/426); fathers (33.6%; 143/426); both parents (3.5%; 15/426); grandparents (3.5%; 15/426); and other guardians (aunts, siblings, 3.5%; 15/426), with no response to the question in 12% (53/426) of cases.

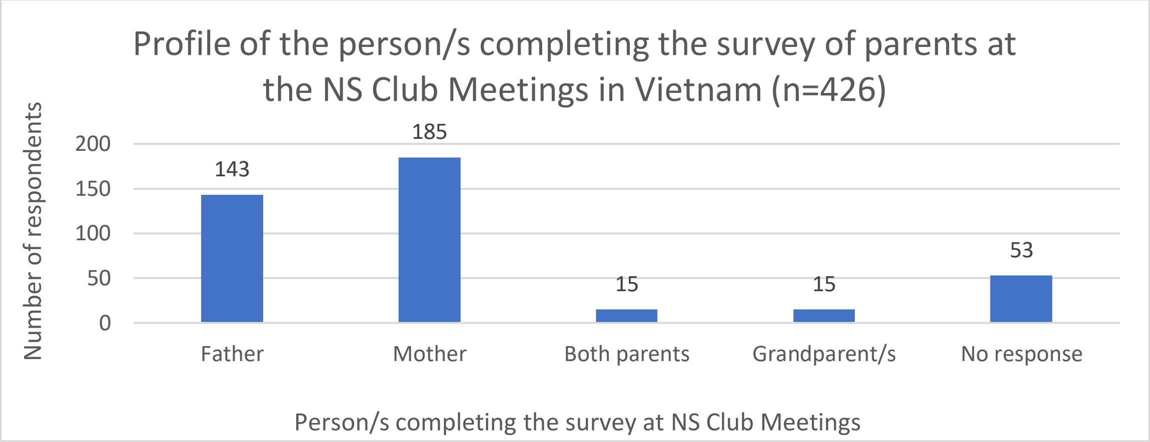


Figure 25 - Profile of the person/s completing the parent survey at NS Club Meetings in Vietnam (n=426)

Child's age

Families were asked to give the child's date of birth and age (Figure 26). Some families responded to one or the other questions, allowing the researcher to determine the age of the children in 99% (423/426) of cases. The average age of children represented in the surveys was 6.8 years (range 1–18 years; mode 5 years; median age 6 years).

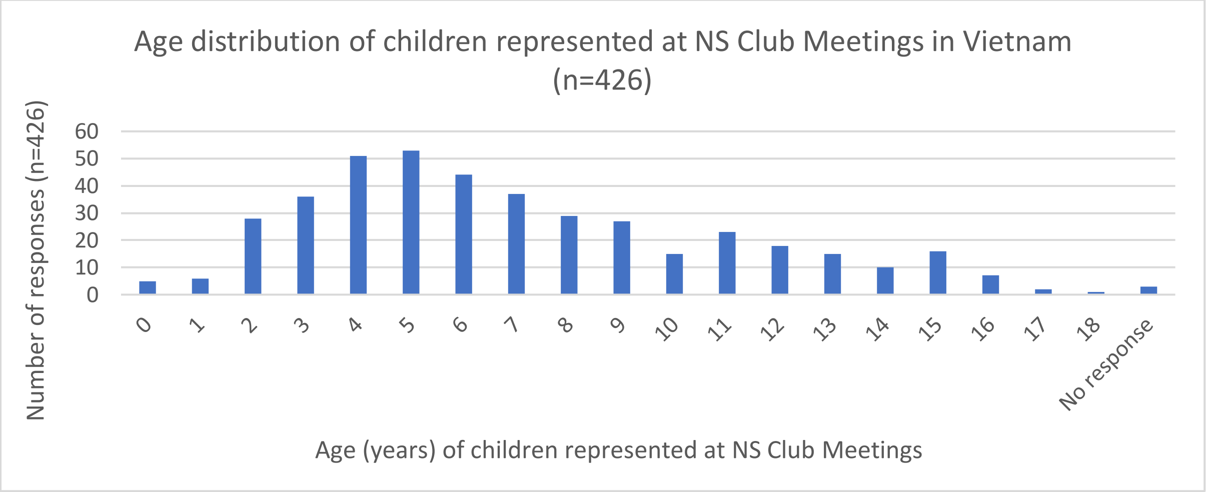


Figure 26 - Age distribution of children represented at the NS Club Meetings in Vietnam (n=426)

Child’s sex

When asked if the child represented was male or female, 95% (404/426) of respondents replied. The majority of children were male (73%; 296/404) and 27% (108/404) were female (Figure 27).

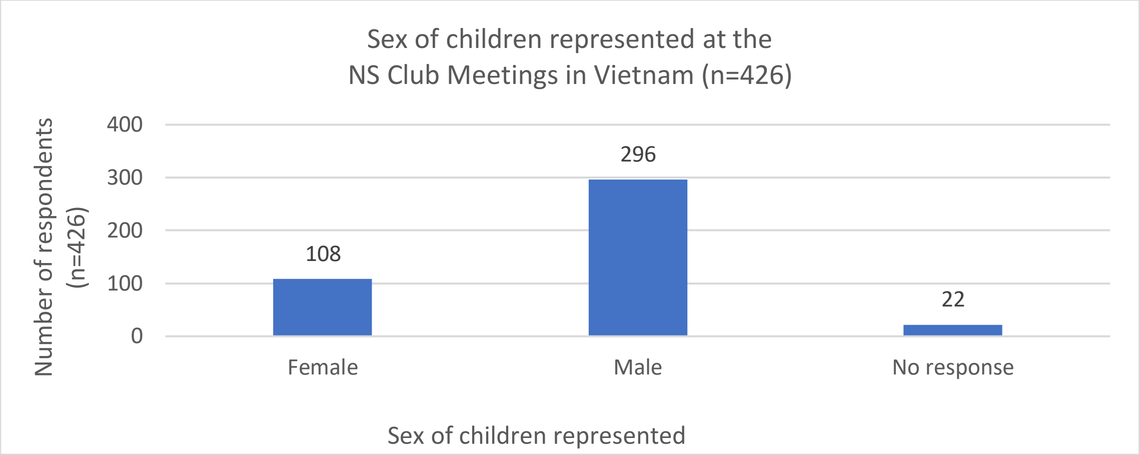


Figure 27 - Sex of children represented at the NS Club Meetings in Vietnam (n=426)

The distribution of age by sex was calculated for the 403 families (95%) who responded to both questions. The age distribution of females and males was broadly similar (Figure 28).

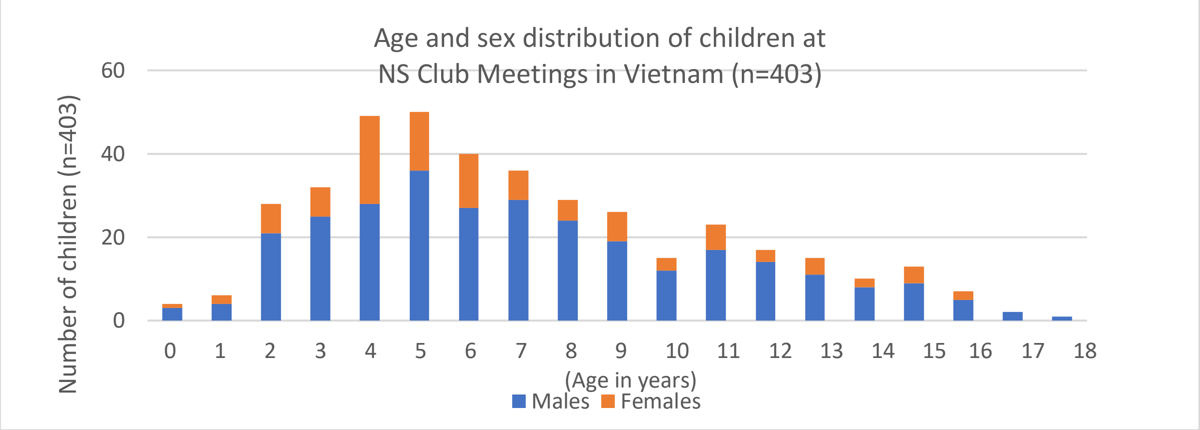


Figure 28 - Age and sex distribution of children at NS Club Meetings in Vietnam (n=403)

Household size and structure

Families were asked to list everyone living in their house and the total number of people living in their home (Figure 29). The response rate was 91% (388/426). The average household size was 4.9 persons (mode 4; median 5; range 2–12 persons).

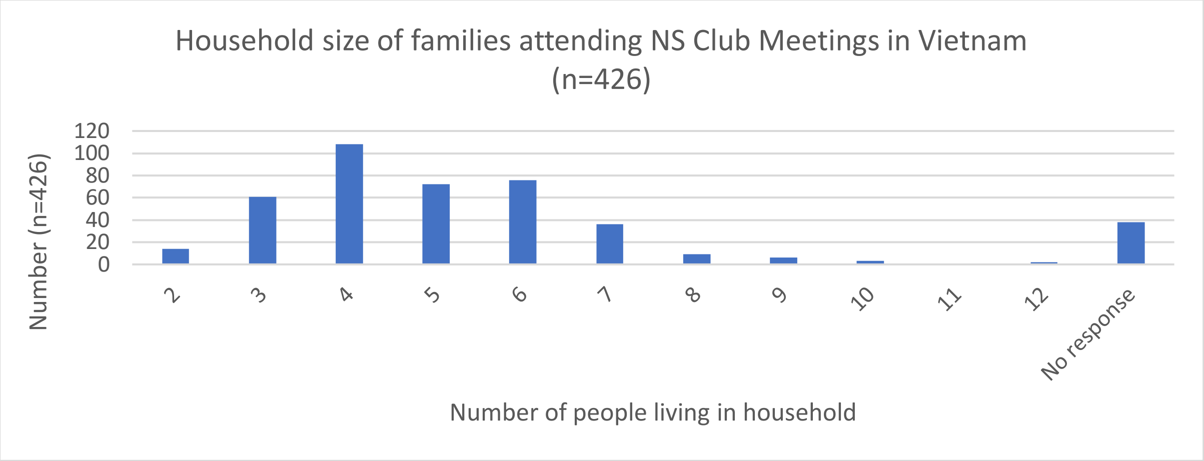


Figure 29 - Household size of families attending the NS Club Meetings in Vietnam (n=426)

Most families (96%; 371/388) stated both parents were living in the family home (Figure 30). One child (1/388; 0.3%) was cared for by grandparents, one child (1/388; 0.3%) was cared for by their single father and 15 children were cared for by their single mothers (15/388; 3.9%). Five single mothers (5/15; 33.3%) stated that they were widowed. Approximately one-third of families (36%; 141/388) had at least one grandparent living in the house.

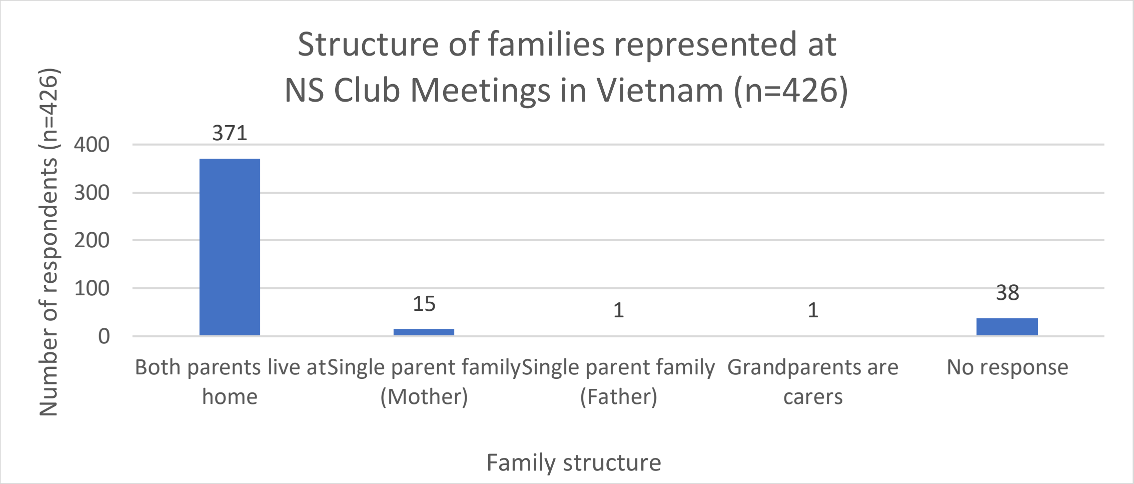


Figure 30 - Structure of families represented at the NS Club Meetings in Vietnam (n=426)

Families were also asked to identify the primary carer of their child with NS, and 94% (401/426) of families responded. In 54% (215/401) of families both parents shared the primary care duties for their child with NS. Mothers were the primary carers in 36% of families (143/401), fathers in 4% (17/401) of families and grandparents were either primary carers (20/52) or assisting the primary carers (32/52) in 13% (52/401) of families (Figure 31).

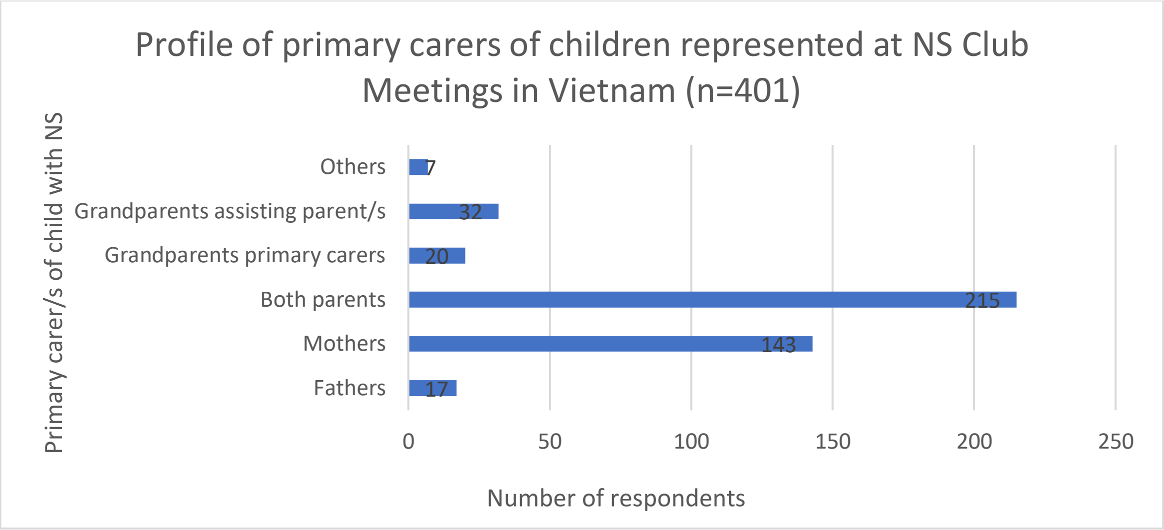


Figure 31 - Profile of primary carers of children represented at the NS Club Meetings in Vietnam (n=401)

Ethnicity

The response rate to this question was 99% (422/426). Most families responding to this question identified as Kinh (411/422; 97%). There were six ethnic minority groups represented by 11 families (11/422; 3%) including Hoa (4), Nung (2), Tay (2), San Riu (1), Dao (1) and Khome (1) peoples (Figure 32).

Of families identifying as belonging to an ethnic minority community, most had a male child with NS (82%; 9/11). The average age of children from ethnic minority groups was 7.5 years. All 11 families had both parents caring for the child, and the average family size was 5.4 persons (response rate 10/11; mode 4; median 5.5; range 4–8 persons).

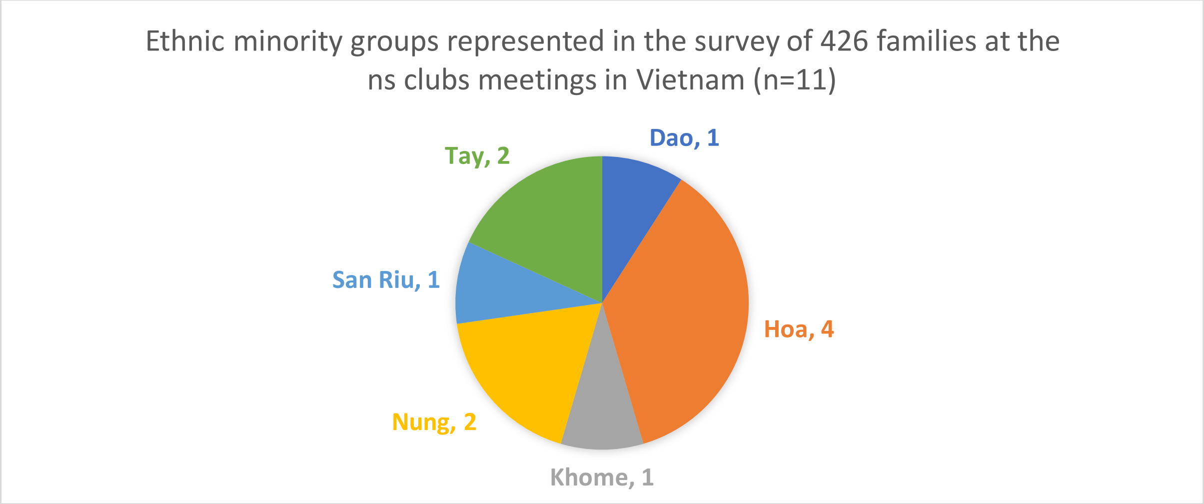


Figure 32 - Ethnic minority groups represented in the parent survey at NS Club Meetings in Vietnam (n=11)

Provinces represented

When asked which province they lived in, 70% (297/426) of families responded. Families came from 46 (74%) of the 62 provinces in Vietnam (Table 10). Predictably, Ho Chi Minh City in the southeast region, the location of two of the three hospitals, and Hanoi in the Red River Delta region, the location of the third hospital, were the provinces with the greatest numbers of families attending the NS Club Meetings (26%; 77/297 and 24%; 70/297 respectively, Table 11).

The Central Highlands region had the fewest families (5/297; 2%) represented at the NS Club Meetings, and the North and South Central Coast region had the lowest proportion of provinces (7/14; 50%) represented at the meetings. Ethnic minority groups live mostly in the Central Highlands and Northern Midlands and Mountains of Vietnam.

Table 10 - Provinces represented by families attending the NS Club Meetings (n=297)

Six regions of Vietnam (96 Provinces)	**Number of provinces**	**Percentage of provinces**	**Number of families**	**Percentage of respondents (n=297)**
1. Northern Midlands and Mountains (14 Provinces)	9	64%	27	9%
2. Red River Delta (10 Provinces)	10	91%	128	43%
3. North and South Central Coast (14 Provinces)	7	50%	17	6%
4. Central Highlands (5 Provinces)	4	80%	5	2%
5. Southeast (6 Provinces)	6	100%	99	33%
6. Mekong River Delta (13 Provinces)	10	77%	21	7%
Total (62)	46		297	100%

Table 11 - Distribution of NS Club Meeting participants by province (n=297)

Northern Midlands and Mountains (14 Provinces)		**Red River Delta (11 Provinces)**		**North and South Central Coast (14 Provinces)**		**Central Highlands (5 Provinces)**		**Southeast (6 Provinces)**		**Mekong River Delta (13 Provinces)**	
Bac Giang	9	Bac Ninh	6	Ha Tinh	3	Dac Nong	1	Binh Duong	5	An Giang	6
Ha Giang	1	Ha Nam	3	Nghe An	4	Lam Dong	1	Binh Phuoc	3	Ben Tre	3
Lang Son	1	Hai Duong	5	Thanh Hoa	3	Dac Lak	2	Dong Nai	6	Ca Mau	1
Phu Tho	5	Hung Yen	6	Binh Thuan	1	Gia Lai	1	Tay Ninh	5	Dong Thap	3
Thai Nguyen	4	Nam Dinh	20	Khanh Hoa	4			HCMC	77	Kien Giang	1
Tuyen Quang	3	Ninh Binh	4	Quang Nam	1			Vung Tau	3	Long An	2
Yen Bai	1	Thai Binh	6	Quang Ngai	1					Soc Trang	2
Hoa Binh	2	Vinh Phuc	7							Tien Giang	1
Son La	1	Ha Noi	70							Tra Vinh	1
		Quang Ninh	1							Can Tho	1
	27		128		17		5		99		21

Location (urban / rural) of family homes and distance from the hospitals

When asked if they lived in a rural or urban area, 74% (315/426) of families responded. In total, 71% (224/315) of respondents indicated they were from rural areas and 29% (91/315) were from urban areas (Figure 33).

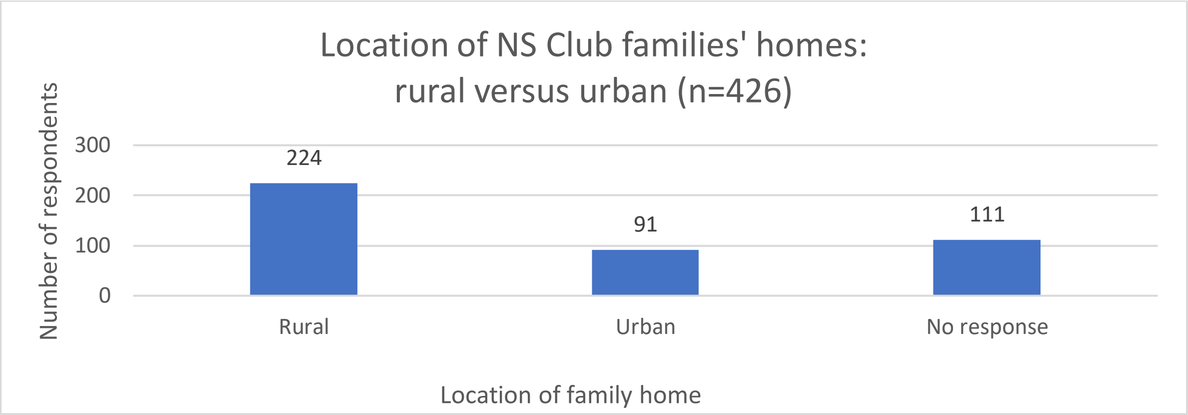


Figure 33 - Location of NS Club families' homes (rural versus urban; n=426)

Similar numbers responded to questions regarding the distance families lived from the hospital (91%; 387/426) and time taken to travel to the hospital from home (94%; 402/426), with 88% (373/426) of families responding to both questions (regarding distance and time).

The average distance families lived from the hospital was 95 km (mode 100 km; median 60 km; range 1–900 km, Figure 34), and the average time taken to travel to the hospital was 3 hours (mode 3 hours; median 2 hours; range 6 minutes to 36 hours, Figure 35). There was a linear association between distance travelled and time taken (Figure 36).

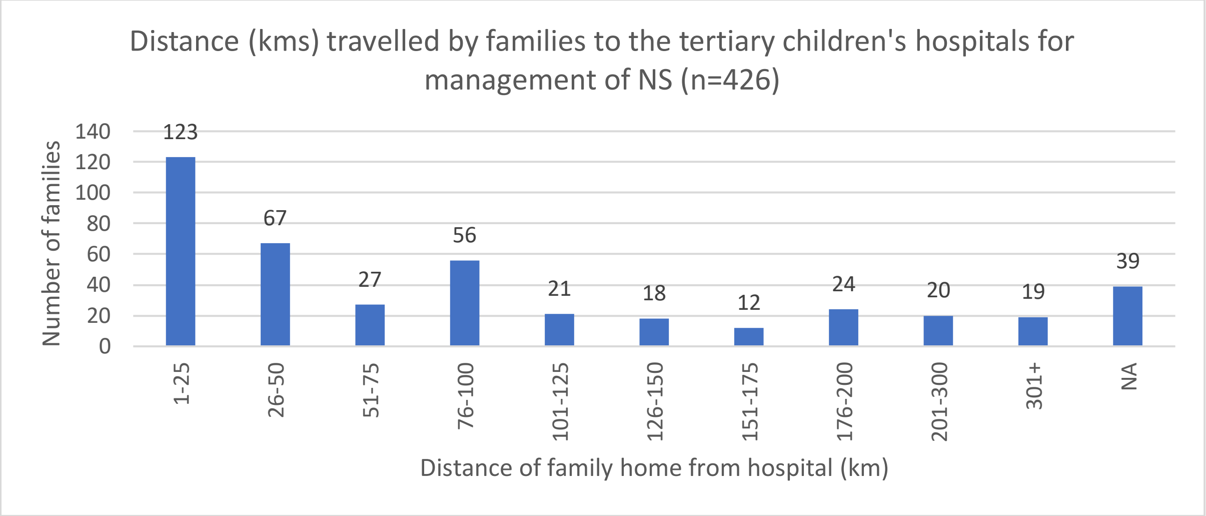


Figure 34 - Distance (km) travelled by families for management of their NS n=426)

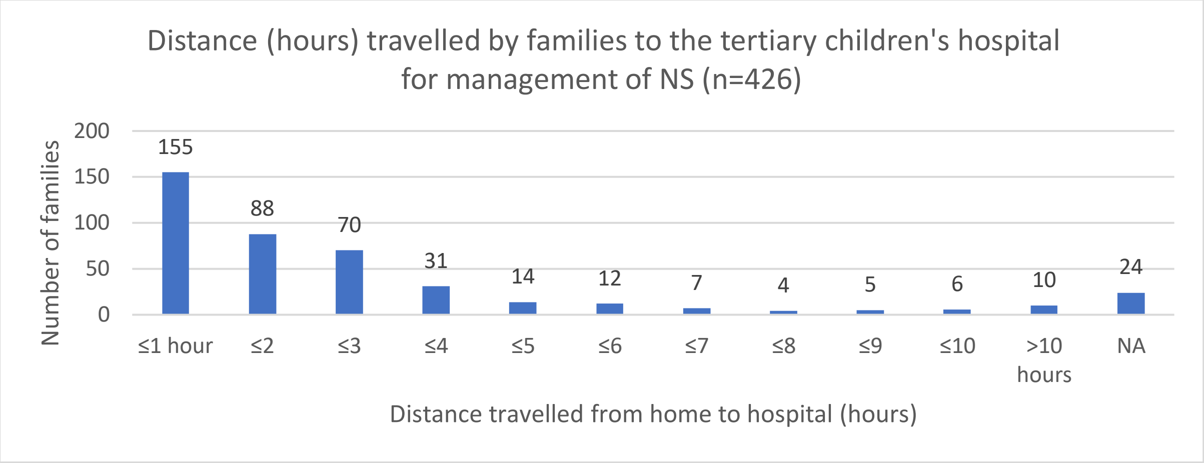


Figure 35 - Distance (hours) travelled by families for management of their NS

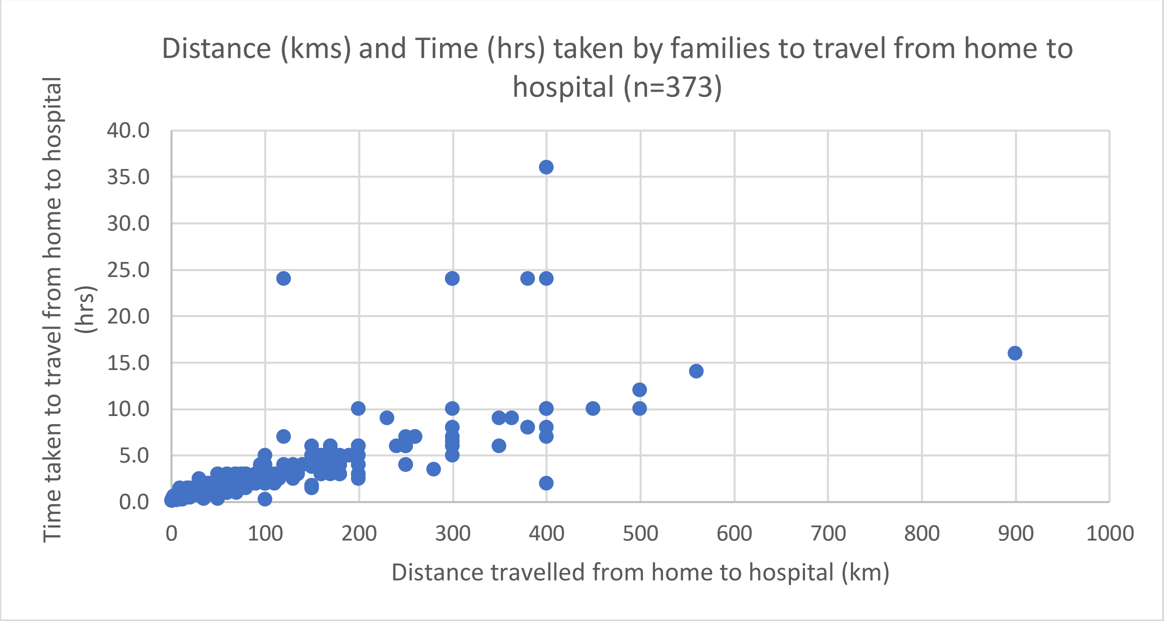


Figure 36 - Distance / time taken by families to travel from home to the NS Club Meetings (n=373)

The majority of families (71%; 273/387) lived within 100 km of the hospitals but a relatively small number (10%; 39/387) lived more than 200 km away. Only two of the 11 families from ethnic minority groups lived within 50 km of the hospitals, and the average distance travelled from home for ethnic minority families was 166 km. Of note, urban or rural status was independent of the distance families lived from the tertiary referral centres. There were urban centres hundreds of kilometres from the hospitals. For instance, two ethnic minority families reported living in urban areas and their homes were 160 km from the tertiary hospitals that their children attended for management of their NS.

Modes of transport

The response rate to the question regarding modes of transport to the tertiary referral centre was 85% (363/426). Motorcycles (51%; 185/363) were the most common form of transport used by families to travel to the NS Club Meeting from their homes. Buses (35%;

127/363) and cars (10%; 36/363) were other common forms of transport used (Figure 37). Simple associations were found between mode of transport and distance families lived from the hospital, with buses, trains and cars (or a combination of these) the most common forms of transport for families living more than 100 km away (Figure 38).

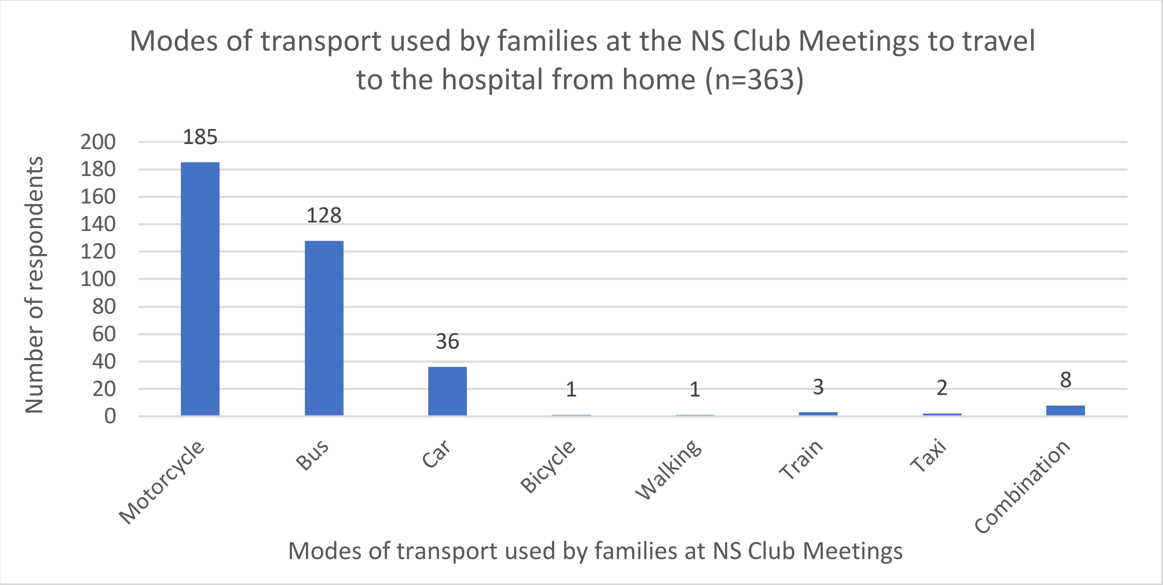


Figure 37 - Modes of transport used by families to attend the NS Club Meetings (n=363)

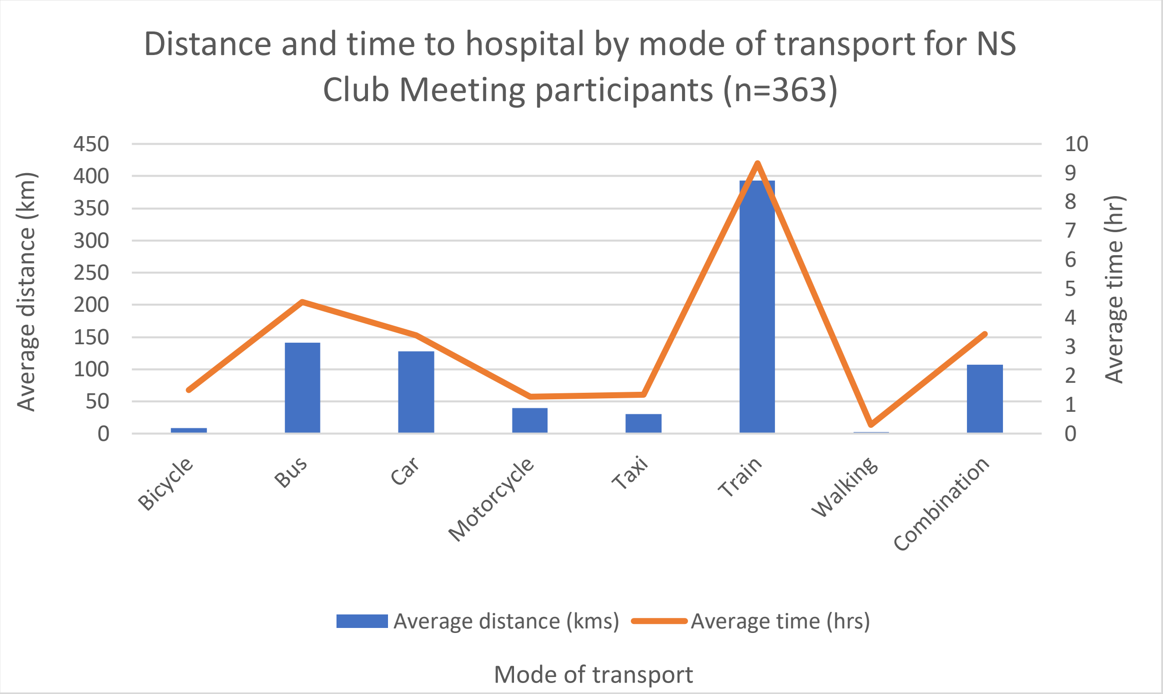


Figure 38 - Distance and time to hospital by mode of transport for NS Club Meeting participants (n=363)

<u>Parental education and employment</u>

The response rate to questions regarding employment and highest educational level achieved by the parents attending the NS Club meeting was 92% (394/426) of families. That said, some respondents only provided the educational status of one parent and details for 42 fathers and 31 mothers were missing. Given this number exceeded the number of expected missing responses (there were only 16 single parent families), they were included in the total non-response rate with the 32 families who did not respond. Hence the total number of responses missing for fathers was 74/426 (17%) and mothers 63/426 (15%).

The educational status of fathers and mothers were similar (Figure 39), with married couples usually having similar educational levels. For instance, 75% of the 40 fathers who had completed university were married to women who had also completed education at university or postgraduate levels. In most families, parents had an education of Year 9 and above, and just over one-third of families had parents educated at or beyond Year 12, viz:

- 55% of all families (235/426) had a mother with an education Year 9 and above
- 56% of all families (238/426) had a father with an education Year 9 and above
- 35% of all families (149/426) had a mother with an education Year 12 and above
- 35% of all families (148/426) had a father with an education Year 12 and above
- 10% of all families (43/426) had a father with a university level education
- 9% of all families (37/426) had a mother with a university level education

The most common careers for fathers were “farmer” (34%), “worker” (21%) and “driver” (7%); mothers described their employment as “farmer” (32%), “worker” (17%) and “housewife” (17%).

Only a very small number of families (7%; 28/385) reported they had a family member able to speak English (response rate 90%; 385/426), underscoring the importance of translating educational resources into Vietnamese language for use by families, given most quality resources on NS available online at the time were not available in Vietnamese language.

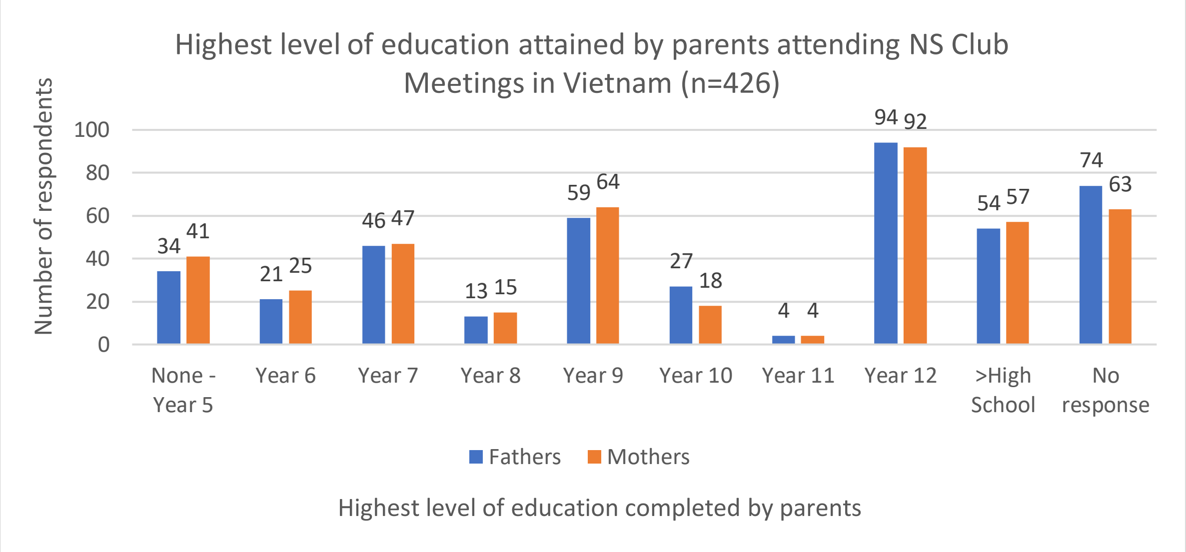


Figure 39 - Highest level of education attained by parents attending NS Club Meetings in Vietnam (n=426)

Income

The response rate to the question regarding sources of income for families attending the NS Club meetings was 86% (368/426). Fathers contributed to the family income in 85% (313/368) of families, and 74% of mothers also contributed to the household income. Relatives contributed to the family income in 11% of families, and other sources helped out another 3% of families. Families were asked to estimate their monthly income, and 76% (323/426) of families responded. The average monthly income for families was 5 million VND (median 1 million VND; mode 2 million VND), with a range of 150,000VND–50 million per month (where 1 million VND equated to approximately AUD $60) [376]. The average score given for financial strain by families was 7/10 (response rate 84%; 358/426). Families with lower monthly incomes reported the greatest financial strain (Figure 40). The average monthly income of single parent families (led by mothers) was 2.2 million VND (response rate 60%; 9/15) and financial strain average score 6 (response rate 73%; 11/15). The average income of ethnic minority families was 5 million VND (response rate 73%; 8/11), and average financial strain score was 7.4 (response rate 73%; 8/11).

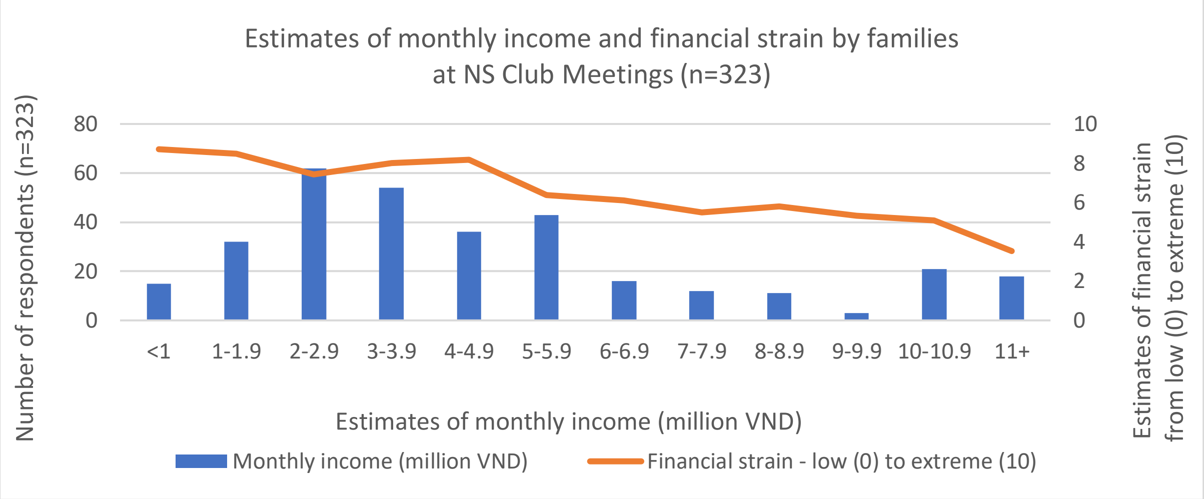


Figure 40 - Estimates of monthly income and financial strain by families at NS Club Meetings in Vietnam (n=323)

Access to the Internet

The response rate to the question regarding access to the internet was 95% (406/426). Just over half of families stated they had internet access (54%; 232/406, Figure 41) but a significant proportion lacked access (41%; 174/406), and 32% (129/406) of respondents noted they had never accessed the internet. Families with internet access achieved this in a range of ways: 39% (91/232) on their mobile phones, 60% (139/232) in their homes, 13% (30/232) in their villages and many with combinations of each.

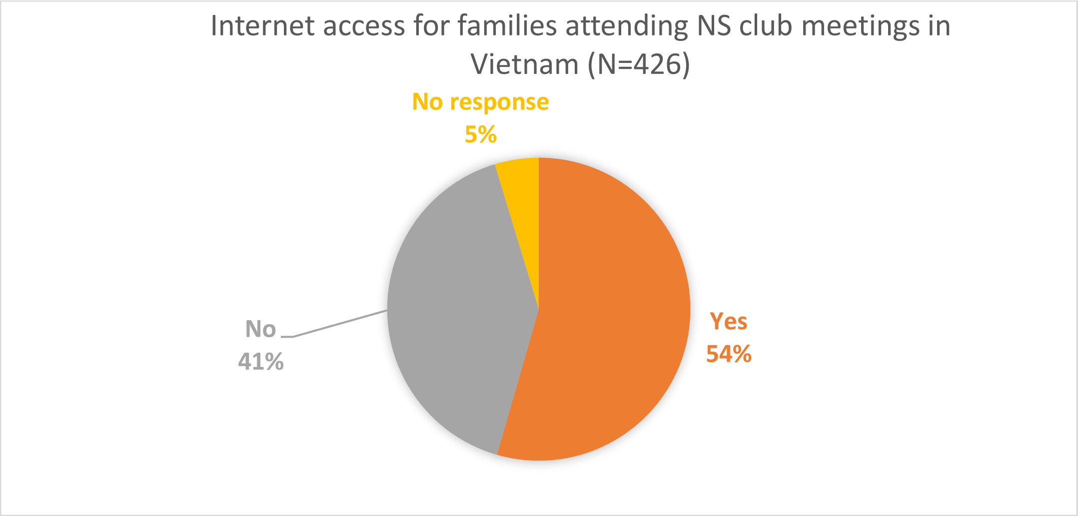


Figure 41 - Internet access for families attending NS Club Meetings in Vietnam (n=426)

4.6.2.2.2 Schooling

There were 7 quantitative and 4 qualitative questions relating to schooling (Table 12).

Table 12 - Questions relating to schooling

Topics	Quantitative questions	Qualitative questions	Survey questions – Schooling profile	Response rate
School attendance	1		Does child attend school?	97%
		1	If no, why not attending?	97%
	1		If not for NS, would still be going?	97%
	1		If no, age stopped school?	78%
	1		If yes, grade now?	78%
	1		If yes, days missed in last 12 months?	82%
		1	If yes, reasons for missing school?	70%
Progress at school	1		Progress with studies (score)	95%
		1	Concerns with social progress at school?	86%
		1	Other general concerns with schooling?	58%
	1		Impact of NS on child's social life last 4/52?	82%
Total	**7**	**4**	**11**	

School attendance

Families were asked if their child with NS attended school, and 97% (415/426) of families responded. Of these, 76% (323/415) stated their child did go to school. Because the question was not specifically directed to parents of school-aged children, it was difficult to determine whether 76% was an underestimate, and many families stated their child was not attending school because they were too young. To clarify this, responses were analysed according to a selected cut-off age of four years based on apparent best fit. There were 348/426 families with a child aged four and over, and most children aged four seemed to be attending school. When parents were asked to scale their child's academic progress at school there were 323 responses, and this was significantly higher than the number of children aged five years and older (297 children), so the cut-off of four years was considered appropriate.

Of the 82% (348/426) children estimated to be of school age (four years and older), only 11% (40/348) of children were identified as not attending school. When asked the reasons their children were not attending school, an additional eight children (all four-year-olds) were excluded because their parents noted they were "too young for school", leaving the actual number of school-aged children not attending school because of NS at 32 (9%; 32/348, Figure 42).

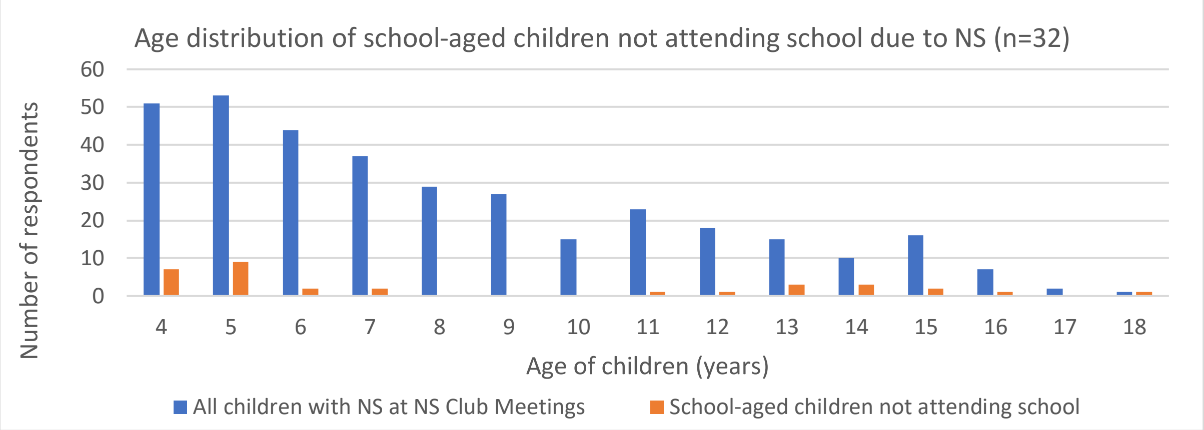


Figure 42 - Age distribution of school-aged children not attending school due to NS (n=32)

When asked to clarify more specifically *why* their child with NS was not attending school, the most common reasons given by families (response rate 97%) were not related to their child's physical wellbeing but rather to a range of other reasons, including parental fears of infection, stringent pursuit of a non-salty diet and avoidance of play (for fear of injury or illness):

> *"(Doesn't attend school) to avoid exposure to cold weather"*
>
> *"We worried that physical activities would make the NS relapse"*
>
> *"He may injure himself. Can't play sport"*
>
> *"I am worried that he will be infected by other diseases"*
>
> *"Had to stay home to follow less salty diet"*
>
> *"Had to go to the hospital for follow-up"*

“He was so tired he couldn’t go to school”

Of the children attending school, 323 families used a numerical scale to represent how their child was coping academically *now* (Figure 43). Responses were mostly positive (average 8; median 8; mode 9), with 76% (244/323) of respondents ranking their child’s current progress at school as good to very good (7+ out of 10).

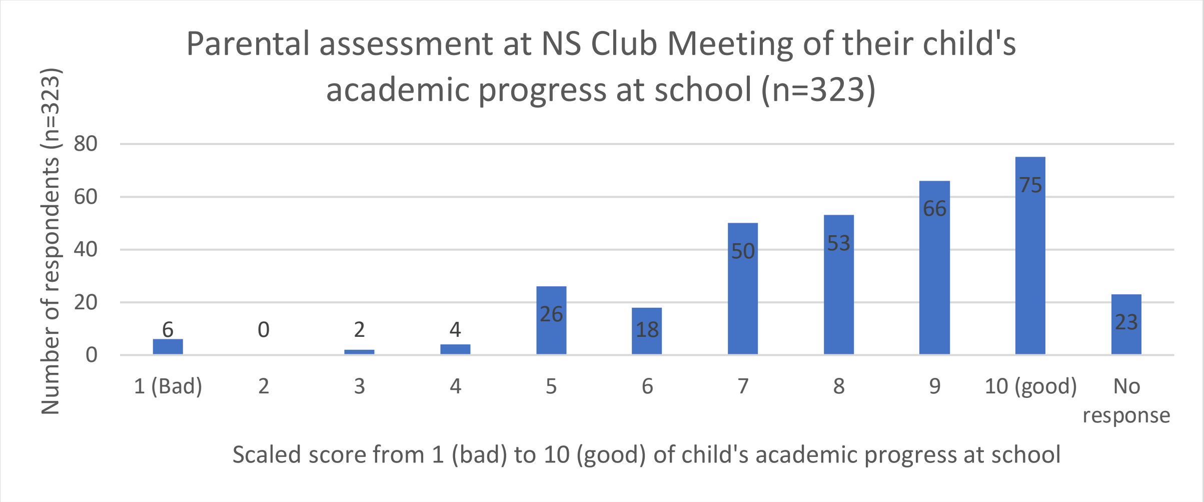


Figure 43 - Parental assessment of children's academic progress at NS Club Meetings (n=323)

Despite these positive scores, parents still expressed significant concerns about their child’s future education and academic prospects, and the quantitative and qualitative data suggested an association with the amount of school children were missing. There were 285 parents (82%; 285/348) of school-aged children who estimated the numbers of days of school missed by their child in the last 12 months. The average number of days missed was 23 (mode 20 days; median 14 days; range 0–90 days). One family stated their child had to repeat first grade because of the number of days missed, and five families simply stated “many” as their estimate of days missed. The most common reasons for children missing school related to physical illness, mostly infections such as the “common cold”, pharyngitis, fever and stomach ache, fatigue, relapses, hospitalisation and routine follow-up with doctors.

Parents were asked to estimate the impact of their child’s physical or emotional health problems on their social activities over the last 4 weeks (Figure 44), and although 67% (241/361) stated the impact was nil or slight, many parents still reported concerns about the impact of NS on their child’s social experiences at school. Social stigma, lack of confidence, effects of missed schooling, the burden of firmly-held beliefs that have no evidence base (such as the need to prevent a child from participating in physical activities because of the risk of fractures and relapses) and physical illness had the greatest adverse impact on social wellbeing for children:

“Can’t catch up with friends because of absences”

“His friends teased him that he is so weak due to NS. It made him sad”

“Since he got sick, he usually gets tired and less communicative with friends”

> *“Not confident because of body deformity”*
>
> *“He had to skip classes when NS relapsed”*
>
> *“She is afraid that her classmates may think her disease is threatening and makes her weak”*
>
> *“I'm so worried because friends at school teased my child due to his disease”*

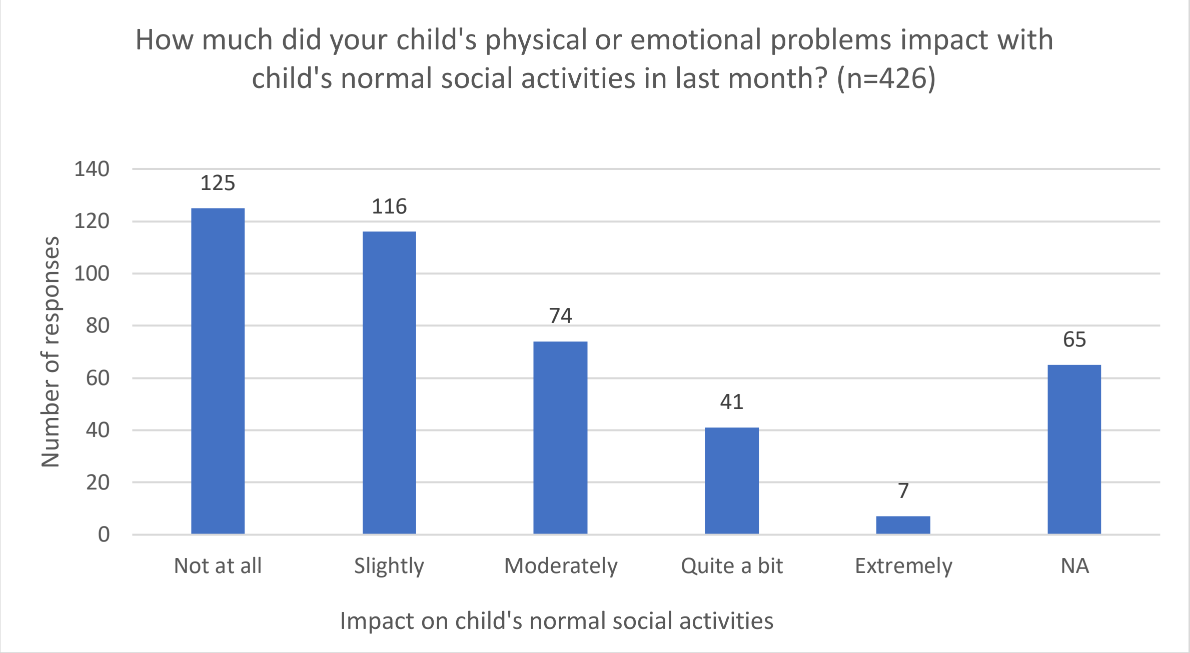


Figure 44 - Parental estimates of the impact of a child's physical / emotional problems on the child's normal social activities in the last month (n=426)

Recognised side effects of steroid therapy (such as facial changes, mood changes and irritability) and other physical side effects of NS were also acknowledged:

> *“My child is very aggressive. It is easy for him to get angry and bite one of his friends”*
>
> *“He can't join excessive physical activities such as football, running, jumping”*
>
> *“I'm worried that his school friends and others notice his face because it looks pale”*
>
> *“Not confident due to oedema”*
>
> *“He is not confident to communicate with his classmates because he looks different.”*
>
> *“He is afraid of having enlarged abdomen and round face”*

4.6.2.2.3 Life with NS

There were 17 quantitative questions investigating families' lives with NS, and interactions with the health system generally (Table 13).

Table 13 - Questions relating to life with NS

Topics	Quantitative questions	Qualitative questions	Survey questions – Life with NS	Response rate
Nature of NS	1		Type of NS?	60%
	1		Is NS steroid sensitive?	59%
	1		Family history of NS?	88%
	1		Time of diagnosis?	83%
	1		Relapses in last 12 months?	82%
	1		Relapses in life	82%
Management of NS	1		Place of diagnosis	51%
	1		First time treated at this hospital?	37%
	1		Inpatient admissions?	92%
	1		Admissions because of NS?	84%
	1		Duration of admissions?	84%
	1		Immunisations up to date?	84%
	1		Had any additional vaccinations?	67%
Quality of life with NS	1		Health 12 months ago?	88%
	1		Health now?	88%
	1		Impact on parents' social life over last 4/52?	82%
	1		Impact on parental SEWB?	78%
Total	**17**	**0**	**17**	

Type of Nephrotic Syndrome

When asked about the type of NS their child had and whether it was sensitive to steroids, the response rate was 60% (255/426). Of those who answered the question on type of NS, the two most common responses described symptoms (33%; 85/255) or said "I don't know" (11%; 28/255). Roughly equal numbers of families stated their child had steroid sensitive NS (10%; 23/255) and steroid resistant / dependent NS (10%; 25/255) (Figure 45). When specifically asked if their child's NS was "steroid sensitive", 79% (200/253) of respondents said yes, 19% (48/25) responded no and 2% (5/253) said "I don't know" (Figure 46).

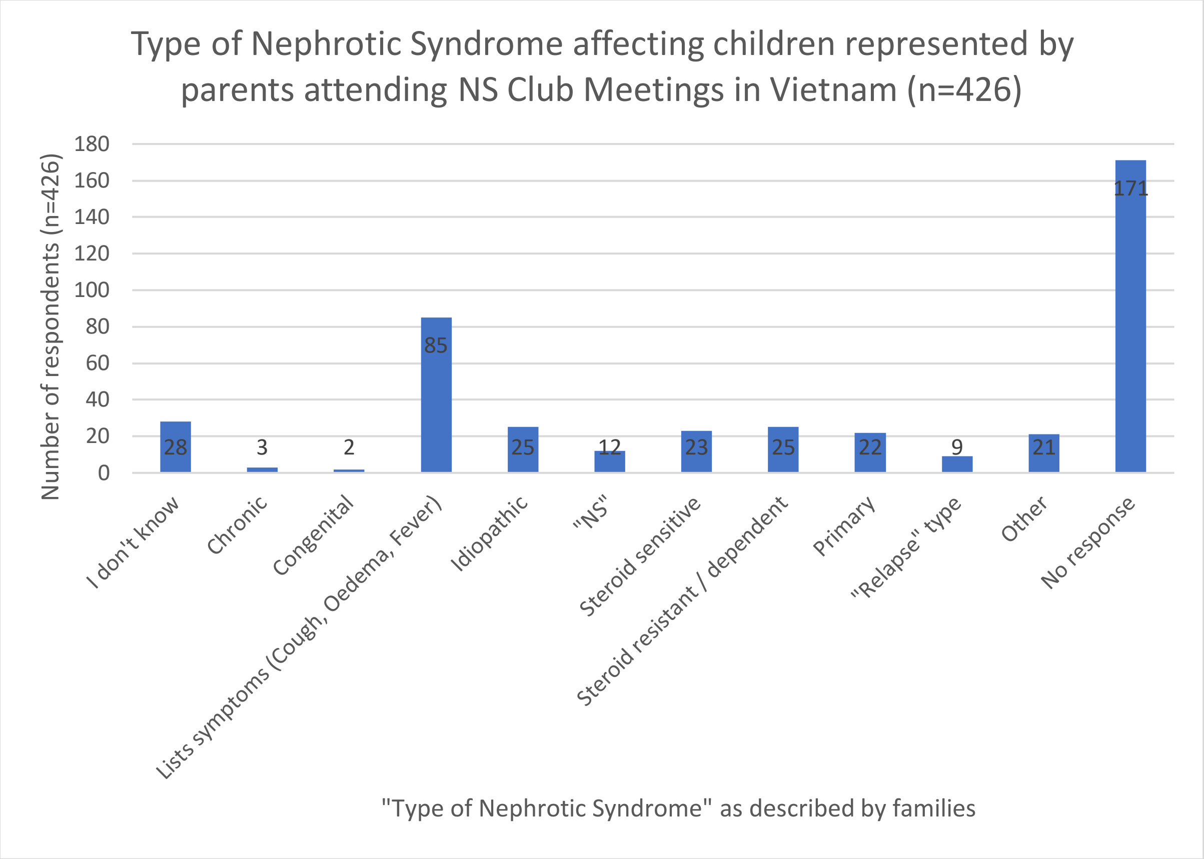


Figure 45 - Types of NS affecting children (as stated by parents) represented at the NS Club Meetings in Vietnam (n=426)

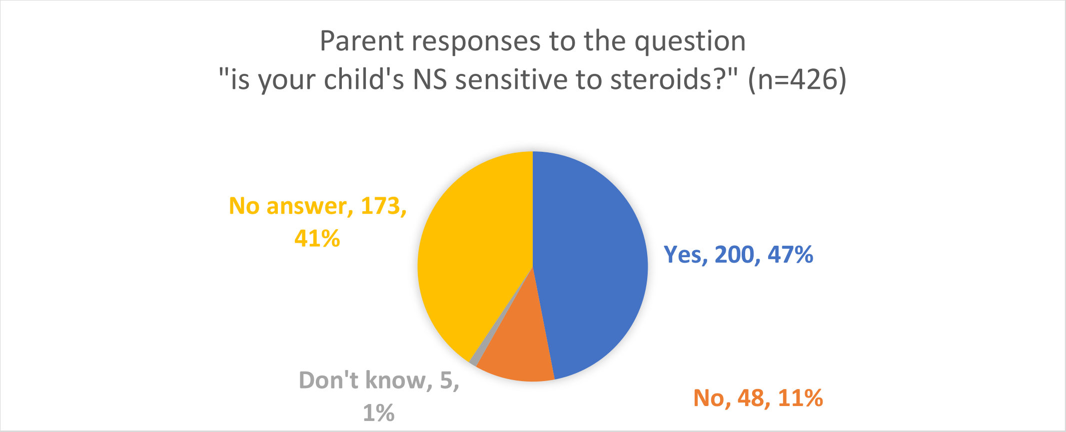


Figure 46 - Parent responses to the question "Is your child's Nephrotic Syndrome sensitive to steroids?" (n=426)

<u>Relapses and hospital admissions</u>

Parents were asked about the number of relapses and hospital admissions their child with NS had experienced, and the response rates were 81% (349/426) and 92% (391/426) respectively. The average number of relapses was 4 (mode 1; median 3; range 0–40; no response 67, Figure 47), where “10” was the maximum number of relapses attributed when families simply replied, “many times” (considered a likely underestimate of the total number of relapses). The high number of children who had had one or zero relapses was consistent with the high number of children diagnosed with NS in the last 12 months who attended the meetings. The average number of hospital admissions for all causes was 3.2 (median 2; mode 1; range 0–40). Most hospital admissions were related to NS (average 2.8; median 2; mode 1), and the average duration of admissions related to NS was 15 days (median 13; mode 10; range 1–150 days) (Figure 48).

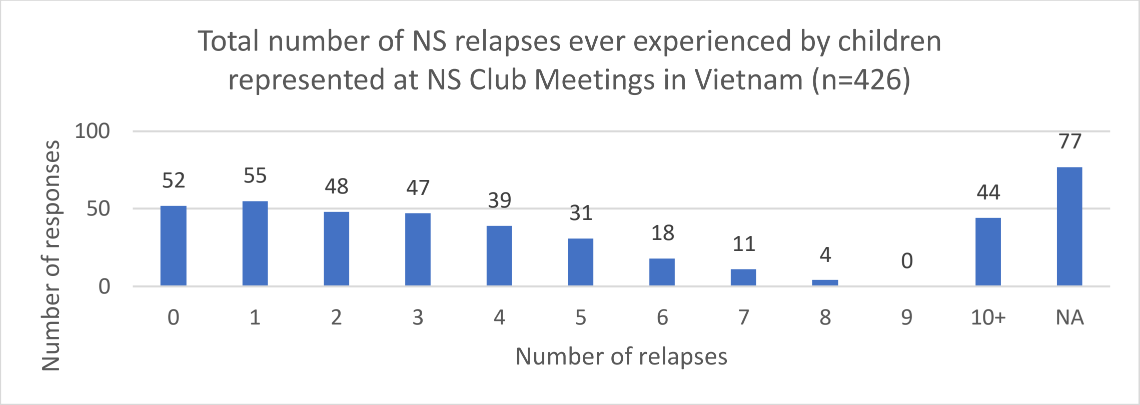


Figure 47 - Parental estimates of number of relapses ever experienced by children represented at the NS Club Meetings in Vietnam (n=426)

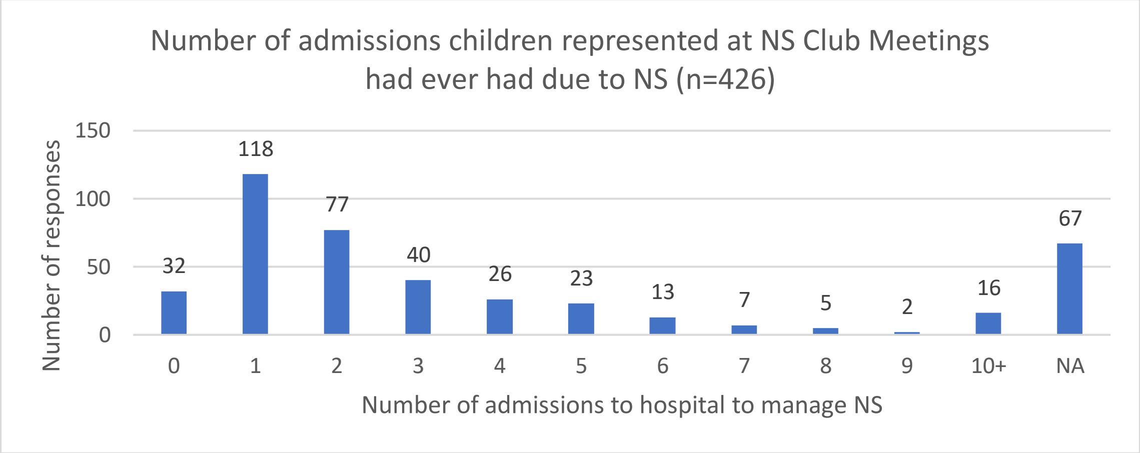


Figure 48 - Parental estimates of number of admissions children represented at the NS Club Meetings had ever had due to NS (n=426)

Diagnosis of NS

Families were asked three questions about timing of the diagnosis of NS: when diagnosis was made; how long the child has had NS; and when the child first attended the tertiary children's hospital for management of NS. There were some misunderstandings with these questions, and whilst 83% (353/426) of families attempted to respond, the number of years since diagnosis could only be determined in 79% (335/426) of cases. A large number of families interpreted the question as meaning what triggered the diagnosis to be made and responded with answers such as "when he had oedema". Of the families who responded with dates and years, the majority of children represented in the surveys had been diagnosed with NS relatively recently. Average time since diagnosis was 1.9 years; mode less than 1 year; median less than 1 year (Figure 49).

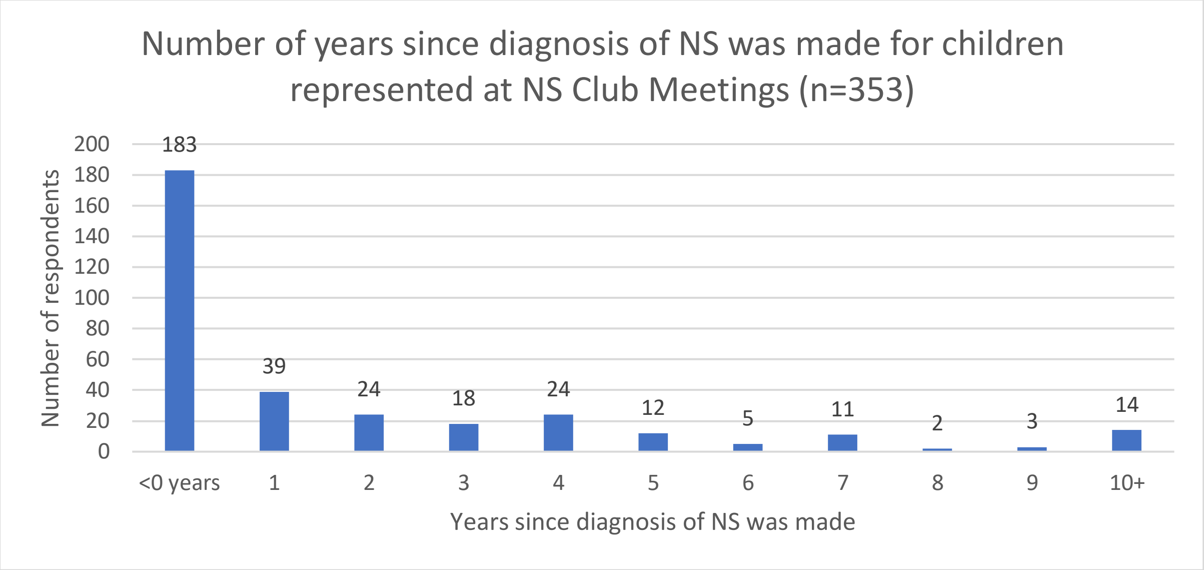


Figure 49 - Number of years since diagnosis of NS made for children represented at the NS Club Meetings in Vietnam (n=353)

Most children (77%; 169/219) were diagnosed with NS at the tertiary referral centre where the NS Club meeting was held (Figure 50). A small number of "local hospitals" were mentioned (4%; 8/219) and 35 other hospitals were specifically acknowledged by the remaining 42 (19%) respondents. Data to determine time taken for families of children diagnosed with NS to be seen at the tertiary referral hospital if they were diagnosed elsewhere was of poor quality (response rate 37%; 158/426). Based on the available data, average time appeared quite short (average 0.25 years; mode 0 years; median 0 years).

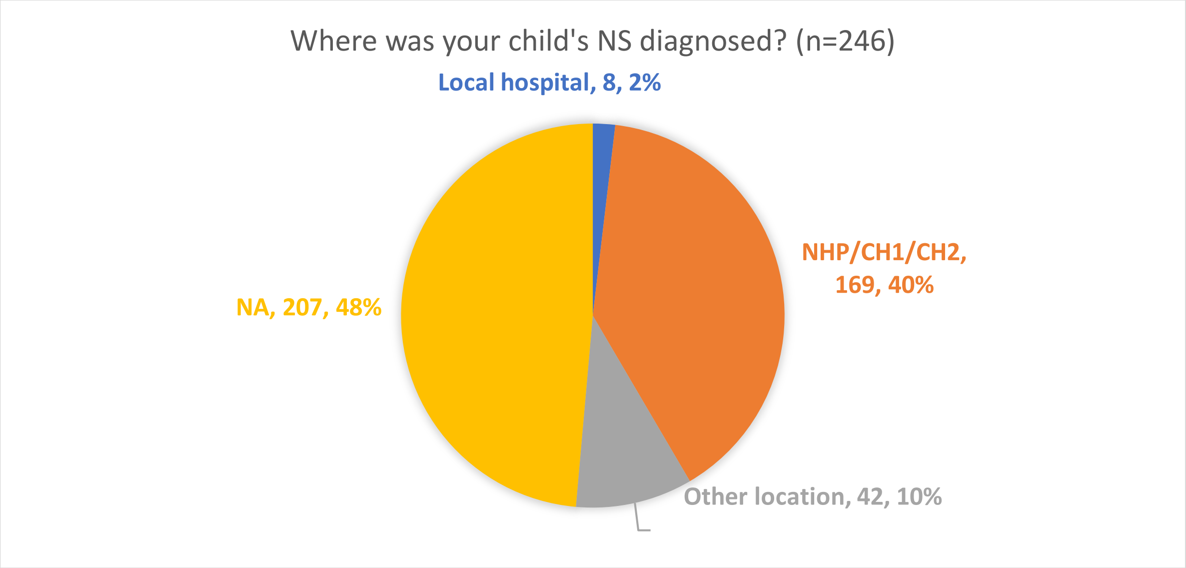


Figure 50 - Where was your child's NS diagnosed? (n=246)

Impact of NS on parental wellbeing

Parents were asked to rate the impact of their child's NS on their own mental health and wellbeing (where a score of 1 indicated a parent "rarely" and a score of 10 indicated they "always" felt a particular emotion); 78% (332/426) of families responded. Families reported feeling anxious (average 7.3; mode 10; median 8) and worried (average 7.7; mode 10; median 8) somewhat more than being depressed (average 5.5; mode 1; median 6) or sad (average 6.8; mode 10; median 7) (Figure 51). Despite the burdens NS placed on families, many families indicated they felt hopeful much of the time (average 7.7; mode 10; median 9) and optimistic (average 6.3; mode 10; median 6), although less commonly did they feel in control (average 6.2; mode 5 and median 6) (Figure 52).

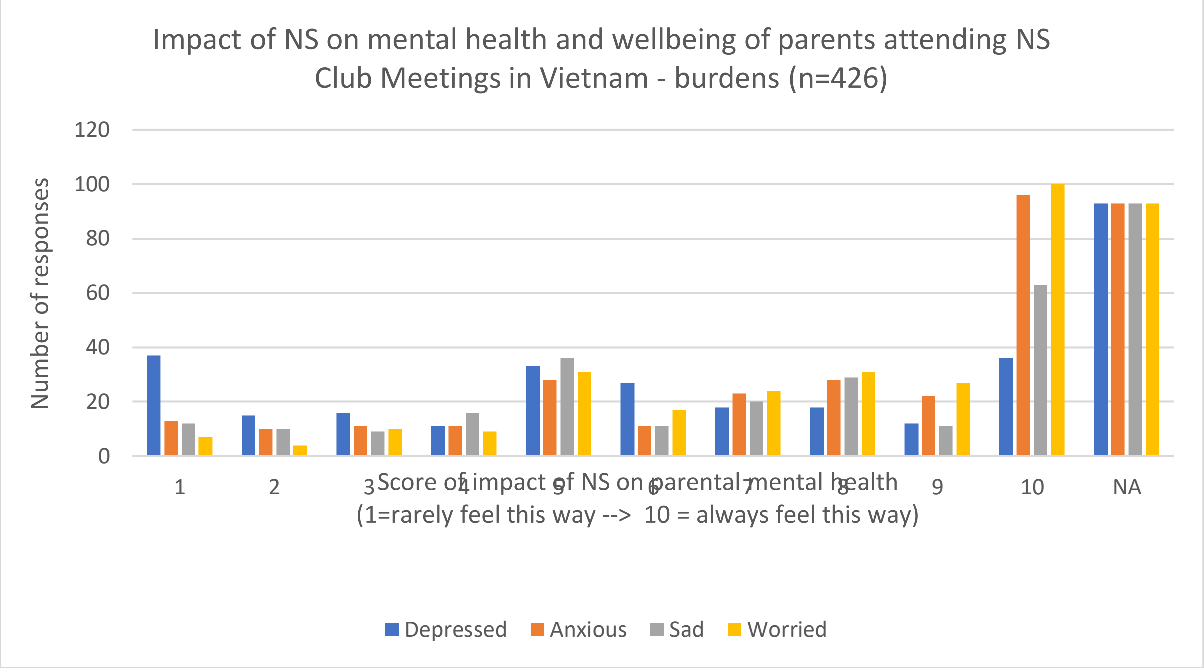


Figure 51 - Impact of NS on mental health and wellbeing of parents attending the NS Club Meetings in Vietnam - burdens (n=426)

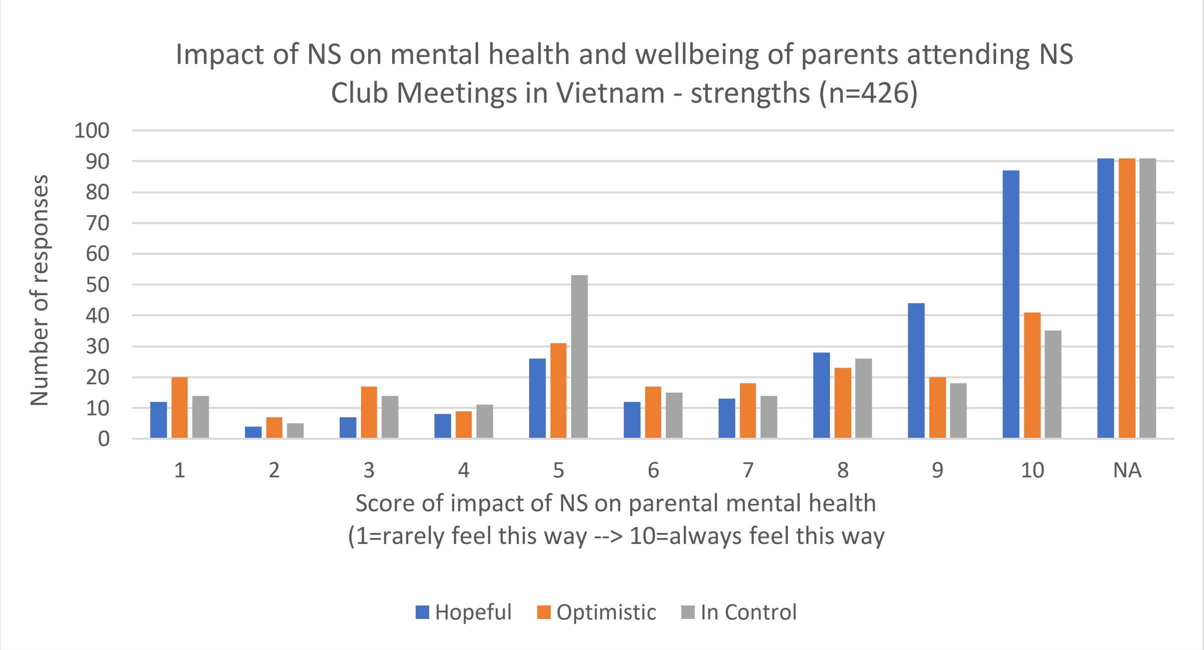


Figure 52 - Impact of NS on mental health and wellbeing of parents attending NS Club Meetings in Vietnam - strengths (n=426)

Impact of NS on social activities

Families were asked to indicate the extent to which their child's physical and emotional problems had affected their own and their child's usual social activities over the last four weeks (Figure 53), with 85% (361/426) and 82% (351/426) of families responding respectively. Responses were compared with the impact of NS on their child's wellbeing to check for associations. The responses were similar for parents and children, with only 2% of families reporting NS had had an extreme impact on either their child's or their own social activities, and 11% of families reporting NS had had "quite a bit of an impact". Overall, the majority of families (67%; 241/361 and 65%; 227/351) felt NS had had no impact or only very slight impact on their family's social life.

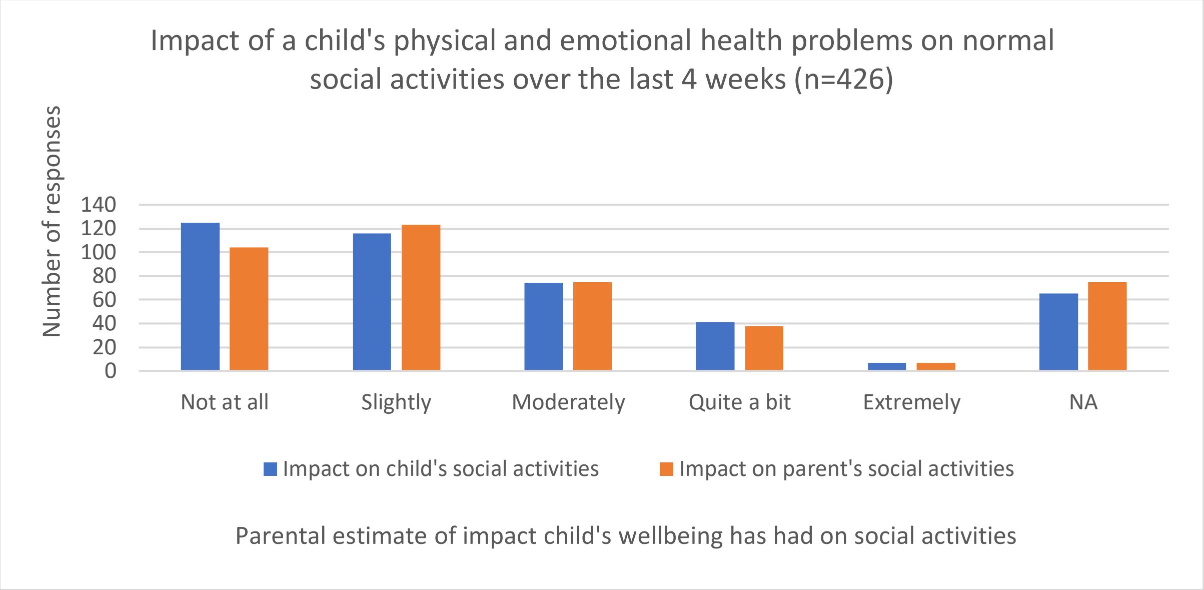


Figure 53 - The impact of children's wellbeing on parent and child social activities (n=426)

Survivor cohort

There were 113 children who had been living with NS for four or more years. The profile of this cohort was analysed to determine any potential determinants of survival (Table 14).

Table 14 - Survivor cohort comparisons: All families attending NS Club Meetings (n=426) versus families of children living with NS for four years or more (n=113)

Profile features	All children (n=426)	Children living with NS for more than 4 years (n=113)
Home location (Rural: Urban)	Rural: Urban 71: 29	Rural: Urban 67: 33
Sex (Male: Female)	Male: Female 73: 27	Male: Female 77: 23
Ethnic minority group (Whole community = 15%)	3% (11): 15%	3% (3): 15%
Single parent family	4% (16)	4% (5)
Parent education level for fathers and mothers	≥ Yr 9 - Fa 56%; Mo 55% ≥ Yr 12 - Fa 35%; Mo 35% University - 10% (Fa); 9% (Mo)	≥ Yr 9 - Fa 51%; Mo 55% ≥ Yr 12 - Fa 35%; Mo 34% University – 8% (Fa); 7% (Mo)
Average income / month (million VND)	5 (mode 2; median 1)	5 **(mode 4; median 4)**
Household structure / family support	Household size = 4.9 persons (mode 4; median 5; range 2-12) 36% of families have at least one grandparent in home; 60% have no support	Household size = 4.8 persons (mode 4; **median 4**; range 2-10) 35% of families have at least one grandparent in home; 57% have no support
Distance from hospital (km)	Average = 95km Mode = 100km Median = 60km Range = 1 to 900km	**Average = 74km** Mode = 100km Median = 52.5km Range = 1 to 400km
Distance from hospital (hours)	Average = 3 hours Mode = 3 hours Median = 2 hours Range = (6 min – 36 hours)	**Average = 2.2 hours** Mode = 3 hours Median = 1.5 hours Range= (15min – 24 hours)
Parents working	Mothers not working = 28%	Mothers not working = 23%
Health insurance	Yes, has insurance = 94% No insurance = 6% Insurance covers all costs = 41% Insurance for <6 years = 49% School insurance = 49% Insurance for poor = 11%	Yes, has insurance = 92% No insurance = 8% Insurance covers all costs = 47% Insurance for <6 years = 20% **School insurance = 84%** Insurance for poor = 16%
Child wellbeing	Not attending school = 9%	Not attending school = 6%
Parental wellbeing (scale 1 / rarely feel → scale 10 / always feel) (average/mode/median)	Depressed = 5.5 Anxious = 7.3 Sad = 6.8 Worried = 7.7 Hopeful = 7.7 Optimistic = 6.3 In Control = 6.2	Depressed = 5.1 ˇ Anxious = 6.9 ˇ Sad = 6.9 ˆ Worried = 7.3 ˇ Hopeful = 7.3 ˇ Optimistic = 5.9 ˇ In Control = 5.9 ˇ

Survival features

Potential health determinants associated with survival were examined for children who had survived more than four years after their diagnosis of NS. Detailed statistical analysis was not possible given the small sample size, but comparison of the survival cohort (n=113) with total cohort surveyed (n=426) and the broader population of children in Vietnam identified the following points:

- Place of residence – survivors were more likely to live in urban areas and closer in terms of time and distance to the tertiary referral hospitals than the broader NS Community cohort (Figure 54 and Figure 55)
- Sex – male children with NS were more likely to survive than females
- Ethnicity – ethnic minority groups were under-represented compared with national figures
- Household size – survivors came from households that were larger than the national average
- Health insurance – survivors were more likely to have health insurance and in particular, school insurance (Figure 56)

Perhaps unsurprisingly, families of children who had been living with NS for four years or more were less likely to express a sense of optimism, hope or feeling of being in control.

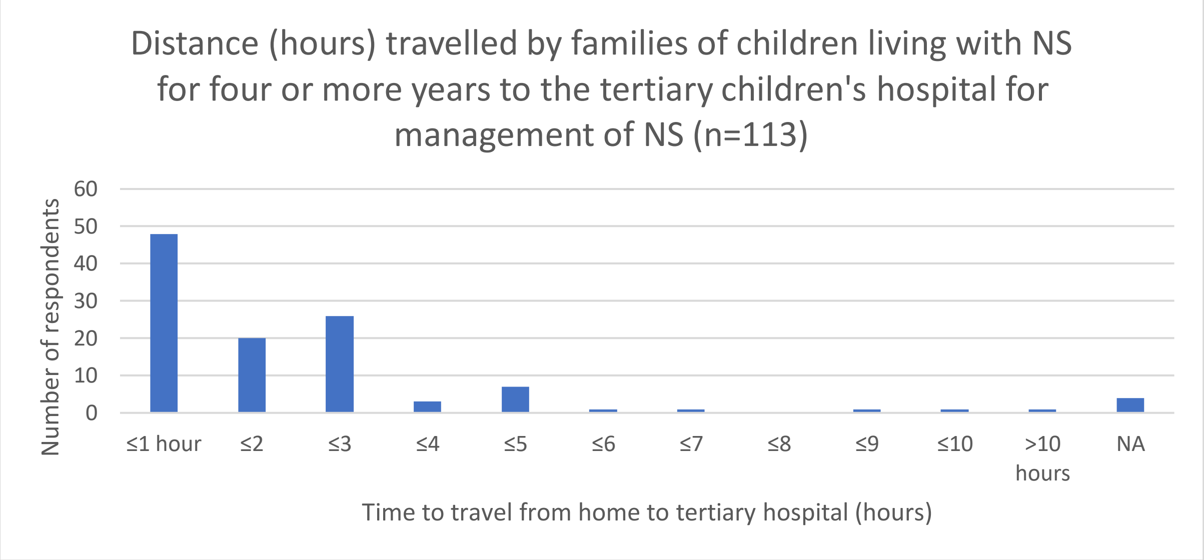


Figure 54 - Distance (hours) travelled by survivor cohort from home to hospital (n=113)

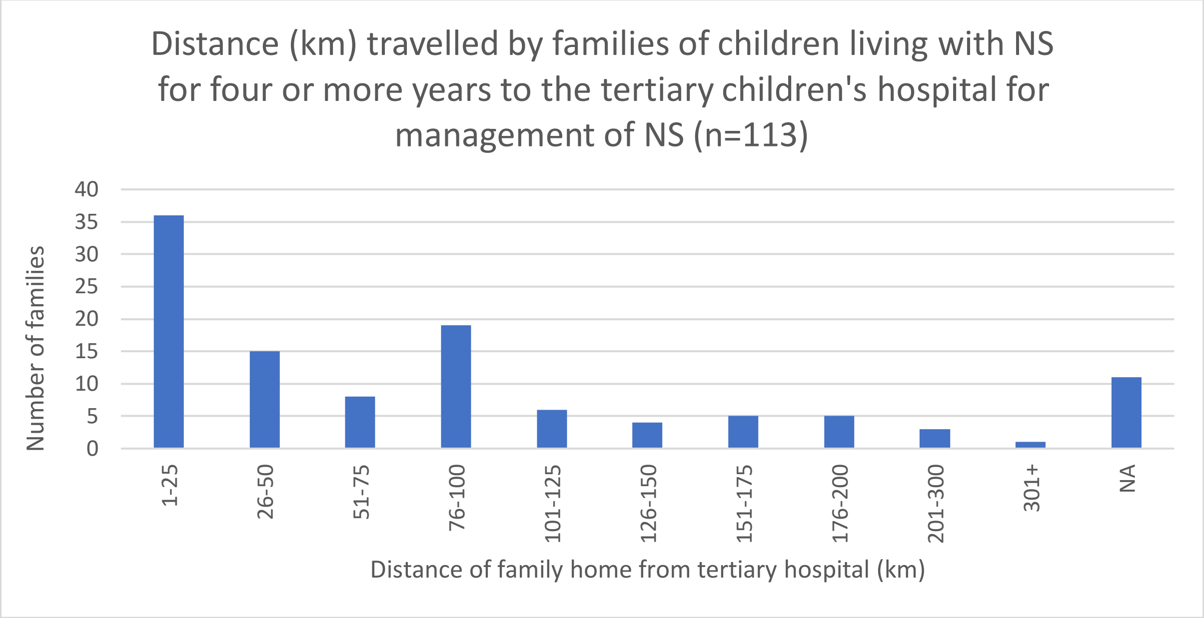


Figure 55 - Distance travelled (km) by survivor cohort from home to hospital (n=113)

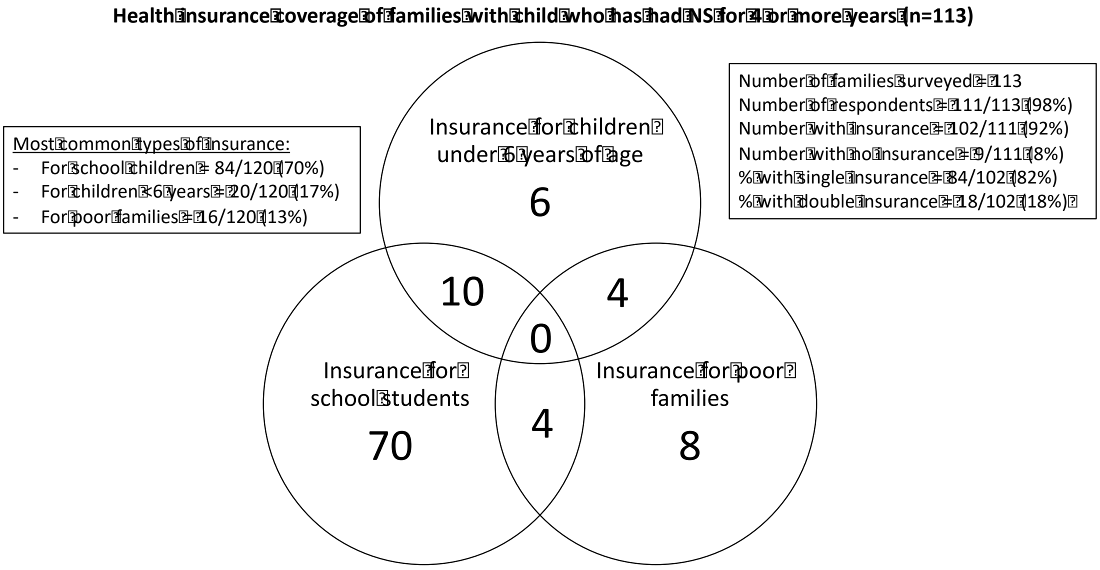


Figure 56 - Health insurance coverage of families with child who has had NS for more than 4 years (n=113)

Overall health and wellbeing

Families were asked to compare their child's general health and wellbeing now with that 12 months ago, and 88% (376/426) of families responded. Whilst families expressed enormous concern and anxiety about their child's health (both now and 12 months ago), when asked to quantify this, results were positive overall, although this may reflect that most children were relatively newly diagnosed with NS. Reflecting on their child's health 12 months ago, families gave an average score of 7 out of 10 (median 7; mode 10), and just 9% of families determined their child's health was poor a year ago (score of <5/10). These numbers were similar to those relating to current health (average score 7; median 7; mode 8), with even fewer families (7%) scoring their child's current health at <5/10.

Family History

Families were asked if there was any family history of NS, and 88% (374/426) of families responded. A family history of kidney disease was noted by 4% (15/374) of families.

Immunisation profile

Parents were asked if their child with NS was up to date with the national immunisation schedule. Of the 84% (358/426) that responded, 78% (280/358) were up to date. If we assume families who did not answer were not up to date, the proportion of children up to date with the national vaccination schedule in this cohort may have been as low as 66% (280/426) (Figure 57).

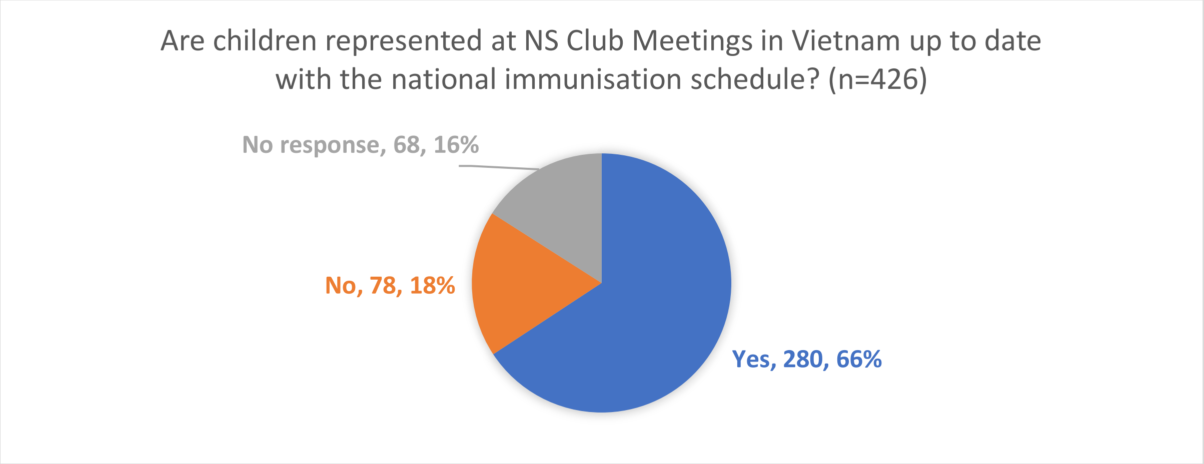


Figure 57 - Immunisation profile of children represented at the NS Club Meetings in Vietnam (n=426)

Families were asked about any additional vaccines their child had been given, and the response rate was 67% (284/426). Only a small proportion of respondents could recall their children having received additional vaccines:

- Hepatitis B vaccine 39% (110/284) and
- Haemophilus influenza 30% (86/284)
- Varicella vaccine 24% (68/284)
- Pneumococcal vaccine 13% (36/284)
- Other vaccine 5% (14/284)

Very few families could recall when their child had their vaccinations.

4.6.2.2.4 Management of NS

There were 16 quantitative and 3 qualitative questions relating to the management of NS (Table 15).

Table 15 - Questions relating to management of NS

Topics	Quantitative questions	Qualitative questions	Survey questions – Management of NS	Response rate
Medicine & equipment	1		Medicines used	91%
		1	Where do you access medicines?	85%
	1		Learned how to test urine?	93%
	1		Test for protein at home?	89%
	1		If yes, how often do you test urine?	89%
	1		Traditional medx used	92%
	1		Current traditional medx	92%
	1		Ever stopped medx against advice?	76%
		1	Why stopped medx?	78%
Access to healthcare	1		Local health professional?	90%
	1		Confidence in local HCP?	79%
	1		Distance to HCP you trust	69%
	1		Time to HCP you trust	69%
Knowledge, confidence & support	1		Confidence in understanding swelling	81%
	1		Access to educational resources	90%
	1		Where from?	90%
	1		Want to learn more?	93%
	1		Confidence in treating swelling	80%
		1	Source of support	77%
Total	**16**	**3**	**19**	

Use of medicines

Families were asked which medicines their child with NS was currently using or had ever used (Figure 58), and the response rate was 91% (388/426). Of concern, only 88% (342/388) of families acknowledged their child had taken prednisone at some point to manage their NS, when this should have been 100%. Of those responding, 11% (43/388) stated they were not sure which medicines their child had used in the past, and 5% (11/388) were unsure which medicines their child was currently using.

Families indicated that cyclophosphamide, cyclosporine, mycophenalate and levamisole were currently being used by 13% (51/388) of children, and 16% (8/51) of these families indicated their child was taking a combination of these drugs, ranging from two to four different drugs, with 71 reports of use in all.

Almost half (47%; 182/388) of families reported use of "other medicines" (either in the past or currently), with the most commonly listed including antihypertensives, diuretics, vitamins and "Oyster 600mg" (a calcium supplement). Families provided information relating to where they generally accessed their medicines (response rate 85%; 364/426), and the most usual sources were hospitals (most usually the tertiary children's hospitals), pharmacies and through the health insurance program.

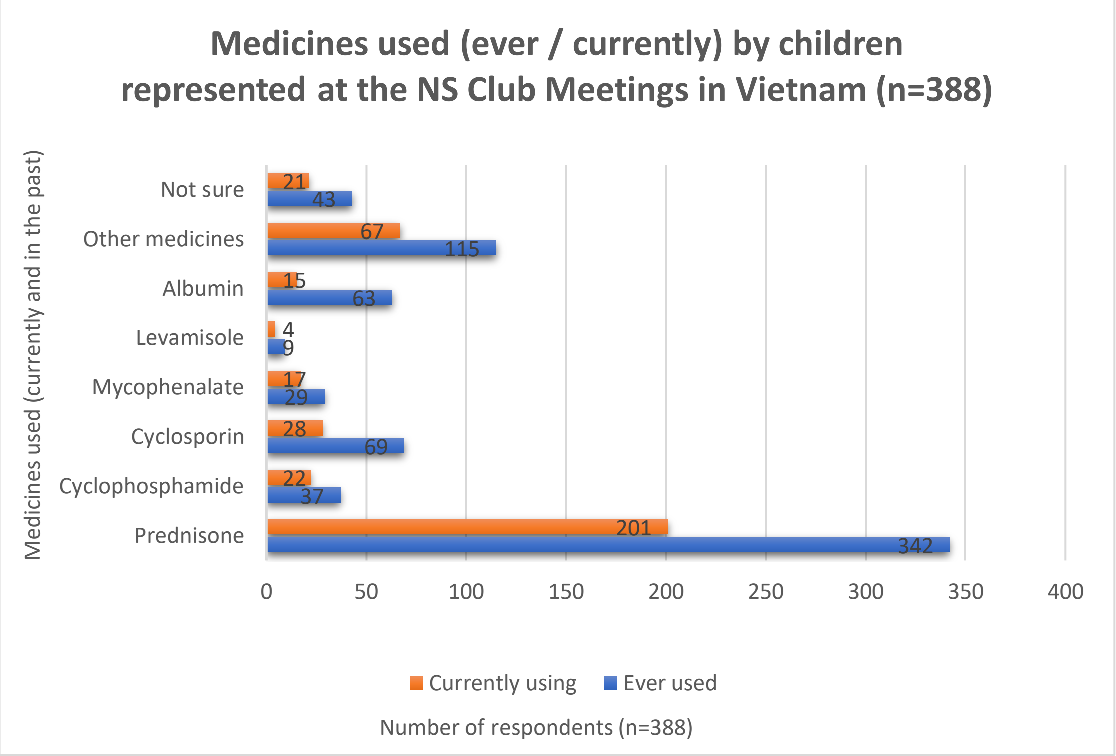


Figure 58 - Medicines used by children represented at the NS Club Meetings in Vietnam (n=388)

Families were asked if they had ever stopped giving their child medications for NS which had been prescribed by their treating doctor or health professionals (response rate 76%;

326/426). Very few families (3%; 9/326) had ever stopped medicines against medical advice, and of these, almost all did so out of desperation:

> *"Yes. We did not have enough money"*
>
> *"Yes, there was nobody to go to the pharmacy"*
>
> *"We stopped taking Neoral for 10 days because of difficulties in finance"*
>
> *"My child stopped taking medicine once because we did not have enough money to buy medicine"*

Wherever possible, families strived to afford treatment:

> "*No (*we have not stopped treatment*) although we have had difficulties with finances*".

Testing of urine at home

Families were asked if they had learned how to test their child's urine for protein using a dipstick (Figure 59), and whether they were doing so (Figure 60). Response rates were 93% (398/426) and 89% (378/426) respectively. There were 153 families (39%; 153/398) who reported they had learned how to test their child's urine with dipsticks. Another 162 families (43%; 162/378) stated they were testing their child's urine at home, but this figure is unlikely to be accurate. Some families interpreted "testing urine at home" to include taking their child to local clinics and hospitals for regular testing. In addition, many families described alternative urine testing methods (for instance, stating "we see if there is foam in the urine"). The frequency of testing was widely variable, with results ranging from "when the child is sick" to "every day", "every week" and "every month".

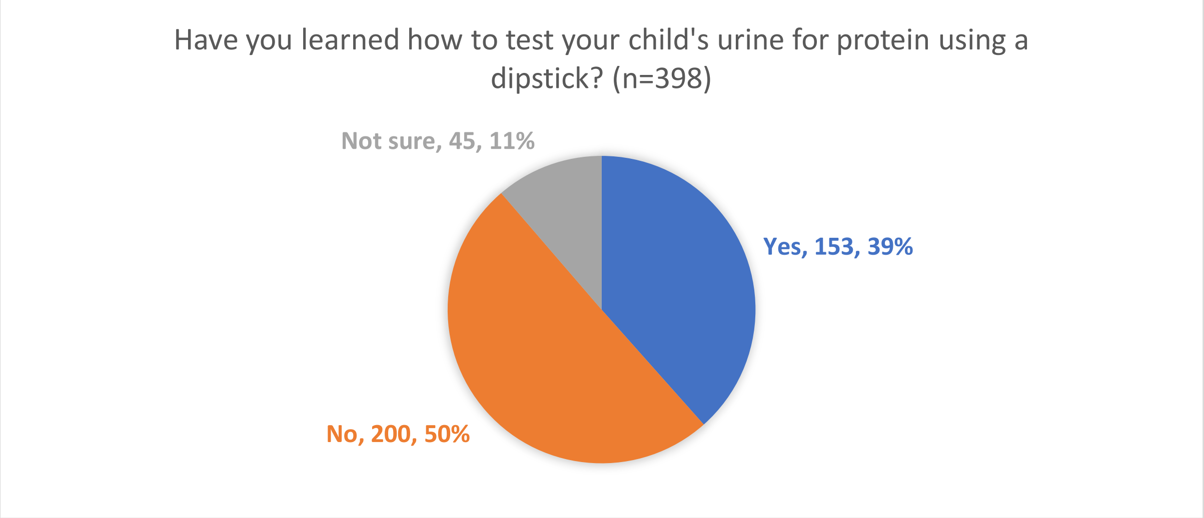


Figure 59 - Have you learned how to test urine at home? (n=398)

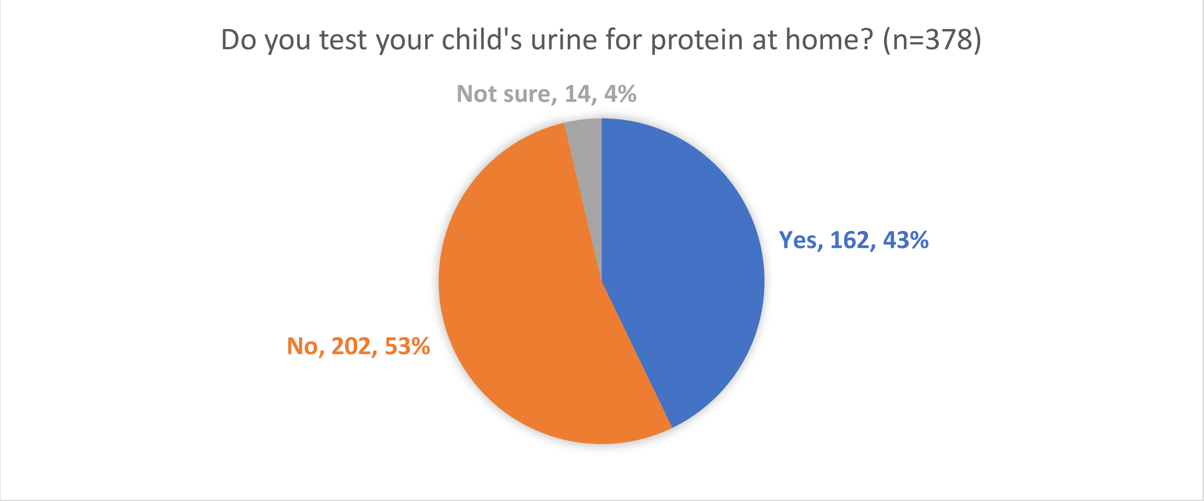


Figure 60 - Do you test your child's urine at home? (n=378)

Traditional medicines use

When asked about use of traditional medicines, 92% (392/426) of families responded. The majority of respondents (92%; 360/392) did not appear to be using traditional medicines. Of those who had ever used traditional medicines (8%; 32/392) only six families (1%) reported currently using them (Figure 61). The amount of money spent on traditional medicines was not insignificant and ranged from 300,000 to 7.8 million over the last six months (average 2 million VND).

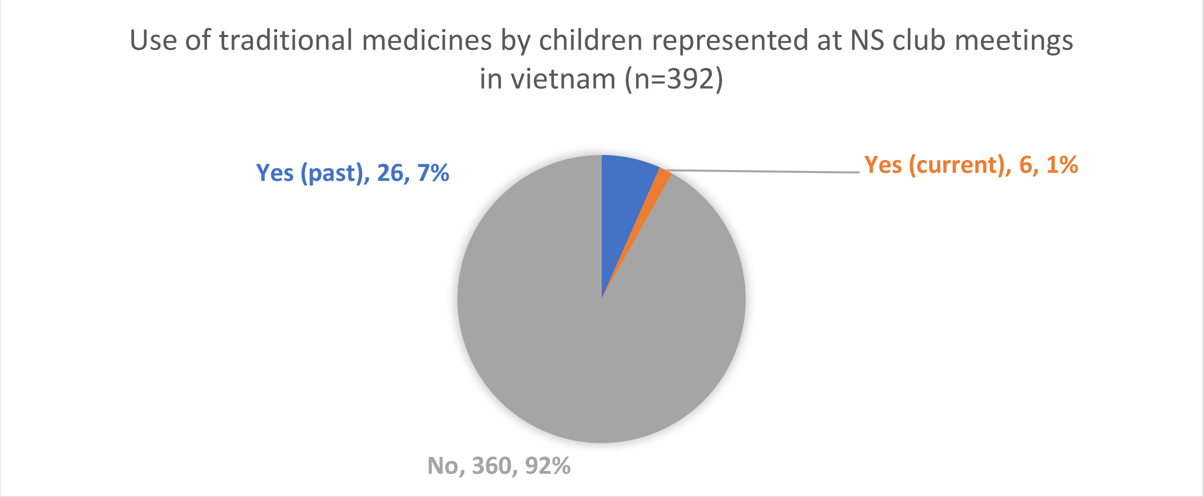


Figure 61 - Traditional medicine use by children represented at the NS Club Meetings in Vietnam (n=392)

Access to quality local health care

Families were asked about access to qualified health professionals in their local area (response rate 90%; 383/426) and how far they had to travel to a health professional they could trust with the management of NS (response rate 69%; 294/426). Families identified significant barriers regarding access and trust. Only 10% (40/383) of families had a health professional in their local area they felt they could trust (Figure 62). The average distance families had to travel to see a health professional they trusted was 39.9 km (median 12 km; mode 10 km; range <1 km to 400 km).

When asked to rank their confidence in local health professionals (Figure 63), families expressed greater confidence in their *own* ability to manage NS (with an average score of 5/10; mode 5, median 5) than the ability of their local health professionals, for whom the average confidence score was 4/10 (median 3; mode 1). A large number of families stated they prefer to attend their tertiary hospital for care because, despite the burden of travel, they felt they could trust the care received.

> "*I always take him to (*name of children's hospital*) when he gets sick*" (parent living 195 km from hospital with travel time of 5 hours with confidence score 1/10 in local practitioners).

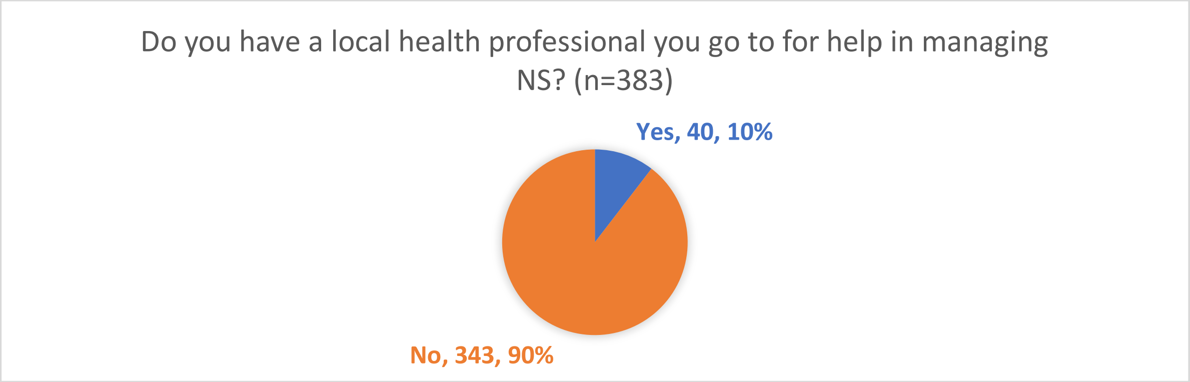


Figure 62 - Access to health professionals in families' local area (n=383)

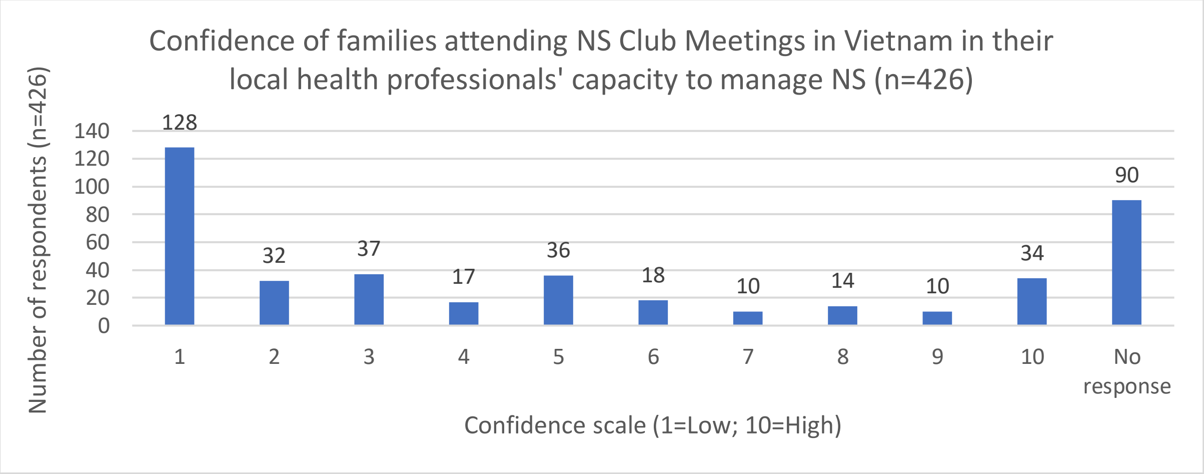


Figure 63 - Confidence in the capacity of local health professionals to manage NS (n=426)

<u>Access to support</u>

Families were asked where they got support to help them cope with NS, and 77% (330/426) families responded. Most respondents (60%; 199/330) stated they did not receive support from anyone. Of those who were able to identify support, the most common sources were health professionals and hospitals; family members, school and community; the government (notably insurance); NS Club meetings and other information sources (such as internet, books).

Knowledge and confidence

Families ranked their confidence level in understanding of NS (response rate 81%; 345/426) (Figure 64) and management of a relapse (response rate 80%; 341/426) (Figure 65). Confidence levels in understanding were low (average score 5/10; median 5; mode 5), as was confidence in relapse management (average score 5; mode 5, median 5).

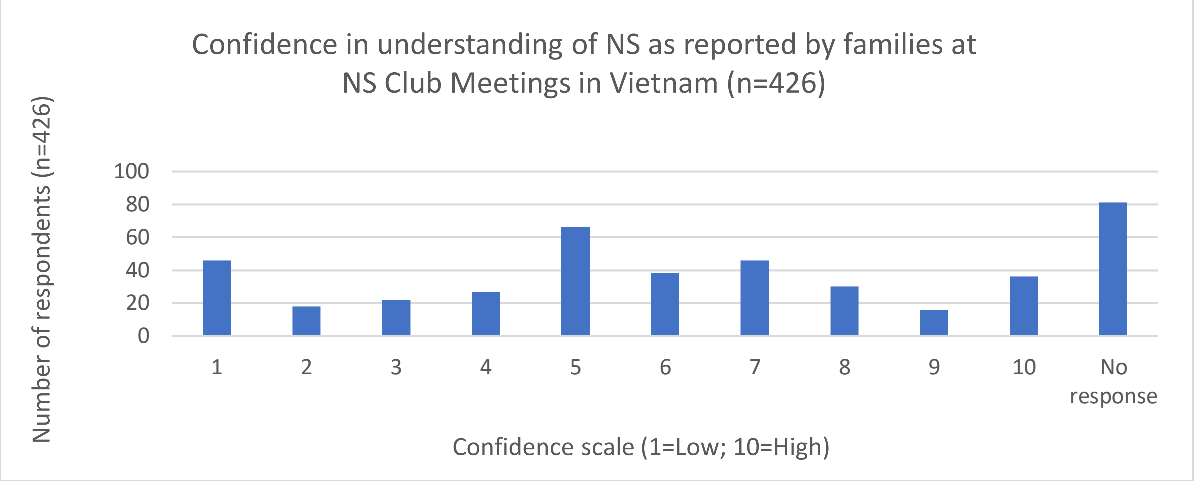


Figure 64 - Parental confidence in their own understanding of NS (n=426)

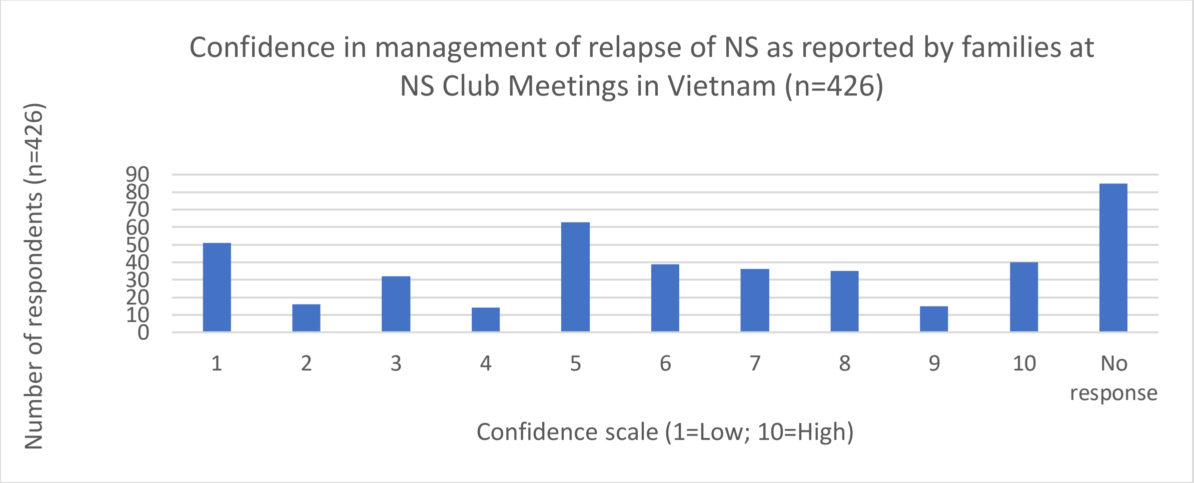


Figure 65 - Parental confidence in their own management of NS (n=426)

Families were asked if they had access to educational resources on NS, and 90% (383/426) responded (Figure 66). Almost half of these families (48%; 185/383) described a range of educational support and material available to them, with the main sources of information being other parents, health professionals, books and the internet. When asked if they would like more information and education on NS, 98% of families (390/397; response rate 93%) indicated they wanted to learn and understand more about NS and how to best care for their child.

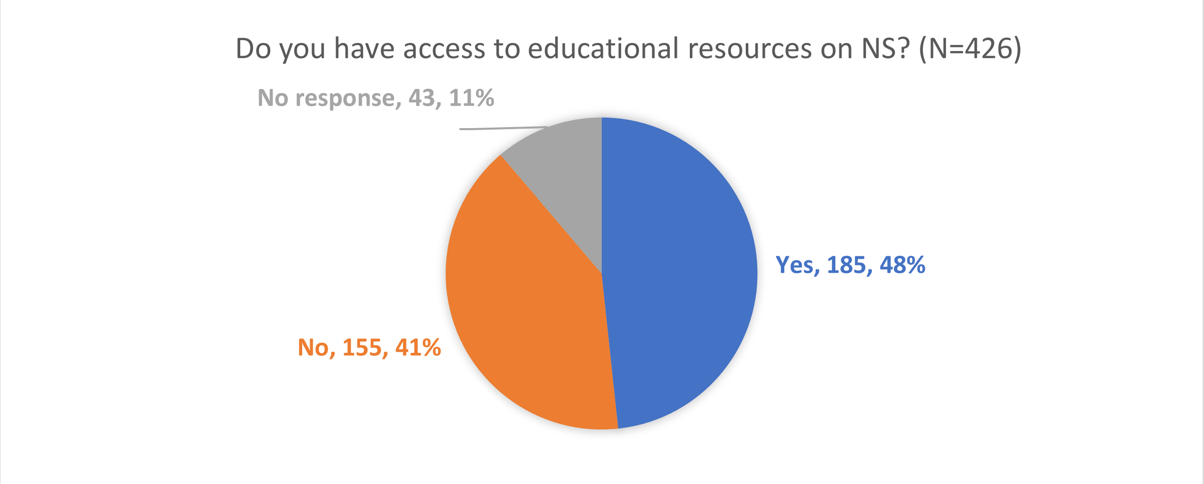


Figure 66 - Parental access to educational resources (n=426)

4.6.2.2.5 Financial impact of NS

There were 7 quantitative and 3 qualitative questions relating to financial burdens associated with NS (Table 16).

Table 16 - Questions relating to the financial impact of NS

Topics	Quantitative questions	Qualitative questions	Survey questions – Financial impact of NS	Response rate
Cost of NS	1		Using last month, total spent on NS?	72%
	1		Using last relapse, total spent on Rx?	72%
	1		% income lost during hospitalisation	72%
	1		Money spent on traditional medx	41%
Financial strain	1		Score for financial strain?	84%
		1	If score is >6 please describe	79%
Health insurance	1		Insurance status	95%
		1	Why no insurance?	88%
	1		If yes, able to reimburse all costs?	82%
		1	If not able to reimburse, why not?	82%
Total	**7**	**3**	**10**	

Financial burdens

Families were asked about the financial strain caused by NS (Figure 67) and to estimate the cost of managing NS (both maintenance treatment and relapses). The response rates to these questions were 84% (358/426) and 72% (306/426) respectively. The majority of families (71%; 255/358) indicated NS caused significant financial strain (scale ≥6). When asked to rank the financial strain that NS placed on families from 1 (low) to 10 (extreme), the average score was 7 (median 8, mode 10). Scores were heavily skewed to the right, with 50% (180/358) of respondents indicating their financial stress scores were 8 or higher and only 13% (50/358) of families ranking financial strain as low (1–3/10).

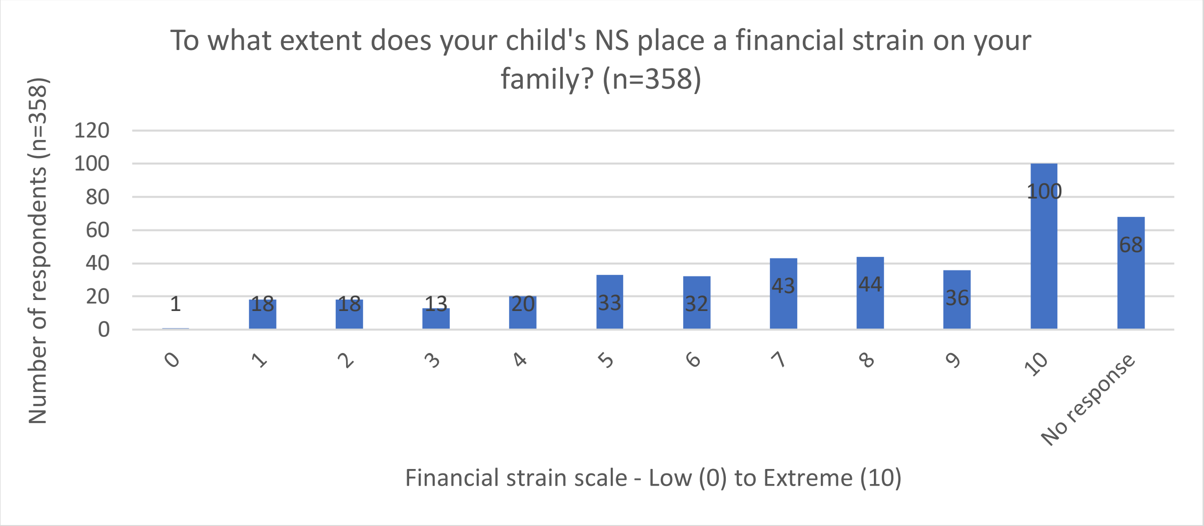


Figure 67 - Financial strain on families attributable to NS (n=358)

Financial strains were extreme when a child with NS had a relapse. Based on the costs associated with caring for their child during the most recent relapse, families estimated the average cost of treatment needed to make their child well again at 4.1 million VND (median 3.0 million VND; mode 1 million VND; range 0 VND–8 million VND). Those who paid nothing stated insurance covered the cost. The percentage of household income estimated to be lost when a child is hospitalised with a relapse averaged 50% (median 50%; mode 50%) but ranged from 0% to 800%.

NS is a chronic health condition and families estimated the monthly cost of maintenance treatment for their child with NS averaged 1.6 million VND (median 1 million VND; mode 1 million VND; range 0–7 million VND).

In terms of accessing medicine and health care, the greatest difficulties identified by families related to transportation (in particular, travel to the hospital pharmacy), lack of information and knowledge, the challenges of providing special dietary requirements and other financial constraints:

> *"We don't have medical knowledge… the hospital is overloaded; it is so difficult to see doctors or get doctors' advice… we don't speak English…"*
>
> *"We live far from the hospital… have difficulties with transportation… we don't have time"*

> *"We don't have enough money for long-term treatment"*

Despite the heavy financial strains, many families shared examples of their deliberate decisions to put their child's health ahead of their families' financial wellbeing:

> *"When my child started having symptoms, we brought him to the local hospital, but his health worsened, so we took him to (tertiary hospital) without a referral letter (and were ineligible for insurance)"*
>
> *"We did not receive insurance because we did not follow insurance policy guidelines. If we went to the hospital which is indicated by insurance, we would have wasted a lot of time"*
>
> *"We did not follow the insurance policy guidelines because we are not satisfied with the local medical services"*

Insurance status

The response rate to the question on health insurance was 95% (406/426). A small minority of families (6%; 26/406) reported having no health insurance of any type for their child with NS. Of the 94% (380/406) of families with health insurance, the majority (87%; 330/380) had one type; 12% of families (45/380) had two types; and 1% of families (5/380) stated they had three types of insurance. The most common combinations of health insurance were insurance for children under 6 years of age and school insurance (67%; 30/45 families); insurance for poor families and school insurance (20%; 9/45); and insurance for poor families and children under 6 years (13%; 6/45). The most common forms of health insurance overall were school health insurance (49%; 212/435); insurance for children under the age of six (40%; 175/435) and insurance for poor families (11%; 48/435) (Figure 68).

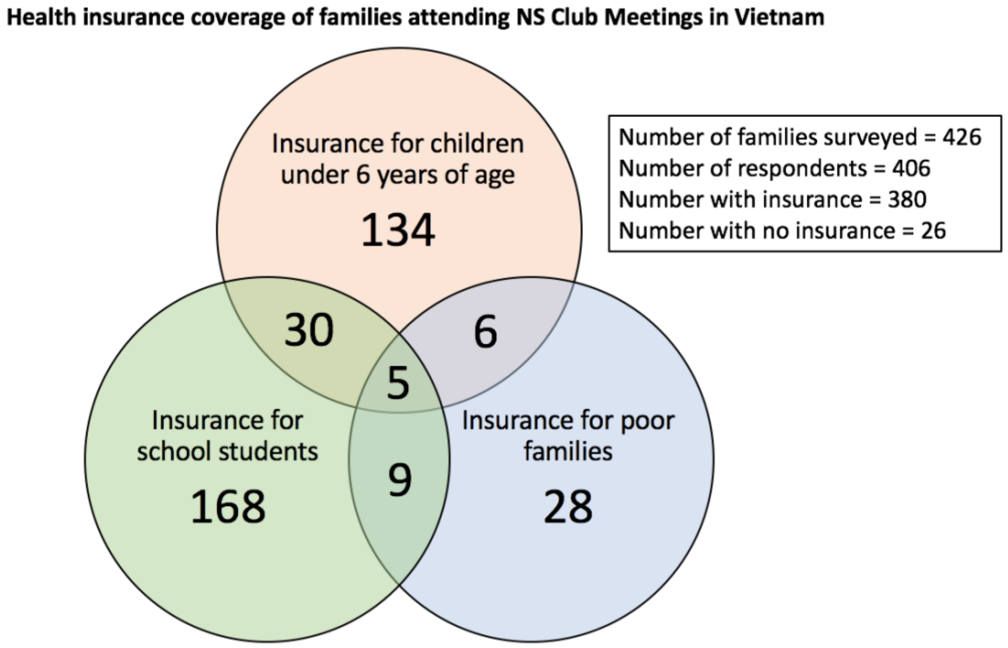


Figure 68 - Health insurance coverage status of families attending NS Club Meetings in Vietnam (n=426)

Families without any health insurance were asked for their reasons for not having insurance, and 88% (23/26) of these families responded. The majority indicated that they did not make a conscious decision not to have insurance, but that getting insurance was “too complicated”, and many indicated their requests for insurance had been declined for failure to comply with insurance policy regulations:

> *“The name on the insurance card did not fit the name on the birth certificate”*
>
> *“There were fewer students wanting to buy insurance in his class, so the teacher did not help them to buy it”*
>
> *“We registered the birth certificate late”*
>
> *“All our expenses were not covered because we did not see local doctors before visiting (Children’s Hospital X).”*
>
> *“But it was really disturbing when we had to go to local hospital to ask for referral letter every month. If the teacher lost the student list, my child would not have any kind of insurance”*
>
> *“The paperwork to get insurance coverage is very complicated”*

Of concern, some families indicated that complying with regulations could have a negative effect on their child’s health:

> *“The procedure to take referral letter of local hospitals is so complicated and wasted a lot of time while we are so busy. Hence we visited (the tertiary hospital) directly”*
>
> *“Because we think we have to spend so much time in the line at the outpatient clinics… that’s why we rather to pay money for treatment costs”*

Families with insurance were asked if it covered 100% of their costs, and 82% of families responded (312/380). Despite the high insurance coverage, only 53% (166/312) of families reported that health insurance covered all their costs. Some families indicated insurance covered 80% of costs, but others found the complex insurance policy requirements were at odds with the needs of families caring for children with chronic health conditions and made eligibility for insurance difficult. This was a major stressor and burden for affected families, particularly where they felt time delays could potentially put their child’s health at risk, and families ultimately had to balance competing considerations around time, costs and health:

> *“Insurance covers 80% if we visited hospital which indicated by insurance. No if we did not follow insurance's instruction”*
>
> *“When my child started having symptoms, we brought him to the local hospital but his health got worse, so we took him to (Children’s Hospital X) without referral letter.”*
>
> *“Getting coverage of insurance wasted a lot of time”*
>
> *“Did not follow insurance policy because we are not satisfied with the local medical services”*
>
> *“We did not use insurance card yet because it would take much time and it’s complicated to get referral letter”*

> *"We volunteer money for his treatment"*
>
> *"My child visited high quality service clinic, we had to pay medications cost and treatment"*

Other examples of policy mismatch included challenges accessing medicine or other care needed for NS that were not covered by insurance, and the experience of families where inpatient costs were covered whilst outpatient costs were not:

> *"My family did not follow insurance's indication because the insurance did not cover medications which my child is taking"*
>
> *"Insurance just covers 80% and we had to pay for lab tests"*

4.6.2.2.6 Burdens and challenges

There were three qualitative questions about the greatest challenges facing families and children and the greatest worries parents have for their children (Table 17).

Table 17 - Questions relating to burdens and challenges associated with NS

Topics	Quantitative questions	Qualitative questions	Survey questions – Burdens and challenges	Response rate
Burdens & challenges		1	Hardest thing about NS for family?	87%
		1	Hardest thing about NS for child?	85%
		1	Greatest worries for your child?	85%
Total	**0**	**3**	**3**	

In discussing the burdens and challenges they faced, families demonstrated remarkable resilience and strength. Key findings are summarised below, and specific details regarding the themes, sub-themes and illustrative quotes that emerged are shown in Appendix 6.

<u>Burden on children</u>

When asked about the hardest thing for their child, families acknowledged many of the children were still too young to express their concerns, but nevertheless shared their own insights into the burden NS placed on their children's bodies, minds and spirits.

The physical burdens of living with NS (such as tiredness, special diet, taking medicines, relapses) were mentioned commonly. However, these physical symptoms were matched almost equally by psychosocial burdens, such as coping with school studies, absence from school, fear of infertility, isolation, stigma and impact of NS on child's self-confidence. Parents' fears for their children's future (including fear of death and desire for a cure) were manifold. Enforced limitations on physical activity, the side effects of medications and parental focus on ensuring their children had a special diet were significant causes of distress for children and their parents, with dietary burdens specifically mentioned by over 30% of survey participants.

Burden on families

When asked about the hardest thing for their family about living with NS, families identified financial stressors as overwhelmingly important, with almost one-third of families mentioning this problem. Families saw a direct link between their financial status and their child's wellbeing, and specifically and repeatedly called out the inextricable links between money, time and health.

The impact of NS on the psychological wellbeing of families was significant, and families communicated their more general feelings of fear, anxiety and worry, and the far-reaching impact these emotions had. Parents expressed an array of worries about their child's health with NS, with key concerns focusing on their child's prognosis and a possible cure. Concerns about renal failure and future ability to get married and have children were also common worries for families.

The burden of preparing special diets that were low in salt were mentioned by a large number of families and in some cases prevented children from attending school and parents from attending work. For a large number of families, the special diet was identified as the greatest burden.

Strengths

Families clearly worked hard to support their children to live their fullest life with NS. Despite the burdens and limited resources available to them, families consistently emphasised their desire to know how to best care for their child and demonstrated their near universal commitment to doing all in their power to act in the best interests of their child, often at significant cost to themselves and their families. Parents participating in the survey shared their vision of always doing what they believed would help their child to their fullest ability, such as providing a special diet, limiting physical activity and travelling long distances to access care. In this regard, families demonstrated remarkable resilience in the face of incredible hardship.

4.6.2.2.7 Recommendations for change

There were 2 quantitative and 5 qualitative questions seeking suggestions and feedback from families on actions needed to improve quality of life and health outcomes for children living with NS in Vietnam, feedback on the NS Club Meetings and how they could be improved in future (if held at all). The survey also invited families to share any questions they may have. Families were diligent in providing recommendations (response rate 77%; 329/426) and 50% of families (211/426) wrote down a question they wanted answered (Table 18).

Table 18 - Questions relating to recommendations for change				
Topics	**Quantitative questions**	**Qualitative questions**	**Survey questions – Recommendations for change**	**Response rate**
Recommendations		1	What should be done?	77%
General feedback / questions		1	Any other questions or comments?	50%
Total	**2**	**5**	**7**	

Recommendations

Families shared a broad range of recommendations with the following five themes emerging from the survey cohort as key priorities for action. More details on sub-themes and illustrative quotes are shown in Appendix 7.

I. Reduce financial burdens
II. Strengthen access to optimal health care
III. Help families learn about NS
IV. Strengthen health and education systems
V. Support the most vulnerable families

I. Reduce financial burdens

For most families, financial burdens, health care and health outcomes were inextricably interconnected. Whilst many hoped for a cure for NS and for more effective medicines with fewer side effects, others sought immediate relief, with changes to the insurance scheme, strengthening of local health care provision and other practical solutions to reduce financial strains of most importance.

Families emphasised the importance of working together to find solutions. Improvements to the insurance scheme, and the need for changes that would allow the health system to support and empower the families of children with chronic and complex health conditions such as NS were emphasised. Opportunities to address a range of specific barriers relating to the existing insurance schemes for families caring for children with chronic conditions were identified.

II. Strengthen access to affordable, quality care

Families wanted more time with doctors, and particularly expressed the desire for improved access to qualified, high quality care in their local area to reduce the need to travel.

III. Help families learn about NS

Families wanted to learn as much as they could about NS and the best ways to manage the condition and prevent relapses. Families had a holistic view of their child's health and were keen for health care to extend beyond just the physical complications of NS. Families appreciated the opportunity NS Club Meetings gave them to connect and learn.

Several families indicated they found the nutritional aspect of NS management (notably following a low salt diet) very stressful, confusing and a significant burden financially and socially. In addition, families emphasised a desire for support to deal with the emotional and psychological burdens of Nephrotic Syndrome that they and their children experienced. Families acknowledged that their education needs were considerable and had innovative suggestions on how health professionals could be supported with this.

IV. Strengthen the capacity of health and education systems to help families cope with NS as a chronic health condition

In addition to the insurance challenges mentioned above, families highlighted a range of other administrative and policy barriers that made it difficult for them to care for their child with a chronic health condition. Families recognised the importance of a range of stakeholders (from government, health and education sectors to media, NGOs and community members more generally) working together at international, national and local levels to help the children, and expressed their hope that the many different partners would work together to improve children’s lives. Opportunities for multisectoral collaboration in terms of supporting children with NS to maintain their education were raised, and indeed families asked other organisations to come together to drive change.

V. Support the most vulnerable families

Some families were clearly living with near-intolerable stress, and families with especial needs were desperate for special help. Families expressed appreciation for the NS Club meeting, particularly because it offered the chance to come together for support, receive new information that help them better care for their children and understand more about NS generally. Of course, all NS families experienced vulnerability to some extent, and requests for a cure were not uncommon.

Additional questions

When offered the chance to ask questions of their own at the end of the survey, about half the families responded, with most focusing on clinical concerns such as how to manage NS, prevent relapses and provide optimal care for their children. Questions about insurance and the chance of a cure for NS also featured. Families expressed gratitude for the opportunity to attend the NS Club meeting and promised to follow their doctors’ instructions. Families clearly cared not just about their own child with NS but for the broader NS Community, and many demonstrated their resilience, gratitude, compassion and commitment to continuing to do their best for their children:

> *“I wanted to say to other families that when your child got NS, you have to work very hard to help them be cure”*
>
> *“I don't have any questions or comments. I will follow doctors' advices completely”*
>
> *“I would like to say thanks to all of you and best regards”*

> *"I wish there will be no children have NS all over the world because NS lasts so long, caused much burdens for families"*
>
> *"I would like to advise other parents not to be depressed and to follow doctors' advice to help their children. My child has had NS from 9/2009 and relapsed many times visited ED of (Hospital X). When my child said "Daddy, save me", I cried and I have tried my best to help my child. These days, he has normal routine as other children do"*

4.7 Part B – Semi-structured interviews with parents / guardians of children living with NS in Vietnam

Aim - Conduct of semi-structured interviews with families of children living with NS at three children's hospitals in Vietnam to better understand the challenges and burdens they face and their key recommendations for change.

4.7.1 Part B Methods

4.7.1.1 Context and purpose

4.7.1.2 Selection of interviewers

4.7.1.3 Selection of participants

4.7.1.4 Materials

4.7.1.5 Data collection

4.7.1.6 Data analysis

4.7.1.7 Ethical considerations

4.7.1.1 Context and purpose of the semi-structured interviews

This component of the research project was designed to facilitate a deeper understanding of the perspectives and felt needs of the community of children and families living with NS in Vietnam at a specific point in time, in particular the challenges and burdens they faced and their recommendations for change. This was to inform future efforts to optimise quality of life for children living with NS in Vietnam.

Semi-structured interviews were selected as the most appropriate data collection method, and a template to guide the interview process was developed for this purpose (see Study One). Interviews were completed between September 2011 and May 2012. A mixed methods approach was taken, with quantitative and qualitative data. During analysis, the researcher took an "open book" approach to the collection and analysis of the qualitative data, remaining open to theories and frameworks that would resonate most strongly with the information to emerge. As a result, no theory was determined at the start of the research project, but rather abductive and retroductive approaches were taken when interpreting the findings [332]. Over time, critical realism emerged as the most relevant overarching framework to guide the researcher, and this social theory informed coding and analysis.

There were two key objectives for conducting interviews with families:

I. Qualitative data collection on the situation, burdens, challenges and recommendations for change. The researcher sought a detailed understanding of the experiences and felt needs of families. Although literacy rates in Vietnam were high (estimated at 94% [54]), it was unreasonable to expect that high quality qualitative data could be collated from the written survey shared during busy Club meetings. Because the subject matter was relatively novel and potentially emotional for families, it was determined face-to-face interviews would offer the best opportunity to seek the qualitative data that would help answer the research questions.

   Pilot testing had indicated an interview spanning approximately one hour would be appropriate, and an interview template with 102 questions covered the following topics with parents (**Error! Reference source not found.**):

   i. Demographics (19 questions)
   ii. Schooling (12)
   iii. Life with NS (28)
   iv. Management of NS (23)
   v. Financial impact of NS (10)
   vi. Burdens and challenges (3)
   vii. Recommendations for change (7)

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	Consultation topics	**Interview questions**		
		Quantitative	**Qualitative**	**Total**
1	**Demographics**	19	0	19
2	**Schooling**	7	5	12
3	**Life with NS**	25	3	28
4	**Management of NS**	16	7	23
5	**Financial impact of NS**	8	2	10
6	**Burdens and challenges**	0	3	3
7	**Recommendations for change**	2	5	7
	Totals	77	25	102
	%	75%	25%	100%

Of the 102 questions in the interview template, 25 (25%) were qualitative and 77 75%) were quantitative. The 25 qualitative questions sought more detailed insights on:

- Schooling (5)
- Life with NS (3)
- Management of NS (7)
- Financial impact of NS (2)
- Burdens and challenges (3)
- Recommendations for change (5)

II. Inform real-time planning for the upcoming NS Club Meetings and other activities of CLAN. The majority of face-to-face interviews were to be conducted ahead of the inaugural NS Club meetings in Vietnam (with the first held in November 2011). It was possible for feedback and recommendations from the interviews regarding actions needed to improve quality of life for children living with NS to inform planning and preparation ahead of the meetings at the hospitals. In the dual role of researcher and President of CLAN the researcher was able to ensure all “easy win” recommendations (i.e. those which offered greatest impact and changeability, and could be achieved within existing resource constraints) were integrated into Club implementation plans. Examples included translation of educational resources into Vietnamese; dissemination of newsletters addressing FAQs and commonly held myths and misunderstandings; selection of lecture topics to address common knowledge gaps; and donation of free dipsticks to promote education around testing of urine for protein at home.

The dual role of the researcher also allowed for insights from the parent interviews to be integrated into CLAN’s strategic framework for action, guiding collaborative action not just at a grassroots level, but also within the global NCD discourse and advocacy arena wherein the researcher was an active participant. For instance, there was opportunity to consider potential synergies between NS and other NCDs of childhood such as CAH, diabetes, autism, childhood cancer and rheumatic heart disease; how potential recommendations emerging from this research project might be relevant more broadly to other NCDs of childhood; and other models of care and alternative frameworks for action in use internationally that might best address the challenges and recommendations shared by families in Vietnam.

Early experience with the pilot interviews (PAR Cycle 3, Study One) had demonstrated most families had little to no understanding of the type of NS their child had, nor any meaningful recollection of medications used to manage NS. For this reason, a specific section (“Section Two”) was added to the interview template and designed for easy completion by treating paediatric nephrologists (with permission from the families) prior to the interviews. The hospital executives generously supported this process and gave permission for staff to assist with completing all 45 interviews (in Study Two), thereby saving the families and interviewers much time.

4.7.1.1 Selection of interviewers

The researcher consulted with the hospital executives of each participating hospital to identify the person/s most appropriate to assist with the interview processes. Interviewers were selected by the hospital executives on the basis of their expertise with NS and child health, English speaking ability, interpersonal skills, reliability and interviewing technique.

Because each hospital necessarily selected different interviewers, the researcher prioritised meeting and working with them at each hospital to ensure a shared understanding of the research project was achieved and systematic, uniform approaches to conducting the interviews put in place, so the processes were as replicable as possible at each participating centre.

In addition to specific measures taken to promote validity and reliability of results emerging from the research project, steps were taken to ensure the safety and wellbeing of all those involved (interviewees and interviewers) at all times. Given the sensitive and emotional nature of the topic, it was important to the researcher that interviewers were willing and qualified to provide appropriate support for families who became upset during the interview but also that they were given ample opportunities to debrief themselves. This informed the rationale for including a survey for interviewers at the end of the interviews (see Part C of Study Two). Interviewers were asked where possible to provide answers to the families' questions at the end of the interview or refer them to the appropriate health professionals as indicated and share with them any educational or other support resources that were available. Fortunately, interviewers reported that families found the interview process almost universally to be a positive experience.

4.7.1.2 Selection of participants

The parent interviews were undertaken at all three children's hospitals, with fifteen families from each hospital selected. From the pilot interviews it was estimated 15 interviews at each centre would be enough to provide a representative sample and achieve saturation of key themes and insights.

All families of children presenting to the participating hospitals for the management of NS (except those children undergoing haemodialysis or peritoneal dialysis) were eligible to participate in the interview process. This inclusive approach to participant selection was thought to offer a strong chance of achieving a representative sample of the broader NS Community, because at the time of the project usual practice in Vietnam meant almost all children diagnosed with NS at peripheral hospitals were transferred to the three tertiary referral hospitals for additional care at the time of diagnosis. As a result, families from distant as well as nearby locations were likely to be available for consultation.

Children receiving haemodialysis or peritoneal dialysis because of end stage renal failure caused by NS were not included. As with the surveys, there was acknowledgment by the researcher that these families represented a unique sub-group of those affected by NS, and this research project was not designed to capture their challenges and burdens, nor was it capable of supporting action that might reasonably be expected to redress inequities or improve health outcomes for this cohort. The researcher would recommend a separate HNA process be undertaken to learn more about the needs of these families. There were no other specific exclusion criteria.

To achieve diversity and representativeness of the broader NS Community, quota sampling was used to determine which families were approached to participate in interviews. The quota criteria were based on epidemiological profiles determined from the literature. This approach offered three key benefits. Firstly, early insights from the pilot interviews in Study One suggested families wanted to participate in interviews, and the challenge would be to limit participation in a fair and equitable way. Secondly, this sampling approach allowed the researcher to ensure the interview cohort was, theoretically at least, as representative of the broader NS community as possible (considering available evidence in the literature) and thereby able to provide a comprehensive understanding of the experiences of all children and families living with NS in Vietnam. Finally, strategic mapping and monitoring of cohort characteristics enabled the researcher to compare and contrast the circumstances of cohorts consulted in the survey with those interviewed and determine if there were significant cohort or sub-cohort differences (for instance, the experiences of children from ethnic minority backgrounds or those children surviving a diagnosis of NS for several years) to identify potential determinants and inform future recommendations for action.

Specific selection criteria are presented in Table 19 and listed below in the sequence used by interviewers to prioritise selection:

1) Attendance at the hospital – families had to be at the hospital already for either inpatient or outpatient care of NS on days randomly selected for interviews. It was not considered ethical to request families to come to the hospital just to assist with the interviews because the financial strains on families were considerable. For this reason, families who were already at the hospital would be amongst those invited to participate.

2) Type of NS – based on known proportions of different types of NS as described in the international literature, children were selected on the basis of the type of NS they had and the time since diagnosis, to achieve an overall mix that matched the known distribution of NS in the literature, and standardised NS severity profiles across all hospitals. Type of NS was the second most important variable because it was potentially the most challenging selection criterion to achieve, and other criteria were reviewed regularly to ensure the desired distribution was obtained. To this end interviewers were asked to ensure that among the 15 families interviewed at each hospital, the following diagnostic ratios were achieved:

    - 30% (5) Steroid sensitive NS (SSNS)
    - 30% (5) Steroid resistant NS (SRNS)
    - 30% (5) newly diagnosed (recognising the majority would have SSNS)
    - 10% (1) End Stage Renal Failure (ESRF - including at least one family of a child receiving haemodialysis)

3) Sex – was important, with the target being approximately 70% males, to reflect international statistics demonstrating NS affects males more than females.

4) Home address – this was to ensure rural families were well represented in line with national statistics showing 70% of families live in rural settings, compared with 30% in urban areas.

Whilst efforts were made to ensure the participants selected for interviews were representative of the broader NS Community, the researcher could not be sure this was achieved in either the survey or interview cohorts, and so a comparison of them was needed to identify any differences that should inform analysis and interpretation of results.

Table 19 - Selection criteria for participants in the parent interviews

Characteristics	Desired
Attending hospital for care	100%
Type of NS	
Steroid Sensitive NS	70%
Steroid Resistant NS	20%
End-Stage Renal Failure	10%
Gender (male: female)	70: 30
Place of residence (rural: urban)	70: 30

4.7.1.4 Materials

The HNA templates developed in Study 1 were used to guide the interviews. Quiet rooms that afforded privacy and engendered a sense of calm for the interviewees were identified and used by the interviewers. Each interview took approximately one hour, and had the potential to stir emotions, so efforts were made to safeguard the wellbeing of participants at all times.

The researcher debriefed the interviewers on a regular basis via Skype and email while the interviews were being conducted, so fresh insights emerging could inform Club planning and critical actions to drive change for families, ensure consistency and accuracy as the research progressed, and offer interviewers an opportunity to debrief regarding any concerns they may have had.

4.7.1.5 Data collection

Interviews were planned to commence in September 2011 following finalisation of the template (Study One), with the hope early insights might identify critical actions that could be taken ahead of and during the November 2011 NS Club Meetings. However, interviewers were not pressured to complete interviews by any set date, and priority was placed on training to ensure all interviews were conducted in a standard way and representative cohorts of participants were selected at all centres. Pilot interviews held at CH1 and NHP (see Study One) meant training and processes were established early in the process in both Hanoi and HCMC, and CH1 interviewers were able to start in October 2011. A face-to-face meeting and training session between the researcher and CH2 interviewer happened in November 2011, after which time interviews commenced there also.

Interviewers were responsible for recording data on the interview templates and each person could choose to do this in English directly or in Vietnamese and translate it into English later (some interviewers chose a mix of both). Photocopies of the templates with translated English results were emailed to the researcher in Australia who entered data into Excel. All interviewers were clear on the approach to interviewing and communicated any suggested improvements to the template for future use as the project progressed.

A cover sheet on the parent interview template prompted all interviewers about process requirements before commencing each interview. These included:

- A routine introduction shared with families at the start of each interview, to include informed consent; information about the research to share with parents, including an information sheet in Vietnamese language; an explanation of confidentiality; and a request for permission to record answers. Whilst early plans had included voice recording, interviewers ultimately decided independently not to use it, primarily in the interests of ensuring families felt as relaxed and safe as possible.

- Acknowledgement that Section 2 had been completed by health professionals (a detailed medical assessment by the treating paediatric nephrologists)

- A reminder to the interviewer to record any questions asked by families on a sheet at the back of the template

- A reminder to the interviewer to complete a section at the back of the template to capture their general impressions and insights from the interview (see Part C of Study 2).

Because each parent interview took about one hour to complete and the complex nature of the selection criteria limited identification of eligible families to interview, the 15 interviews at each hospital took place over about three months. As a result, there was ample opportunity for the researcher to stay updated on progress and liaise with the interviewers on a regular basis between interviews.

4.7.1.6 Data analysis

The data collected using templates in the surveys and interviews were similar and therefore managed in similar ways. Interview files were individually numbered, and this non-identified number was used in Excel spreadsheets and future analysis to identify interview responses. English responses were entered into a spreadsheet (Excel version 16.43, Microsoft 365 subscription), and data for each of the three hospitals were kept separate to facilitate individual analysis (with results reported back to the hospitals in February 2013), but then also collated into one de-identified set of 45 responses that informed the results presented here in Study Two.

Once in the Excel spreadsheet, quantitative responses were analysed and compared to the survey responses to check for unexpected patterns and trends. Because of small sample sizes detailed statistical analyses were not completed. Qualitative data were entered into NVivo and thematically coded with coding discussed with key stakeholders.

4.7.1.7 Ethical considerations

Acknowledgement of the potential to harm families from distress during interviews was considered an especial risk, so specific training and encouragement of all interviewers to optimise awareness of this was a focus. Having health professionals complete interviews worked well, because they had expertise to assist families during difficult discussions. Wherever possible, interviewers were asked not to interview families they cared for on a regular basis in case this had adverse effects on longer term patient–doctor relationships for any reason because of power imbalances.

There was early acknowledgement that families welcomed the chance to be interviewed because it gave them a rare opportunity for personal time with a qualified health professional to talk about NS and their child. Interviewers were asked to make the process beneficial for the families as much as possible, so families might benefit as much as the researcher and interviewers (who were all paid at agreed rates). In particular, interviewers were asked to ensure there was sufficient time for questions at the end of the interviews, and to record the questions asked. If interviewers did not know the answers, they were asked to follow up with someone who did and help the interviewee with their query.

In reporting insights from the interviews, care was taken to ensure no data specific to any particular hospital (beyond the numbers of families interviewed) were included in this report. All hospital level data and reports were shared with executives at each hospital in February 2013.

4.7.2 Part B Results

4.7.2.1 Process insights – Implementation and response

4.7.2.1 Parent interview findings

4.7.2.1.1 Demographics

4.7.2.1.2 Schooling

4.7.2.1.3 Life with NS

4.7.2.1.4 Management of NS

4.7.2.1.5 Financial impact of NS

4.7.2.1.6 Burdens and challenges

4.7.2.1.7 Recommendations for change

4.7.2.1 Process insights – Implementation and response

There were 45 semi-structured interviews completed with families of children living with NS in Vietnam (15 interviews at each participating children's hospitals) between September 2011 and May 2012 (Figure 69). The purpose of the interviews was to collect qualitative data that would inform a deeper understanding of the challenges and burdens facing families living with NS in Vietnam and facilitate translation of recommendations for change into critical action.

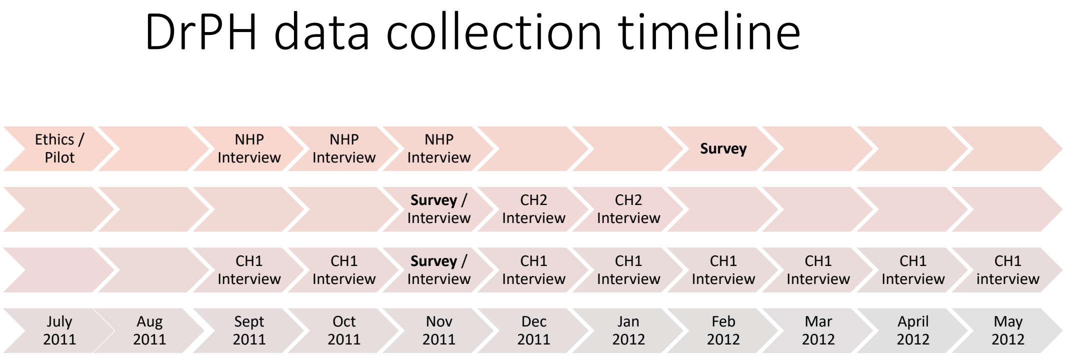


Figure 69 - DrPH data collection timeline

The quota sampling approach to guide participant selection was applied at all hospitals as agreed, and prioritised selection by:

- attendance at the hospital for care
- type of NS
- sex and
- place of residence.

This plan worked well, and the researcher was satisfied with the degree of "fit" achieved across the three hospitals (Table 20).

Table 20 - Selection criteria for participants in Study 2, Part A (Parent interviews; n=45)

Characteristics	Desired parent interview cohort	Achieved parent interview cohort	Parent survey cohort
Attending hospital for care	100%	100%	n/a
Type of NS			
Steroid Sensitive NS	70%	60%	n/a
Steroid Resistant NS	20%	33%	n/a
End-Stage Renal Failure	10%	6%	n/a
Gender (male: female)	70: 30	73: 27	73: 27
Place of residence (rural: urban)	70: 30	64: 36	71: 29

Each interview took approximately one hour to complete. The interviews were conducted by Dr Le Van Hao (at the National Hospital of Pediatrics, Hanoi), Dr Huynh Thi Vu Quynh

(Children's Hospital 2, HCMC) and Dr Thi Thanh Binh (Children's Hospital 1, HCMC). Interviewers were paid at previously agreed hourly rates for their time. It was planned for interviews be conducted in outpatient and inpatient department settings at each hospital to avoid additional burden of travel for families. Names were recorded on survey sheets to assist with completion and tracking (e.g. section on health details that had to be completed by health professionals), and then de-identified (by person and hospital) through the allocation of an individual number to each participant for reference when data were entered into Excel for analysis.

The staggered process of interviewing allowed time and opportunity for the researcher to liaise with interviewers and support the implementation process as needed. The researcher travelled to Vietnam in February, July and November of 2011, and used these visits to meet with, train, support and learn from the interviewers as much as possible. The researcher prioritised face-to-face and Skype meetings with all interviewers both before and after small clusters of interviews (usually 3 to 5 at a time), to allow for de-briefing and sharing of any specific queries, insights, comments or concerns as the interviews progressed.

By the time inaugural NS Club Meetings were held in HCMC in November 2011, all 15 parent interviews had been completed at NHP in Hanoi by LVH with support where needed from local paediatric nephrologists, and several interviews conducted at both CH1 and CH2 in HCMC. Rapid communication of findings to the researcher in Australia (with completed templates emailed to the researcher in English) meant the interviews informed preparations for the Club Meetings as planned and guided critical action to redress inequities. All 45 interviews were completed by May 2012.

Anecdotally, as was the experience of the researcher during the pilot interviews, very few families refused to participate when invited to be interviewed. Families were almost universally keen and enthusiastic to have the opportunity to speak in some detail with a health professional about their child's health. During the pilot phase families queued outside the interview room on the hospital ward wanting an opportunity to participate, and interviewers reported similar responses to the main interviews. All families responded to all questions asked during the interview process. Where possible, analysis included all 45 responses, although in some instances additional responses were captured by the interviewers from less structured discussions, and these data points were included where relevant. All results were collated and presented as coming from a single cohort (representing the NS Community of Vietnam), and insights relating to individual hospitals are not provided in the thesis.

4.7.2.2 Parent interview findings

Fifteen semi-structured parent interviews were completed at each participating hospital (45 in total). Interviews were conducted in the outpatient (51%; 23/45) and inpatient (49%; 22/45) departments of the hospitals.

4.7.2.2.1 Demographics

The interview template included 19 quantitative questions to support demographic profiling and facilitate comparisons between the interview cohort and the survey cohort.

Age

The average age of patients represented in the interview cohort was 7.2 years (range 2–15 years; mode 5 years; median 7 years).

Sex

The majority of children represented in the interviews were male (73%; 33/45) with 27% (12/45) identified as female.

Ethnicity

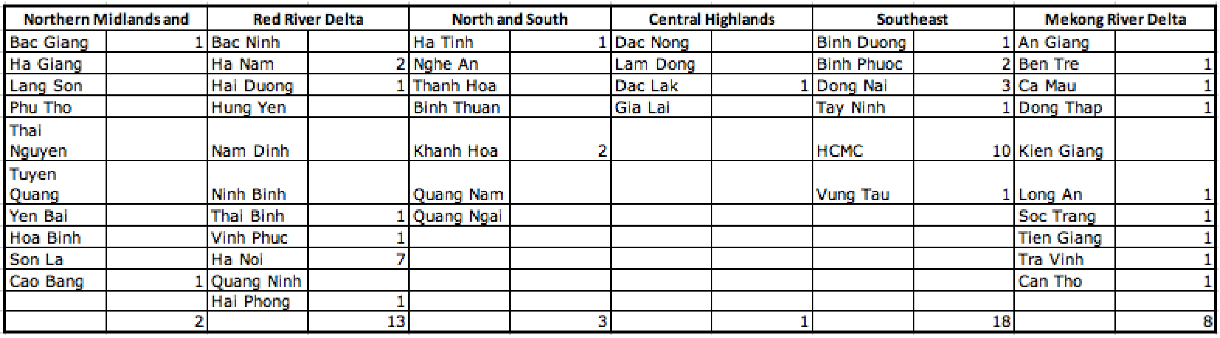
One family chose not to respond to this question. Almost all (98%; 43/44) identified as belonging to the Kinh ethnic group, which represents 85% of the Vietnamese population. One family (2%; 1/44) identified as a member of the Nung ethnic minority group.

Home life

Table 21 shows the provinces where families who were interviewed resided. There were 40% (25/62) of all provinces represented, and similar to the survey cohort, Ho Chi Minh City (22%; 10/45) and Hanoi (16%; 7/45) were the provinces with the greatest numbers of families represented.

The majority of families (64%; 29/45) were from rural areas, with 36% (16/45) from urban areas. The most common methods of transportation were bus (long distances) and motorbike (for closer distances). The average distance families lived from the hospital was 127 km (range 1–700 km; mode 70 km; median 70 km), and the majority of families (64%; 29/45) lived within 100 km of the hospital. The average travel time to the hospital was 3.7 hours (range 0.2–31.5 hours; mode 2.5 hours; median 2 hours) and 38% of families (17/45) lived within an hour’s travel of the hospital.

Table 21 - Representation of interview participants by province (n=45)



Northern Midlands and		Red River Delta		North and South		Central Highlands		Southeast		Mekong River Delta	
Bac Giang	1	Bac Ninh		Ha Tinh	1	Dac Nong		Binh Duong	1	An Giang	
Ha Giang		Ha Nam	2	Nghe An		Lam Dong		Binh Phuoc	2	Ben Tre	1
Lang Son		Hai Duong	1	Thanh Hoa		Dac Lak	1	Dong Nai	3	Ca Mau	1
Phu Tho		Hung Yen		Binh Thuan		Gia Lai		Tay Ninh	1	Dong Thap	1
Thai Nguyen		Nam Dinh		Khanh Hoa	2			HCMC	10	Kien Giang	
Tuyen Quang		Ninh Binh		Quang Nam				Vung Tau	1	Long An	1
Yen Bai		Thai Binh	1	Quang Ngai						Soc Trang	1
Hoa Binh		Vinh Phuc	1							Tien Giang	1
Son La		Ha Noi	7							Tra Vinh	1
Cao Bang	1	Quang Ninh								Can Tho	1
		Hai Phong	1								
	2		13		3		1		18		8

Household size

The average number of people living in households was 4.8 persons (mode 4 persons; median 4 persons). Many families had extended family living with them rather than large numbers of children. Only one family had more than three children, whereas 47% (21/45) of families had at least one grandparent living with them. Mothers were most usually the primary carers (30/45; 67% of cases) with extended family members providing additional strong support. Fathers were primarily the breadwinners (39/45; 87% of families).

There were five single parent families represented in the interviews (5.45; 11% of all families). One child lived in a household without a mother ("she left") and 4 children lived in households without a father (two fathers had died). No families could recall a family history of NS.

Internet access

Internet access was not widespread. The majority of families at all centres had never accessed the internet (67%); almost one-quarter had access to the internet at home (24%) and the others accessed the internet in their village (7%) or on their phones (2%).

Parental income and education

The average monthly income was 5.2 million VND (range 0.5 to 30 million VND; median 4 million VND; mode 1 million VND). It was difficult to elicit quality information about financial status, although estimates of the money spent to manage the most recent relapse indicated the average cost was around 8 million VND (ranging from 120,000 VND for management as an outpatient to 80 million VND). Key expenses included medicines, travel and special diet.

The education level of families is shown in Figure 70. Parent education levels were generally evenly matched:

- 51% (23/45) of families had a mother with an education level of Year 9 or above
- 49% (22/45) of families had a father with an education level of Year 9 or above
- 31% (14/45) of families had a father with an education at Year 12 or above
- 24% (11/45) of families had a mother with an education at Year 12 or above

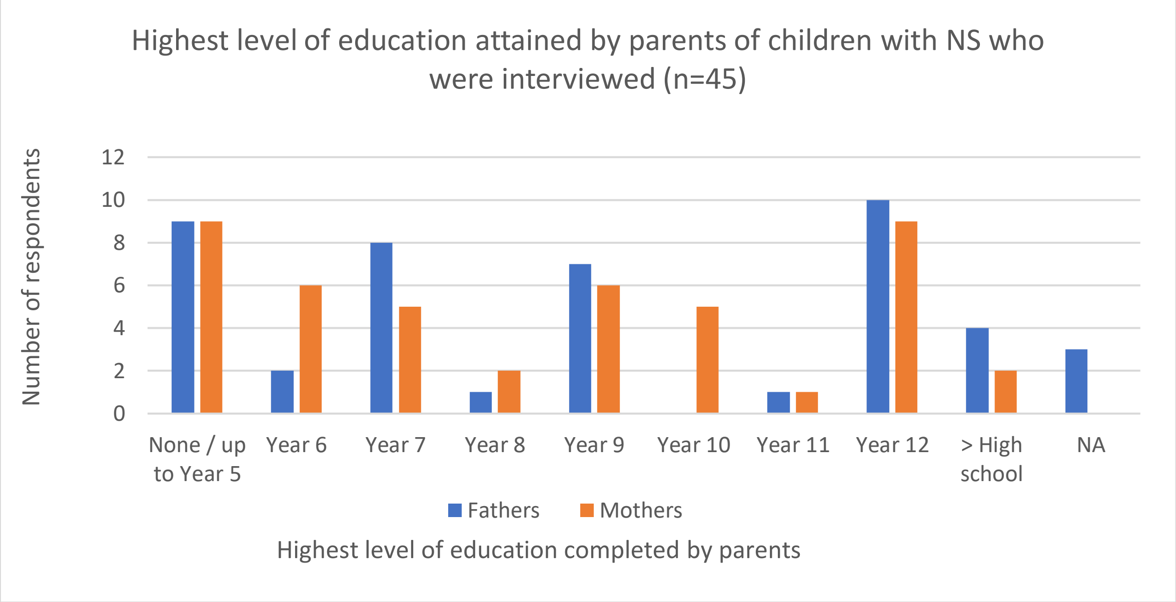


Figure 70 - Highest level of education attained by participants in the parent interviews (n=45)

4.7.2.2.2 Schooling

The interview template included 7 quantitative and 5 qualitative questions about schooling.

<u>Attendance at school</u>

The majority of children (87%; 39/45) were aged four years and older and eligible to attend school. Of the 39 school-aged children represented, 13% (5/39) were not attending school. The most usual reasons given for not attending school were because the child was sick and to allow for the special low-salt diet the child:

> *"Diagnosed one year ago and decided not to send him because of fear he would see other kids eating food that he can't eat (salty foods) which would be a problem"*

The school-aged children who were attending school were missing significant schooling hours. The average days lost in the last 12 months was 41 days per child (median 14 days; range from 0 days for the children newly diagnosed with NS to a maximum of an estimated 180 days lost for one year). Several children (including one aged 7 years) had never been to school because of their NS.

Reasons for missing school related in the main to management of relapses and routine scheduled follow-ups at the hospital's outpatient department, although two families also reported the reasons related to the child's need for a "*special diet*".

> *"Every day we take him home before lunch time because of his special diet. Special diet has very little salt or fish sauce. If it was not for NS he would go all day."*

Many families reported limitations placed on their children's attendance at school related to the need to maintain a special diet, reduce physical activity (to avoid injury and relapses) and other cautionary steps to maintain good health (such as avoiding the sun and adverse weather). When asked about academic concerns for their children there were mixed responses. A number of families communicated confidence in their children's ability to stay on track with their studies:

> *"We worry about our child studying; left behind due to being away"*
>
> *"No - child always has good results at school"*
>
> *"We are afraid our child will not be able to follow school activities and subjects (but this has not actually happened)"*

For children with severe and relapsing NS, families held grave fears that their child might slip so far behind they would be prevented from continuing their education (as per education policy stipulations). Fear of children not catching up with schooling after absences was stressful for families on many levels, not least because it then affected access to health insurance for children attending school, with subsequent financial consequences:

> *"Yes, she has skipped one school year already and I am afraid it may happen again and she may not be able to follow the school program"*

When asked about their child's social progress at school, most families were positive and indicated their children were active and engaging well. Other families, however, identified concerns that could potentially be addressed with targeted education, support and reassurance:

> *"Has less friends (others are afraid of NS being transmitted); child can rarely join her friends in outdoor activities because they cause oedema"*
>
> *"Yes she saw her friends playing but she couldn't join; she feels inferior"*
>
> *"We asked teacher not to let him do too much physical activity or play outside too much. Doctor reminds us of this – to reduce physical activity because when you take medicines they can lead to bone breakages"*
>
> *"Yes she was Cushingoid and fat – she was teased by her friends"*
>
> *"She doesn't participate in social activities because I am afraid of the influence on her health"*

4.7.2.2.3 Life with NS

There were 23 quantitative and 4 qualitative questions designed to obtain a picture of the families' lives with NS and their interactions with the health system generally.

Type of NS

A spectrum of NS was reflected in the interviews, most particularly by the data provided by health professionals completing "Section Two" of the template, which was dedicated to capturing health details. As per the selection criteria, most children (60%; 27/45) had steroid sensitive NS; the remaining children (40%; 18/45) had a mix of steroid dependent and steroid resistant NS (15 children) and end stage renal failure (two of the children with SRNS had gone on to renal failure / end-stage renal failure, and one child was undergoing haemodialysis).

Diagnosis of NS

Children represented in the interviews were, for the most part, recently diagnosed with NS: 22% (10/45) of children had been diagnosed within the last six months (since June 2011); the others had been diagnosed up to two years ago (median time at diagnosis was 1 year ago; range 0 to 11 years ago). Interestingly, similar to the survey cohort, when asked to score their child's health out of 10 (1 being very poor health and 10 being very good health), families rated their child's current health (6.5/10; mode 8; median 7) as very similar to their health 12 months ago (score 7.4/10; mode 7; median 7).

Families readily shared stories about their experiences when their children were first diagnosed with NS, and had no trouble recalling these stories in some detail even after many years in some cases. The diagnosis of NS in a child was almost uniformly stressful, with many families experiencing misdiagnosis at peripheral hospitals before finding their way to a correct diagnosis at the tertiary referral centres. Financial burdens, fear of the unknown, fear of death and uncertainties around prognosis and prospects for their children (particularly their chances of marrying and conceiving children) were key stressors for families at diagnosis:

> *"We were scared of death; the long time needed to treat; and the need for a big amount of money"*
>
> *"The most stressful thing is we don't know what NS is. Why did it happen so fast? Does that mean his kidneys are failing? Does he have to have a kidney transplant? We didn't have any information about NS. But the doctors have explained to us and we feel better now."*
>
> *"Yes, we are scared that if she has kidney failure there will be no cure (kidney dialysis treatment, kidney transplant). For a poor family like us there is no way we can cover that."*
>
> *"We worry that if he can't be cured, it would badly affect his health. Moreover, money is the problem; countryside family like us can't afford such long-term treatment like this."*
>
> *"We worried our child can't have child when married"*

Information about NS received from health staff and other families was a major source of relief and support for families at this time. Observed periods of wellness between infrequent relapses were another reassurance to some, whilst for others psychological and financial support from family and community were a great comfort:

> *"Asking other parents and doctors; having right understanding; calming down; his grandfather was also a traditional doctor and relieved the unpleasant feeling"*
>
> *"The doctors support us; we have good medicine. We followed the prescription here for 10 months and she was losing her hair and had rashes. We stopped the medicine and switched to traditional medicines and this is the consequence (swelling recurs). We saw lots of other children with the same problem and shared our thoughts with their parents. This made us feel less shocked"*
>
> *"I have the knowledge about the NS syndrome from the Internet, from health staff. They said that my son can be cured."*

When asked how the stress of diagnosis could be reduced, the overwhelming majority of families emphasised the importance and power of information in allaying fears and anxieties. Health staff, booklets, club meetings and other families were the main sources identified as helpful. For the truly poor and impoverished families, and for the parents of children with severe illness, very little was seen to be currently relieving them of their stress and distress. Urgent requests for financial support for the poor and relief from their overwhelming fear of losing their children to poverty were strong messages from these families.

> *"The doctors and other NS patients' families provided and shared NS information with us. That made us feel a lot better."*
>
> *"Accessing financial support from provincial TV station… reading books"*
>
> *"We are countryside people so we live very close to each other. But they can only support me emotionally. Nobody can help me with money because we are all farmers, we are all so poor and have to rely on our rice field. Every time he goes to the hospital, people can only give him a couple thousand VND. In 1999 we have a second baby, so our life was much harder since then."*
>
> *"We all have to try our best. Relatives and families do ask and show their concern about her, but it's just the family. We hope the doctors can cure her. The government should have some concerns about this because it's long-term treatment - especially about the insurance system. We can't cure it in a day or two"*

Expressed needs - attendance at hospital

Information around previous admissions and hospital presentations showed that almost all children (except the newly diagnosed) had been admitted several times to hospital for NS (average number of admissions 5.7; mode 2; median 2). This number did not reflect total relapses (average 5.7; mode 4; median 4 – where maximum estimate of "11" given where families stated "many times"), so it would appear many relapses were being managed at home and through outpatients.

Admission stays were generally quite long (average 17 days; median 14; mode 14) with a range from two days to 360 days. Likewise, visits to hospital OPDs for management of NS were numerous, and the average at two of the three hospitals was 24 visits (the third hospital was not included in this analysis because the numbers did not appear to be accurate and perhaps represented a misunderstanding with the question). Admissions and presentations to hospital (either as inpatients, outpatients or to emergency) for children with NS for other conditions did not seem to be high.

4.7.2.2.4 Management of NS

Immunisation profile

Almost all children were up to date with the national vaccination program (87%; 39/45) but there was significant opportunity to use additional vaccinations as a strategy for reducing infection risks in this vulnerable community. Only 47% (21/45) of children had received any vaccines (such as varicella, Haemophilus influenza, pneumococcal, hepatitis B) in addition to the national schedule, and only 16% (7/45) of these children appeared to have received more than one type of additional vaccine.

Medicines used

The most common medicines used (in addition to / instead of prednisone) were:

- Cyclosporin (ever used by 38%; 17/45 children)

- Cyclophosphamide (ever used by 29%; 13/45 children)
- Mycophenalate (ever used by 16%; 7/45 children)

Use of traditional medicines

Families had clearly understood the importance of not using traditional medicines. Of the 29% (13/45) of families reporting to have ever used traditional medicines, only one was still using them (and these were given free by their pagoda). All other families had stopped the use of traditional medicines in the last 6 months. This was particularly important given the cost of traditional medicines was high. Families reported spending around 2 million VND per month (15 million for 6 months' treatment), the equivalent of approximately 50% of the average family income in this cohort.

Cessation of treatment

Only two families had ever ceased medication against medical advice, and in both cases, families believed they were acting in the best interests of their child:

> *"Because she lost her hair and had rashes so we decided to stop using the medicine by ourselves"*
>
> *"When treated at (hospital) the oedema was recurrent so we tried another way with traditional medicines"*

Confidence in understanding / ability to explain

Families indicated they did not feel confident in their understanding of NS (average score 5.8; mode 5; median 6). There were seven families who indicated they had attended NS Club meetings before the interview (average confidence score of 6.4; mode 6; median 6), and these families all stated that much of their information was coming from the booklets and education sessions received at the Club Meetings:

> *"From the doctor, textbook, the nephrotic syndrome club, the booklet from CLAN. From the internet"*

Families' lack of confidence in their knowledge of NS was undoubtedly justifiable. When asked to describe what NS was and why their child developed swelling, families were almost universally at a loss to explain anything accurately. Families who had attended the NS Club meetings generally fared better, but even they still required further education and support before their descriptions could be described as accurate in any way.

> *"Renal damage; when eating so much protein and salt and physical activities - leads to oedema"*
>
> *"He couldn't urinate, got swelling, hands and legs become bigger, then could not walk. That is all."*
>
> *"This was caused by allergy. The kidneys can't properly operate so it filters all kind of body waste."*

> *"At first, virus is there and it circulates in the body and may affect your heart and lungs and may destroy all nutrition you ate in last few days"*
>
> *"When he feels tired / he has pain in his joint / at night he can't sleep / he asks for massage / then I'd predict something will happen / then fever and then fast relapse. At school he cries and the eyes get swollen and he gains weight and we see doctor and they send us to the hospital. With prednisolone treatment the side effect is swelling of the joint, so to cure this you need to take other medicines."*

Parental perceptions of prognosis were generally negative and pessimistic. From fears of death, to renal failure, dialysis, transplantation and failure to have children and marry, the fears of families presented a heavy burden.

> *"Can cause kidney failure and infertility in the future."*
>
> *"Her life will be hard, I don't even know if she can be cured. If she has kidney failure it would be the end of her."*
>
> *"Advised by doctors that with medication may reduce immune system of child; and may get married but not have children; other normal kids can go in the sunshine and wind and rain and cope with weather but this child can't; may need to drop school (we saw a child like this once - now on dialysis)"*
>
> *"If not treated, the patients will have renal failure, malnutrition. Treatment with prednisolone can cause some complications: hypertension, diabetes and osteoporosis"*

Families reported a slightly higher confidence in their ability to manage relapses (6/10; mode 5; median 5), however it is worth noting that their proposed actions were limited to "*take the child to the hospital*" or similar.

Access to educational resources

Access to educational material was limited. Again, the seven families who had attended Club meetings reported having access to information, but it was clear most families were starved for information and 100% of families interviewed stated they would like more information on NS. Many families also indicated a willingness to help other families in the same situation if they could.

> *"Yes - especially when I leave the hospital and doctors are not around, so I need to learn how to take care of her"*
>
> *"Yes. The more I get information about NS, the more I can help my child and also other families"*

Testing of urine at home

Less than half (21/45; 47%) of families interviewed were using urine dipsticks, although those who had attended NS Club meetings were more likely to do so. None reported self-initiating treatment with steroids at the start of a relapse:

> *"First thought is to go to hospital - only the hospital can help and tell us what to do next"*
>
> *"Take him to the doctor immediately, we can't act and give him medicine by ourselves"*
>
> *"Use warm water bags on abdomen helps with urination; reduce water intake; salt restrict meals; see Dr if not recovering"*

Confidence in local health professionals

Families living near a tertiary hospital all reported 10/10 confidence in the care received. By contrast, almost all families living outside the immediate vicinity of the tertiary centres expressed extremely low confidence in local health professionals (3.5/10) and shared their preference to travel for care they could trust (average time about 1 hour; range 20 minutes to 10 hours) rather than risk repeating previous bad experiences of missed diagnoses and perceptions of botched care:

> *"I do not trust local HCPs very much. My boy got this a year ago and they provided conflicting information - they said we should rely on traditional medicines"*
>
> *"The doctor in local town is just for common things - fever, cough, cold"*

4.7.2.2.5 Financial impact of NS

There were 8 quantitative and 2 qualitative questions relating to the financial burdens that NS places on families. Families routinely identified financial burdens as one of the most difficult challenges they faced and rated financial stress at an average score of 6.8/10 (mode 10; median 7):

> *"When our child is sick we worry more; we have to spend more; we have to stay home more to care for him and this means we have less income coming in."*
>
> *"We are so poor. Finance is the biggest problem. We love our son but we can't do anything because we don't have enough money (crying)."*

A common predicament for families was the accrual of enormous debt. Whilst families could often borrow money from relatives, they also appreciated this solution was short-term and short-lived. There is also the appreciation that accrued debts must ultimately be repaid. The stress and guilt associated with borrowing money from extended family weighed heavily on families.

> *"I can expect help the first time, but not the second".*

> *"Psychological difficulties and burden; lucky to get all psychological support from extended family; everyone agreed no matter how much it costs we will pay what we need as a family; both of us are farmers so it's tough for us; parents also farmers with no insurance and no pension; mother works hard outside in the field and hard to provide all care for child"*

Cost of treatment

Families reported losing between 0 and 100% of their monthly income when their child's NS relapsed. The average cost of managing a relapse was estimated at 2 million VND (mode 800,000 VND; median 1.12 million VND; range 120,000 VND to 30 million VND) and the average cost of maintenance therapy each month was 1 million VND (median 800,000 VND; range 100,000 to 5 million VND). The greatest expenditures each month were for medicines, investigations, travel, special diet and lost income (caring for their child).

Insurance status

Almost all families had health insurance coverage for their children (93%; 42/45). Most families had government insurance for those children going to school (49%; 22/45) and children under the age of six (36%; 16/45). There were four families (9%) with insurance for poor families.

Of the 7% (3/45) families with no insurance, the reasons given most usually related to bureaucratic barriers to access.

> *"We have to pay 100% of costs because we went to (tertiary hospital) on Saturday (and therefore were not able to complete all the paperwork within 24 hours) because we were frantic with worry (example of insurance not covering costs because parents did not follow protocol)"*
>
> *"Didn't follow protocol so we pay 100% of costs"*
>
> *"We don't have marriage certificate yet, so he doesn't have birth certificate so he cannot get the insurance"*

Families who had actively decided not to get health insurance expressed deep regret:

> *"It's a bad time for us and we are at a great disadvantage. It's very hard for us. We feel anxious and tired. Our child used to be healthy so we felt we didn't need insurance."*

For families with health insurance, incomplete coverage of costs was a common theme, with 48% (20/42) of families indicating not all costs were covered. Families often expressed their frustration with the complexities of the health insurance systems, and their frequent inability to meet set requirements, leaving them unable to receive financial support.

> *"Local hospital agreed to care for our child but we have no trust in them so we went to (name of tertiary hospital). But in the insurance card they specify the hospital you must go to and his card covers him for (name of provincial hospital). The local*

> *hospital sent him there last time but we came to (name of tertiary hospital) instead so now the insurance doesn't cover us."*
>
> *"The insurance only pays 30% because I go straight to (tertiary hospital) instead of going to (the local) hospital"*
> *"All our expenses were not covered because we did not see local doctors before visiting (name of tertiary hospital)."*
>
> *"We didn't follow protocol so we pay 100% of costs"*
> *"I pay 30% of costs because I go straight to (name of tertiary hospital) instead of to (name of provincial hospital)"*

When families were able to meet insurance policy requirements, it was usual for 80% of costs to be covered. Non-medical expenses were not covered:

> *"80% of the expenses are covered because we go to the right hospital. We have to pay for the other 20% and medicine expenses."*
>
> *"Health care fee and medication cost covered but expenditure for transportation and daily meals is not"*

While families were aware that insurance for the poor would cover many costs, there was acknowledgement of processes that need to be followed to apply for this type of insurance, and families uniformly appeared committed to working hard and doing all they could to avoid losing everything they owned so as to avoid fitting the criteria for this particular insurance bracket. For families relying on insurance for children at school, there was the additional stress of even greater financial hardship if their child was so ill that they could not attend school.

4.7.2.2.6 Burdens and challenges

There were three qualitative questions seeking insights relating to burdens and challenges experienced by the children and families living with NS. Thematic analysis identified five key issues relating to the experience of living with NS in Vietnam (sub-themes and illustrative quotes are shown in Table 22):

I. Financial burdens
II. The nature of NS as a chronic condition of childhood
III. Myths and misconceptions compounding an underlying lack of knowledge about NS and how to manage it
IV. The psychological impact of NS on children and families
V. The social consequences of NS on children and families

<u>Financial burdens</u>

Undoubtedly, financial burdens were mentioned most frequently by families and were identified as the major burden, and the inherent link between time, money and health was clearly communicated. Loss of income, debt and increased expenditure were all key concerns, and there were several interconnected vicious cycles that played out for many families. For instance, families taking time off work to care for their children experienced consequent loss of income, which meant they could not afford treatment costs. Likewise, families from poorer, remote areas who did not trust local health professionals had to travel to tertiary centres, but long travel times meant these vulnerable families lost opportunities to earn an income while at the same time they had to pay for unforeseen travel, accommodation and treatment costs. Similarly, insurance often did not help at the time it was needed most. When children were sick, they could not attend school and were not eligible for school insurance. When children were seriously ill families who could not trust local doctors travelled to tertiary centres without completing required paperwork and did not qualify for much needed health insurance coverage.

Insurance was a great help to families who could access it, but those who could not were exposed to financial risk. For the poorest families, insurance for poor families provided a safety net. Families relied heavily on their extended families for support to cope with NS but were mindful such support was finite.

The nature of NS as a chronic condition of childhood

As a chronic health condition NS drains the resources of families over prolonged periods of time and in a multitude of ways, financially, emotionally, physically, spiritually and socially. For many families, even early resilience can be worn down over time, and without sustained support families and children gradually succumb. In this way chronicity is an especial burden in and of itself. The mismatch of NS as a chronic health condition with a health system that is structured to deal with acute conditions most effectively makes the burden harder to bear. There were only tiny glimpses into some families' journey to utter bankruptcy, misery, devastation and death, and in this regard the researcher respectfully acknowledges families of children who had already passed and were not consulted as a consequence. Indeed, some families were noted to have gone very quiet during parts of the interviews and were unable even to voice their greatest concerns and burdens.

Myths and misconceptions compounding an underlying lack of knowledge about NS and how to manage it

Some unexpected burdens for families that were very prominent were those about maintaining a “special diet” (low in salt) for their children and preventing children from playing games and being physically active because of fears their child would fracture their bones. Such myths and misconceptions were responsible for significant burdens on families and children alike (e.g. families paid large amounts of money for special diets; children were kept home from school to have special diets; children were not allowed to play with friends for fear of fracturing bones), and evidence-based facts on these matters were quickly identified as urgent messages to share with families at the NS Club meetings in November 2011 and February 2012.

Psychological impact

Fear of the unknown, fear of death, fear of renal failure, fears for the future and pessimistic thoughts regarding their child's prognosis and future marital and reproductive prospects were common themes. There was an attempt to quantify the psychological status of families, with questions relating to the impact of NS on their feelings:

- depressed (average score 5.4/10; mode 5; median 5)
- anxious (average score 6.9/10; mode 10; median 7)
- sad (average score 6.4; mode 10; median 7)
- worried (average score 6.8; mode 10; median 7)
- hopeful (average score 7.6; mode 8; median 8)
- optimistic (average score 6.4; mode 8; median 7)
- in control (average score 6; mode 8; median 6.5).

Interestingly however, when asked to rank the physical health of their children with NS, parental assessments were relatively positive (from a score of 7.4/10 one year ago to 6.5/10 currently) and these quantitative assessments did not seem to reflect accurately the pervasively high levels of anxiety and fear expressed in other parts of the interview.

Social impact

When asked about the greatest hardships for children living with NS, families focused on social impact. Restrictions placed on children by the special diet, inability to play, missing school, and limited outdoor play because of perceived fears of the sun and weather had negative effects on children. Attendance at school appeared to have a positive influence on health and wellbeing, not just for children but also for parents particularly in terms of reducing financial burdens.

Culturally, a child's future marital prospects were very important to families. Older children had worries about their future, particularly related to missed schooling and employment opportunities. Those who had maintained strong links with friends seemed to be doing better psychologically, and encouragingly, when asked to scale the impact of their child's emotional and physical health concerns on social activities over the last four weeks, few families indicated the impact was more than moderate (Figure 71).

Family support

Families played a vital role in helping parents cope with the demands of caring for their children who are living with NS. Financial support (either through direct loans or helping parents go to work to earn an income) was considered especially helpful, although there was acknowledgement that such support was necessarily limited and not sustainable. Grandparents played a major role in caring for children, and clearly needed to be considered when planning education and training sessions.

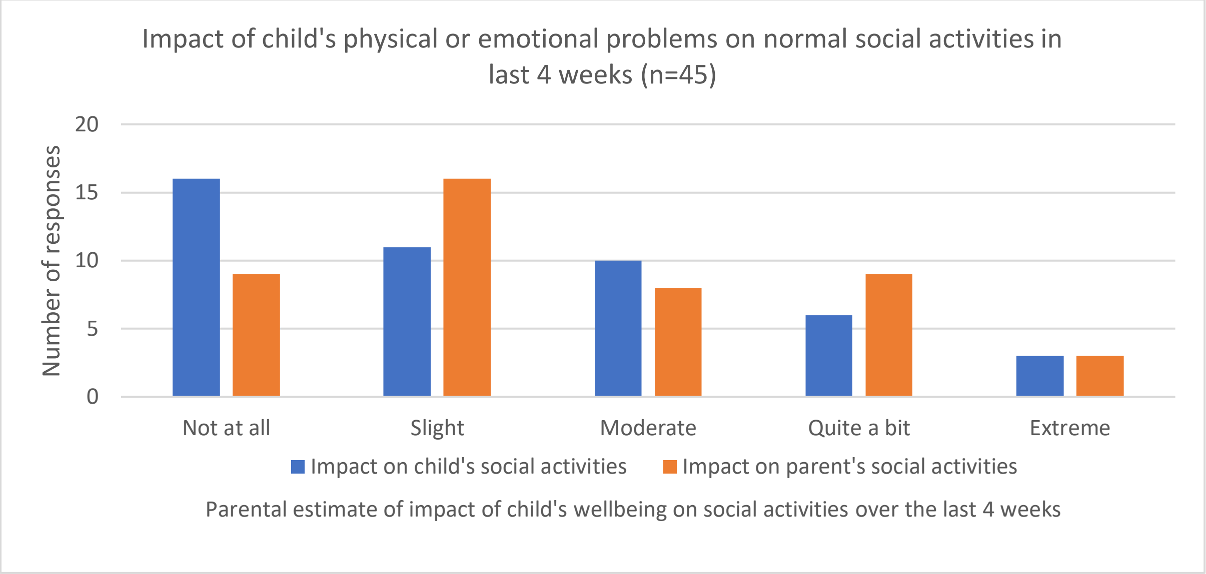


Figure 71 - Impact of child's physical / emotional wellbeing on normal social activities in the last 4 weeks (n=45)

Table 22 - Challenges, burdens and strengths as shared in the parent interviews		
Theme	**Sub-themes**	**Illustrative quotes**
Financial burdens	Financial burdens	*"Finance - so much money spent on treatment since getting disease; reduced money for income when admitted"* *"We are so poor. Finance is the biggest problem. We love our son but we can't do anything because we don't have enough money (cry)."* *"I am very worried about the finances because only her father goes to work, I am a housewife. My home is a bit far from the hospital - it is inconvenient to travel."* *"Sometimes we have to borrow money because of not being able to afford costs; have borrowed money and have got a loan of 10 million but could not pay back loan so we are living in grandmother's home"*
	The inter-connectedness of time, money and health	*"I have to off my work when I take him to the hospital."* *"We have business at home. If my son has to be admitted to the hospital, I have to take care him, it influences my business"* *"Mum has been off work so there has been less income"*
	The capacity of health insurance to impact on financial wellbeing (can be positive and negative)	*"This time he has to stay for only 3 days. We did not get covered by the insurance and had to pay 3.5million VND"* *"We receive donations 100-200,000 VND at a time, but not so much; having insurance for poor family is a support"* *"We have no difficulty affording treatment – it's paid for by insurance for poor family"* *"She has insurance for children less than 6 years old. That helps us very much"*
	The importance of support from families (financial, emotional, practical)	*"The financial strain. We have a big extended family. My parents have 8 kids including myself. On husband's side there are 9. So it's a big army. Whole army mobilised to give money to come here because we are poor."* *"Finances are hard - we can borrow money from family but we need to return it to them in future."* *"We are lucky to get all psychological support from extended family; everyone agreed no matter how much it costs we will pay what we need as a family. Both of us are farmers so it's tough for us (parents also farmers with no insurance and no pension; Mum works hard outside in the field and hard to provide all care for child)"* *"My aunt helps with the money, she still pays the salary although I am not work, (She works for her aunt). Another aunt help me take care my child"* *"I (Mum) go to work and grandparents care for him and they know less than me about NS"*
The nature of NS as a chronic condition of childhood	Physical burden of NS on children's bodies	*"At relapse time could not totally play with his friends; prevents from physical activities"*
	The chronicity of NS	*"Whole extended family aware of finances. I can expect help this first time only. I can't expect help a second time. Buying health insurance is an option in 2 months before she goes to school. We encourage her that she can get back to normal but it will take some weeks."* *"Financially. We are tired because it's a long-lasting, chronic disease."* *"We don't really understand… but people say the longer he can stay alive the better. We don't know. We are scared because we don't have money and we don't want to lose our child. We love him more and more but we can't do anything. (Cry loudly)"*

Table 22 - Challenges, burdens and strengths as shared in the parent interviews

Theme	Sub-themes	Illustrative quotes
		"His mother left. Family is financially struggling (his grandfather is disabled). Our future is very uncertain." *"His disease is recurrent all the time. He always cries and sticks to his grandmother. He doesn't like his father. His father beats him when he cries. There was one time the doctor had criticized his father of the red mark of a hand on his face."* *"(Paused, did not want to say about this)"*
Myths and misconceptions compounding an underlying lack of knowledge about NS and its management	The adverse impact of myths and non-evidence based approaches	*"Special diet must be strictly followed and can last for many years, not by days or weeks"* *"We are very worried. Schooling is not as good as other kids his age so may fall back - social impact is negative. He wants to play a lot but not supposed to do activities; he tires sometimes but more usually we have hard time keeping him still when he wants to play."* *"Special diet must be strictly followed and can last for many years, not by days or weeks"*
The psychological impact of NS on children and families	Emotional and psychological burdens – particularly fears and anxieties	*"I have to stop my work when I take him to the hospital. I usually have pessimistic thoughts about my son"* *"I'm afraid of being able to afford treatment fee"* *"Always anxious and worried due to child's NS"* *"This is a difficult time for our spirit and mental health"* *"I'm afraid of relapsing"* *"Worry about renal failure"*
The social impact of NS on children and families	Societal and stigmas and cultural considerations	*"In long term I worry if she will get older and be able to have her own family. It's harder to get a husband because people in our community know and so she is less wanted by males. Are there problems having children?"* *"She is not good looking (because of short height) which might influence her career / ability to have babies in the future"* *"Worried about how she looks: fat and short… will it influence her social life?"*
	Positive impact of continued schooling (including due to insurance links)	*"The child answered - I feel bored but not when going to school"* *"Not enough time to take care of her son especially when admitted; financial issue was previously significant but not now due to school insurance"* *"He's sad because he can't go to school. His dream is to go to school, get a job and help his poor parents. He also sad because he doesn't get to see his friends and also worries about his future."*

4.7.2.2.7 Recommendations for change

The parent interviews offered preliminary insights into families' recommendations for change and, where possible, informed early planning for the inaugural NS Club meetings in Vietnam (see Chapter Five). There were 4 quantitative and 3 qualitative questions to facilitate consultation on these matters.

Families had six main recommendations, and the themes were similar to those emerging from the parent surveys (Table 23):

1. Provide relief from financial burdens
2. Optimise medical management
3. Help families learn more about NS and
4. Provide support for the most vulnerable families
5. Strengthen health systems to support families
6. NS specific innovations

Relief from financial burdens

Requests for support to overcome the financial strains and stresses that families experience were very common. A charitable foundation was suggested by several families. The inability of the existing insurance system to protect families from financial devastation and poverty were significant, with the current system offering little flexibility for families dealing with life-threatening complications. Many families were forced repeatedly to sabotage their chances of securing insurance monies to secure and prioritise the safety and wellbeing of their child, for example families had to to consult local health practitioners with little knowledge of NS so that their insurance covered treatment when they arrived at the tertiary centres. Families were keen to escape the cycle of debt and poverty, and indeed, helping children attend school would also help the next generation escape future cycles of poverty.

Help families learn more about NS

Requests for more information about NS and the appropriate management of NS were overwhelmingly the most frequent items to emerge from the long interviews. Families much appreciated meeting one another ("*experience sharing between families*") and speaking with health professionals, but they genuinely craved more detailed information. The benefits of meeting caring doctors willing to spend time with families to explain NS to them cannot be over-estimated. Without this support families feel very isolated and lost. Language is a significant barrier because families' inability to speak English limits access to quality, safe and reliable information online.

Families are desperate to upskill themselves and learn the best ways to care for their children. Families overwhelmingly indicated NS Club meetings would be helpful (average score 9.5/10) and 96% (43/45) of families indicated they would attend if possible. The two families who said they were "unsure" of attendance indicated distance was the sole barrier. Families requested a focus on knowledge and information sharing and provision of financial support for families as their key recommendations for the Club Meeting preparations to focus on.

Optimise medical management

Many families recommended improving the knowledge and training of local health professionals. Families suggested that building the capacity of local health professionals to provide safe, good quality and timely care for children living with NS would improve the situation for many families in a sustainable and scalable fashion. Another suggestion was the establishment of a “hotline” that could be available 24/7 to families with questions about how to manage NS. The inevitable recommendation that doctors and researchers find a cure for NS came from many families.

Provide support for the most vulnerable families

Families acknowledged specific sub-groups of the NS Community were experiencing greater difficulties than others, and they requested specific actions to support families living in the most vulnerable circumstances. Examples included the very poor, those living furthest from tertiary centres, and those children with the most severe forms of NS. Often families self-identified as amongst the most vulnerable, but on the whole there was compassion and consideration for others they had seen who were worse off than themselves.

Strengthen the health system to support families

Families highlighted systemic issues within society they believed were stopping children diagnosed with NS from achieving their full potential. Bureaucratic red tape associated with insurance was the most common complaint, but specific opportunities to drive real change, such as investing in local health systems, improving access to affordable care and helping families have more time with qualified health professionals were noted also.

Targeted NS specific innovations

Families acknowledged the value of support groups as a means of networking, informing and supporting parents, and requested support to establish strong platforms.

Table 23 - Key recommendations emerging from the parent interviews		
Theme	**Subtheme**	**Illustrative quotes**
Reduce financial burdens	Provide financial support / income opportunities	“Help treatment and help with finances (if any)”
		“Financial support for patients and families”
		“Families need to work hard to earn income to afford treatment.”
		“There should be support programs for child with special condition, long-term treatment (medicine, finance support)”
	Connect families with systems that offer financial support	“There should be support programs for child with special condition, long-term treatment (medicine, finance support)”
		“Support from the sponsors”
		“Charity foundation for poor families.”
		“Organisations and the community should support the child financially so they can have a better life.”
	Strengthen the existing insurance system	“The insurance pays at least 50% the cost of immunosuppression drugs.”
		“100% insurance policy for children.”
		“Insurance is the best thing we can expect from the government. If classified as a "poor" family it can help, but I am not classified as poor in my commune”
		“Insurance for all parents, especially poor families; supporting in study at school”
		“Insurance for all kids; For insurance like in my case - why can't I use my insurance here at (the tertiary hospital)? That’s my only point - can't hope for more.”
Optimise medical management (bio-medical-social)	Provide the necessary medicines	“Provide good health services and medications”
		“There should be support programs for child with special condition, long-term treatment (medicine, finance support)”
	Find a cure	“They should have one special medicine to cure this. There are too many kinds of medicine right now. Do they have one special / powerful medicine?”
		“The doctors require better medicines that can cure the illness.”
		“Have a good drug to treatment the NS for no relapse”
		“Having a better way to treat the child with corticosteroid resistant NS”
	Help families stay more hopeful	“See doctors and do the treatment well and always hope for good result”
		“You need to be supported to be able to get over this. Cured or not, it's just fate, we can just try to do our best.”
		“Parents must persist; try your best to overcome this difficult time. You should not be too worried because this can be cured, medicine can help, and we should be optimistic.”
	Increase access to qualified health professionals	“Need have very good and enthusiastic doctors”
		“Provision of information of current state of children in more regular (predictable) way so families are less anxious.”
		“Having a hotline (directly consult for the families when they need)”
Help families learn about NS	Provide information on NS	“Try your best to give your child a healthy, low sodium and carbohydrate diet. Avoid moving around and have medicine on time.”
		“Need provided for education and information to cure their child”
		“Provide sufficient information for parents, especially about periodic re-examination.”
		“Communicate system to support the patients. Need to be educated about the disease”

Table 23 - Key recommendations emerging from the parent interviews

Theme	Subtheme	Illustrative quotes
		“Give more information about NS”
		“Internet (I will access the internet in near future); NS club meeting; Teaching how to cook for children with NS”
	Empower parents to care for children at home	“Knowledge about NS (for taking care at home)”
		“Teach children how to take good care of their hygiene and their parents how to take care of their children to prevent NS.”
		“Need provided for education and information to cure their child”
		“Provide sufficient information for parents, especially about periodic re-examination.”
Special support for the most vulnerable families	Especial support for poor families	“Provide more information about NS, prevention, policies for poor families. There are too many people who are so poor, for me this hasn't affected me much.”
		“Financial support for poor patients”
		“For poor families like me, support from charities is very much needed (100% insurance and other support). The question is how to get the money to save the children. Don't fall into debt. Many families here have sold everything they have but still don't get enough money.”
		“The communities should support, there are many poor families who couldn't take care of their child.”
		“Insurance for all parents, especially poor families; supporting in study at school”
		“Financial support for poor patients”
		“For poor families like me, support from charities is very much needed (100% insurance and other support). The question is how to get the money to save the children. Don't fall into debt. Many families here have sold everything they have but still don't get enough money.”
		“The communities should support, there are many poor families who couldn't take care of their child.”
		“Charity foundation for poor families.”
		“If classified as a "poor" family it can help, but I am not classified as poor in my commune”
	Remote locale	“Help poor families from the countryside”
	Severe illness	“There should be support programs for child with special condition, long-term treatment (medicine, finance support)”
Strengthen the health system	Improve access	“Provide good health services and medications”
		“Help patients access tertiary services to have exact diagnosis and good treatment”
		“Provide sufficient information for parents, especially about periodic re-examination. Don't make my mistake (loss to follow-up) - it would be so regrettable.”
		“Improve diagnosis and treatment standards at all levels of the health system; no trust in provincial system (especially lower levels)”
		“Get them to hospital early”
		“Improve diagnosis and treatment standards at all levels of the health system; no trust in provincial system (especially lower levels)”
	Strengthen local health systems	“Improvement the local health system; Organizing the meeting clubs”
		“Improve diagnosis and treatment standards at all levels of the health system; no trust in provincial system (especially lower levels); provision of

Table 23 - Key recommendations emerging from the parent interviews		
Theme	**Subtheme**	**Illustrative quotes**
		information of current state of children in more regular (predictable) way so families are less anxious."
	Support from government and hospitals	"I don't know what to say. I hope for the help from the government and the hospital. I couldn't do anything to help him, only doctors can help him."
		"Communicate system to support the patients. Need to be educated about the disease"
	Increase time with doctors	"Doctor comes in everyday and says what happened but has no time to explain why / what is the reason; doctors keep saying "be patient" but I don't want general details - I want more details."
		"Providing information and knowledge about NS; going to see Dr for advice"
		"I don't know what to say… I couldn't do anything to help him, only doctors can help him."
Focus on NS specific activities to support families	Support programs and organisations for NS	"There should be support programs for child with special condition, long-term treatment (medicine, finance support)"
		"Experience sharing between families"
		"Need to encourage, console; support in spirit"
	Help families to share experiences	"Establishing the families club which help the new family and each other; support from health staffs, give more Information; Improvement the local health system"
		"Provide enough knowledge; share experiences together between parents"

4.8 Part C - Survey of health care professionals on their completion of Part B (interviews with parents / guardians of children living with NS in Vietnam)

Aim - Conduct of a written survey of health professionals immediately after their interviews with families of children living with NS in Vietnam to better understand novel insights regarding the challenges and burdens families face, and their recommendations for change.

4.8.1 Part C Methods

4.8.1.1 Context and purpose

4.8.1.2 Selection of interviewers (participants)

4.8.1.3 Materials

4.8.1.4 Data collection

4.8.1.5 Data analysis

4.8.1.6 Ethical considerations

4.8.1.1 Context and purpose

Spending an hour with families gave interviewers deep insights into the challenges and burdens families of children living with NS face and their recommendations for change. Interviewers were asked to share these insights at the end of each interview using a survey template provided. There were 4 qualitative questions (Table 24), and they related to:

- General reflections
- Insights emerging from the interview
- Challenges and burdens
- Recommendations for change

The purpose of these survey questions was to:

- Maximise insights the research project could glean from the time health professionals had spent with the families
- Minimise additional burdens on other health professionals by doing more interviews given how time poor everyone was (acknowledging interviewers were being paid for their time) and
- Offer interviewers a chance to debrief after a potentially emotional experience

Table 24 - Topics included in the health professional survey templates (for completion following parent interviews; n=3)

Consultation topics		HCP Survey		
		Quantitative	Qualitative	Total
1	**Demographics**	0	0	0
2	**Schooling**	0	0	0
3	**Life with NS**	0	0	0
4	**Management of NS**	0	0	0
5	**Financial impact of NS**	0	0	0
6	**Burdens and challenges**	0	2	2
7	**Recommendations for change**	0	2	2
	Totals	0	4	4
	%	0%	100%	100%

4.8.1.2 Selection of interviewers

Interviewers were selected by hospital executives at each hospital on the basis of:

- Their expertise (paediatric nephrology / psychology / research)
- English skills
- Desire for research experience and learning
- Interest in the topic
- Willingness to be involved
- Other (that researcher may not have been aware of)

4.8.1.3 Materials

Printed templates were provided to the interviewers by the researcher. Face-to-face and Skype training and debriefing sessions were conducted throughout the period of time (usually some months) until interviews were completed.

4.8.1.4 Data collection

Four brief written questions captured responses at the end of interviews. Interviewers shared the data with the researcher with other data collected from interviews. Responses were de-identified on entry into Excel.

4.8.1.5 Data analysis

All qualitative responses were collated and coded by the researcher.

4.8.1.6 Ethical considerations

Responses were de-identified to protect interviewers. Opportunities were also made for interviewers to debrief in person and over Skype. Interviewers needed to know their input / thoughts were valued and sought. This survey facilitated a systematic approach to consulting the interviewers, to ensure all insights were captured. Responses were separated from interview participant data so that all insights were completely de-identified.

4.8.2 Part C Results

4.8.2.1 Process insights – Implementation and responses

4.8.2.2 Findings from the health professional surveys

4.8.2.2.1 General reflections on the interview

4.8.2.2.2 Key impressions of the family (challenges and burdens)

4.8.2.2.3 Recommendations for change

4.8.2.2.4 Other comments

4.8.2.1 Process insights – Implementation and responses

The approach of asking health professionals to complete the survey template on completion of each interview worked well. There was 100% completion by all interviewers, and although there was strong saturation of data overall, a small number of fresh insights emerged.

4.8.2.2 Findings from the surveys

4.8.2.2.1 General reflections on the interview

The interviewers used this question to summarise their experience of the interview. In some cases, the notes reflected the emotional states of the interviewees, providing richer context and insights than the recorded responses alone had gleaned:

> *“Shares a lot of emotion”*
>
> *“He talked little but seems very emotional and had to keep himself together, not crying, especially when talking about his son’s health and future. Sometimes he stopped for a minute or two before he can continue answering in a difficult way. To answer scaled questions he used his fingers to point instead of saying words”*
>
> *“Self confident interviewee”*
>
> *“She says very little but her face showed her worries. Her answers are genuine and reliable”*
>
> *“The mother looked calm, but tired and sad”*

> *“Good interview. The parents really want to share their feeling, their experiences with their child’s disease. We felt comfortable when we talked with each other”.*

> *“She cried very much through the interview. I think this is the chance for her to share her emotion, her opinions”.*

In other cases, the interviewer offered unique insights that could strengthen approaches to future HNAs:

> *“Parents sometimes could not understand questions and needed the interviewer to give more explanation”*

> *“Poorly educated interviewees; sometimes didn’t understand question and needed more explanation”*

Sometimes the debriefing notes provided rich insights into the complexity of the situations some children were living in, and highlighted specific aspects of the interview that may otherwise have been overlooked:

> *“His 63 year old grandmother must take care of him because his mother has left. His father has a new wife and he is hot-tempered so it’s basically just the two of the grandparents taking care of each other. His grandfather is disabled”*

> *“His parents are not with him at the moment; the grandmother always takes care of him when admitted”*

> *“The family is not very poor but from a rural area. Both parents are minority ethnic people. Have managed pretty well until now, but seemed to be worries a lot. They said they will try their best, but it will depend on the child’s fate”*

4.8.2.2.2 Key impressions of the family (challenges and burdens)

There was strong alignment of insights regarding challenges and burdens with those shared by families, but the stories, descriptions and analysis shared by the interviewers often provided additional depth and richness.

The need for families to have access to quality information and educational resources to help them learn more about NS was clearly conveyed.

> *“(She has) no proper knowledge about NS; lacks ability to find information herself about NS”*

> *“Even though he has access to the internet he hadn’t enough information about NS and had some misunderstandings about NS”*

> *“She is a good responsible mother. But she knew very little about NS. She doesn’t know the complications, what can happen with her child. She had no idea about hypovolaemic shock or infection. She only knows if the urine dipstick turns green she needs to go to the hospital”.*

The complex interplay between the broader social determinants of health was clearly highlighted in the comments shared. Families were often caught in vicious downward cycles.

> *"Low education; poor; financial issues are their greatest concern"*
>
> *"Really poor family – finances are significantly important issues; totally don't have knowledge about NS, but knowledge seems not to play an important role in their case though"*
>
> *"Wants to care for his child but has less information about NS; really wants to get more information but has less time to do this due to work so he can afford treatments and expenditures"*
>
> *"This family is very poor. The parents have to travel far away from their home to earn money. They are workers – not very good jobs. The grandmother takes care of the child. The child has NS which is resistant to drugs and has a very bad prognosis. The very much wants to go to school, but she never goes to school"*

Some of the protective factors for families were highlighted also:

> *"Rich and highly educated parents; pretty confident in child's care; easy to access medicines and health care service"*
>
> *"High level of education… increase in income leads to less stress and a better job; coping well and past the crisis stage, now wants to know about cure and future and details about NS information from specialists; insurance makes a big difference and minimises the strain. No community… support, but grand-parents care for child every day; difference between self-employed and employment by government – takes leave and keeps income"*

4.8.2.2.3 Recommendations for change

Most recommendations shared by the interviewers had already been captured in the interview results. In particular, the importance of reducing financial burdens and improving access to information on NS for families and local health care providers were clear priorities.

> *"Help families improve care of their children in the home"*
>
> *"Financial burdens are extreme. The insurance issues process should be faster"*

However, some fresh ideas also emerged:

> *"Consultant Club (for paediatric nephrologists)"*
>
> *"Need an organisation to support families with money. Or they can help find a good job for parents. Have a special school for the children with chronic diseases"*
>
> *"Need to support in spirit. Maybe need psychologists"*

> *"Normally the parents are the best care takers, but in this case and in other extended families the grandparents also need information and support. If they get that, they would be very helpful"*

4.8.2.2.4 Other comments

The interviewers captured the strengths, courage and bravery of the families:

> *"They are hard-working, but they have too many difficulties. Even though they are sad and scared of losing their kid, they somehow have learned to adapt. Possibly good mental recovery. The child is very weak, the mother and child hold hands from the start of the interview. They are sad but strong and show their courage. They seemed to be trying to overcome the challenge."*

> *"…but they are strong and have stood up to fight against destiny. They don't blame it on any other people".*

Despite the best efforts of families, the chronicity of NS takes a toll on families, and despite even every effort, for some families there comes an end to the capacity and resources families need to keep fighting:

> *"Purely peasant family. They silently fight against the NS for the last year. Not even a year has passed, but already they feel tired of the financial burden, despite the 80% coverage by insurance…"*

> *"His grandmother… has just sold her land in (district name) for 200 million VND. Because of her age and some other reasons she doesn't remember exactly about his visits to the hospital in the past and their expenses. It took a long while for an approximate figure on costs"*

> *"The mother is very scared that her child will not make it alive. She doesn't know where to get money (approximately 5 million per month) and she has nothing else to sell"*

> *"Common concept in Vietnam that if one member of the family has serious illness then the whole extended family goes bankrupt"*

In all, the interviewers' comments helped to bring a human face to the statistics and data. Their summarised re-telling of the stories helped capture complex scenarios and provided powerful quotes.

4.9 Stage Two Conclusions

Table 25 - Stage Two Conclusions	
Case study notes: Stage Two of the HNA (Study Two) – Identifying health priorities	
How was a profile of the community developed?	The researcher used the term "the NS Community of Vietnam" to include all people living with NS in Vietnam. The literature indicates NS primarily affects children, and that the majority of children grow out of NS and go on to enjoy normal renal function in adulthood. For this reason, this HNA was conducted in collaboration with the three largest children's hospitals in Vietnam and sought to consult with a representative sample of the NS Community and other stakeholders, in the hopes of learning more about the NS Community, their burdens and challenges, and what can be done to improve health outcomes and redress inequities for children living with NS in Vietnam.
What data were available on the health of the population?	There was limited existing data on NS in Vietnam available to the researcher at the start of this HNA. A review of the literature and consultation with experts in Vietnam and Australia provided some insights into the expressed, normative and comparative needs of the NS Community, but no information was available on the felt needs of families.
How was information gathered about the population's and service providers' perceptions of needs?	Data collected during this HNA focused on understanding the felt needs of the NS Community of Vietnam and included 426 surveys with families of children living with NS in Vietnam; 45 semi-structured interviews with parents and carers of children living with NS in Vietnam; and 45 surveys completed by health professionals conducting the parent interviews. Mixed methods and participatory action research approaches were used in the collection of data for this HNA.
What barriers were encountered?	- Limited resources and tight timelines - Translational and cultural barriers - The need to avoid overburdening health professionals - The risk of consulting and not implementing action to drive change - NS is a little-known chronic condition, and the preventable morbidity and mortality associated with NS risks being given low priority because it labours in the shadows
How were these barriers overcome?	- NS Club Meetings at all three participating hospitals were the public spheres used for data collection and they enabled cost-effective and efficient collection of data. Careful planning and consultation with local stakeholders ensured a project timeline was agreed early and strategic consultation schedule was maintained. - A cultural mentor guided the researcher through all phases of the project, and regular face-to-face meetings with hospital executive

Table 25 - Stage Two Conclusions	
Case study notes: Stage Two of the HNA (Study Two) – Identifying health priorities	
	and health professionals were prioritised for governance, planning, administration and review purposes. Translations were completed by approved and qualified health professionals. - Expert interviewers and translators were paid at agreed hourly rates for their time and completed surveys after each interview to optimise the insights emerging from their prolonged interactions with families (and avoid the need to consult other professionals). - Fundraising efforts in Australia enabled critical actions to be completed in real time to benefit the NS Community, improve health outcomes and redress inequities. A shared CLAN Action Plan for NS in Vietnam outlined and communicated all collaborative efforts. - This project had been identified as a key public health priority by Vietnamese health authorities, and the strong support received from all local stakeholders was a key success factor. The researcher committed to regular, comprehensive and transparent reporting and consulting with local authorities throughout the project to ensure actions were tracking in accordance with local requirements and preferences.
What were the key issues for the Community?	- Key **challenges and burdens** facing the NS Community of Vietnam identified through consultation with stakeholders included the physical, emotional, social and financial toll of NS on children and families; barriers to access to quality healthcare; the potential impact of NS on educational and vocational aspirations of children; policies and health systems that do not operate in the best interests of children living with chronic conditions; and the need for more information and educational resources in Vietnamese language relating to NS. - A range of **determinants** influencing health functioning and survival for children living with NS in Vietnam were identified. They included gender; ethnicity; distance families live from tertiary hospitals; family structure; household income and parental education levels; access to quality healthcare, qualified health professionals and information on NS; health literacy; health insurance; support systems; and child and parental wellbeing. - **Recommendations for change** identified by stakeholders included reducing the financial burdens on families; increasing availability of educational resources, information and training for families and health professionals, with special focus on dispelling Community myths and misconceptions; improve access to affordable and quality healthcare at all levels - especially in local healthcare settings; empowerment of and support for families to care for their children; involvement of the education system in solutions; provision of

Table 25 - Stage Two Conclusions	
Case study notes: Stage Two of the HNA (Study Two) – Identifying health priorities	
	especial support for the most vulnerable families; and NS specific initiatives to drive change.
What priorities were chosen and why, in terms of impact and changeability?	Priorities for action to improve health outcomes and redress inequities were included in the CLAN Action Plan in real time and included: - training families on the use of urine dipsticks at home (and provision of free dipsticks) - translation of educational resources on NS into Vietnamese language (with special focus on booklets for families to take home; videos; FAQs and myth-busting factsheets) - educational lectures on NS for families - advocacy and awareness regarding the needs of the NS Community (involved the development of a video on the NS Community and Club Meetings, reports, meetings with hospital and Ministry officials) - training of health professionals (local and national) - conduct of NS Club Meetings (for education, support and advocacy) - financial support to families to attend NS Club Meetings - encouragement of families to support children to attend school
What evidence informed your decision?	The researcher's past experiences implementing CLAN's five pillars and strategic framework for action informed early planning for critical action until such time as more specific insights from the consultation period was available. During parent interviews families were asked what priorities they would like addressed at the inaugural NS Club Meetings, so these insights further informed the initial priorities for action included in CLAN's Action Plan which guided collaborative translational critical action. Critical realism provided a strong social theory that justified imperfect critical actions throughout. Commitment to equity at all stages helped guide the identification of priorities for critical action. Analysis of the health determinants relevant to those children living with NS who had survived for the longest period of time (ie four years and over) revealed a number of "survival features" common to this "survivor cohort", and prioritisation of action to address determinants most amenable to change (ie achievable and able to be resourced) in the short-term were given especial priority.

STAGE THREE OF THE HNA – Assess Priorities for Action (SUMMARY OF STUDIES 1&2)

4.10 Introduction to Stage Three

In this third and final section of Chapter Four the researcher seeks to summarise the findings of Studies One and Two and reflect on the key findings therein to inform Stage Three (Assess priorities for action) of the HNA (see Table 1). In Stage Three, the researcher stans back and objectively considered the importance of Nephrotic Syndrome as an issue that affects children in Vietnam, and whether it warranted consideration as a public health priority. The researcher had initially agreed to focus this thesis on NS because local stakeholders prioritised it as a public health concern, and because their rationale at the time appeared strong, but it was important to reflect objectively as to whether such focus was warranted.

The evidence collected throughout the HNA to date is revisited, its quality considered, and it is then used where appropriate to consider four main aspects of NS in Vietnam as the key to assessing health priorities for action [6]:

1. Impact on health functioning (size and severity)
2. Potential for change
3. Acceptability of proposed actions
4. Resource feasibility.

In considering health functioning, the researcher acknowledged the WHO's holistic definition of health [337] as "*a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity*". In this regard, a consideration of the impact of NS on health functioning took into account all aspects of children's and families' lives that were covered in the consultation process, with especial focus on the challenges, burdens and strengths that were identified.

After considering the scale and severity of the impact of NS on the health functioning of children and families in Vietnam, in Stage Three the researcher analyses the proposed recommendations and interventions identified during the research, and considers which actions are most feasible in the context of changeability, acceptability and resource availability. Insights emerging from this process then inform an analysis of the critical actions taken and an assessment of the extent to which CLAN's Strategic Framework for Action and five pillars were able to inform effective and efficient action in real time to improve health outcomes and redress inequities associated with NS in Vietnam.

Table 1. Overview of DrPH Thesis structure

Chapter Number	Structure of thesis	Stages of the Health Needs Assessment
1	**Introduction**	Introduction to the HNA
2	**Literature review and initial consultations**	Background context - NS and other chronic conditions of childhood in Vietnam and other resource-poor settings
3	**Research methods**	Underlying axiology, ontology and epistemology
4	**Study One and Study Two (HNA Stages 1-3)**	
	Study 1 Participatory Action Research (PAR) approach to the development of project foundations and information gathering templates to facilitate consultation with key stakeholders to strengthen understanding of challenges and burdens facing children and families living with NS, recommendations for change and identification of critical actions that could be taken within this HNA.	**Stage 1 – Getting started** - Identify the population (who, where, why?) - Aims and objectives - Who was included in the project team? - Who was included in the stakeholder group? - What resources were required?
	Study 2 Implementation of HNA templates Part A – Parent surveys Part B – Parent interviews Part C - Health professional survey	**Stage 2 – Identify health priorities** - How was a profile of the population developed? - What data were available on the health of the population? - How was information gathered about the population's and the service providers' perceptions of needs? - What barriers were encountered? - How were these barriers overcome? - What were the key issues for the population? - What priorities were chosen and why, in terms of impact and changeability? - What evidence informed your decision?
	Summary of Study 1 and 2	**Stage 3 – Assess priorities for action** - What interventions were considered most effective and acceptable? - How were resource needs met?
5	**Translation Findings** - Translation of insights from consultation into critical action to improve health and reduce inequalities - What did we learn? - Recommendations for NS in other countries / for other chronic conditions of childhood	**Stage 4 – Planning for change** - Summary of the action planning process
		Stage 5 – Moving on / Project review - How well was the action plan implemented? - What was achieved by the project? - How did it contribute to reducing inequalities? - What was learned through the project's successes and challenges? - What needs to happen next? - What new priority was chosen for the population? - What main message from the last HNA will you take forward to the next?
6	**Conclusion**	
	References	
	Appendices	

4.11 Review of the evidence base (summary of Study One and Two)

The evidence used to inform Stage Three includes:

- Chapter Two - literature review and consultation with experts
- Chapter Four – Stage One / Study One
- Chapter Four – Stage Two / Study Two

This section commences with an assessment of the quality of the evidence presented in Study One and Study Two, followed by summaries of the key findings relating to questions regarding:

- Challenges, burdens and strengths
- Health determinants
- Recommendations for future action.

Assessing the quality of the evidence in Study One and Study Two

The extent to which the findings from Stage Three can be relied upon to inform an analysis of NS as a health priority and provide an understanding of the burdens and challenges experienced by families living with NS and their recommendations for change depends to a large extent on the quality of data collected, and how well the cohort that was selected represented the broader NS Community of Vietnam. In considering limitations of the research with regard to validity, reproducibility, sampling and bias, it was important to evaluate processes and outcomes, with specific focus on analysing the profiles of the cohorts of families that were consulted (426 families surveyed and 45 families interviewed) in some detail.

Process considerations

Study One was committed to the development of quality tools that would facilitate consultation with families of children living with NS in Vietnam using semi-structured interviews and written surveys.

Response rates

A review of the response rates to the surveys, engagement with the interview processes and quality of the data collected suggests the templates functioned well. The response rates to questions in the surveys were generally high (average 82%; mode 82%; median 84%; range 37%–99%), however, reflection on questions that had a response rate of less than 80% offered some insights into improvements that could be made in subsequent iterations. For instance, designers of future HNAs may look to strengthening data collection with respect to the following:

- Income and expenditure – transparency regarding exact costs and the nature and extent of the financial burdens experienced by families could be strengthened. More detailed financial diaries with individual families may offer stronger insights

- Educational concerns – involvement of teachers, hospital education support staff and Department of Education personnel would be an important consideration for future HNAs

- Clinical information – the health literacy of different populations should inform the best questions and approaches to collecting these data. The approach taken with the interviews (with health professionals responding to questions of a clinical and technical nature) was very effective where literacy levels are lower. Vaccination histories from parents were particularly unreliable, and given the potential benefits of comprehensive immunisation coverage, this should be an area of future focus

- Previous health care history – families clearly needed strong support with recall in this regard, particularly where children had had numerous relapses. Again, the involvement of health professionals and patient files would be preferred

- Access to quality local health professionals – this is of significance to families, and it would be useful for future HNAs to consider innovative geo-mapping technologies that could assist in this regard. More accurate clarification with some families about whether they lived in rural or urban areas could also be achieved with digital solutions.

Whilst the templates used to guide information gathering processes in this HNA worked very well overall, future HNAs should adapt the tools offered in the CHEAR Toolkit to fit local contexts and Community circumstances. A uniform approach to HNAs seeking to understand the situation for children living with chronic conditions in resource-poor settings is not appropriate, and cultural guidance for researchers working as outsiders would be essential.

Logistics and technology

Technology has changed considerably since 2011–12 when data were collected for this project. The researcher strongly recommends that future HNAs make use of technological advances, including interactive digital options for engaging with Community members in real time. Manual collection of data, whilst important in some situations, is time consuming and resource intensive, and risks draining limited capacity and focus from initiatives that can more directly benefit communities.

Pilot interviews as a means to rapid assessment of need and priorities

A large quantity of high-quality information was gleaned quickly during pilot interviews. Saturation of insights was achieved sooner than expected. Future HNAs would be well advised to focus on face-to-face, in-depth and semi-structured interviews with families at an early stage to guide the overall project and data collection processes.

So what did we learn from the data that were collected?

Cohort profiles

The survey and interview templates used to guide consultation with families were similar (Table 26), so the quantitative data collected in each consultation process could be used to compare and contrast the profiles of the interview and survey cohorts (Table 27).

Whilst the interview selection criteria meant the process for selecting families was structured, the researcher acknowledges some families were perhaps more likely to agree to participate (for instance families desperate for information) and this may have skewed the selection process. Data collected were considered representative of the cohort, acknowledging again that families with literacy challenges were less likely to have participated.

Table 26 - Comparison of questions asked in the parent surveys and interviews

Consultation topics		Survey questions			Interview questions			HCP Survey		
		Quantitative	Qualitative	Total	Quantitative	Qualitative	Total	Quantitative	Qualitative	Total
1	**Demographics**	19	0	19	19	0	19	0	0	0
2	**Schooling**	7	5	12	7	5	12	0	0	0
3	**Life with NS**	20	0	20	25	3	28	0	0	0
4	**Management of NS**	16	3	19	16	7	23	0	0	0
5	**Financial impact of NS**	7	3	10	8	2	10	0	0	0
6	**Burdens and challenges**	0	3	3	0	3	3	0	2	2
7	**Recommendations for change**	0	2	2	2	5	7	0	2	2
	Totals	69	16	85	77	25	102	0	4	4
	%	81%	19%	100%	75%	25%	100%	0%	100%	100%

On comparing the survey and interview cohorts, however, it was reassuring to note the profiles were remarkably similar overall. Although it was not possible to calculate statistical significance given the small sample sizes involved, the most notable differences seemed to be the enhanced capacity of the interviews to facilitate consultation with families with the following features:

- Single parent households
- Lower parental education
- Place of residence far from the hospital (in terms of time and distance)
- Older children not attending school (perhaps with more severe NS)

These factors emerged as potential determinants of health functioning and aligned well with the early acknowledgement by the researcher that the interview process potentially offered the greatest opportunity for consultation with families living in the most vulnerable circumstances, particularly with regard to the capacity of interviews to capture insights from parents with low literacy and education levels. As expected, comparisons of the interview and survey cohorts (and beyond that, sub-cohorts of children who had survived many years living with NS) further contributed to an emerging understanding of the survival determinants revealed in Study Two (Table 14) and helped prioritise critical actions to help children survive and thrive with NS.

Table 27 - Cohort comparison - comparing families surveyed (n=426) with families interviewed (n=45) Fa=Father; Mo=Mother; Yr=Year

Profile features	**Families surveyed (n=426)**	**Families interviewed (n=45)**
Age	6.8 years (range 1-18 years; mode 5 years; median 6 years)	7.2 years (range 2-15yrs; mode 5 years; median 7 years)
Home location (Rural: Urban)	Rural: Urban 71: 29	Rural: Urban 64: 36
Sex (Male: Female)	Male: Female 73: 27	Male: Female 73:27
Ethnic minority group (Whole community = 15%)	3% (11/426): 15%	2% (1/45): 15%
Single parent family	4% (16/426)	**11%** (5/45)
Parent education level for fathers and mothers	≥ Yr 9 - Fa 56%; Mo 55% ≥ Yr 12 - Fa 35%; Mo 35% University – Fa 10%; Mo 9% Internet access - 54%	≥ Yr 9 - Fa 49%; Mo 51% ≥ Yr 12 - Fa 31%; Mo 24% University – Fa 2%; Mo 0% Internet access – 33%
Average income / month (million VND)	5 (mode 2; median 1)	5.2 (mode 1; median 4)
Household structure / family support	Household size = 4.9 persons (mode 4; median 5; range 2-12) 36% of families have at least one grandparent in home	Household size = 4.8 persons (mode 4; median 4; range 3-8) 47% of families have at least one grandparent in home
Distance from hospital (km)	Average = 95km Mode = 100km Median = 60km Range = 1 to 900km	Average = 127km Mode = 70km Median = 70km Range = 1 to 700km
Distance from hospital (hours)	Average = 3 hours Mode = 3 hours Median = 2 hours Range = 6 min to 36 hours	Average = 3.7 hours Mode = 2.5 hours Median = 2 hours Range = 12mins to 31.5 hours
Parents working	Mothers not working = 28%	Mothers not working = 22%
Health insurance	Yes, has insurance = 94% No insurance = 6% Insurance covers all costs = 41% Insurance for <6 years = 49% School insurance = 49% Insurance for poor = 11%	Yes, has insurance = 93% No insurance = 7% Insurance covers all costs = 44% Insurance for <6 years = 36% School insurance = 49% Insurance for poor = 9%
Child wellbeing	Duration of NS = 2 years Not attending school = 9% Health score now = 7/10 Health score 12 months ago = 7/10	Duration of NS = 2 years Not attending school = 11% Health score now = 6.5/10 Health score 12 months ago = 7/10
Parental wellbeing (scale 1 / rarely feel → scale 10 / always feel) (average/mode/median)	Depressed = 5.5 Anxious = 7.3 Sad = 6.8 Worried = 7.7 Hopeful = 7.7 Optimistic = 6.3 In Control = 6.2 Confidence in knowledge = 5/10 Confidence in management = 5/10	Depressed = 5.4 Anxious = 6.9 Sad = 6.5 Worried = 6.8 Hopeful = 7.6 Optimistic = 6.4 In Control = 6 Confidence in knowledge = 6/10 Confidence in management = 6/10

Survival features

When comparing survey and interview cohorts (Table 27) and in the context of comparisons with the survivor cohort identified in Study Two (Table 14) and the broader Vietnamese population, it was encouraging to find the HNA instruments identified several features that could be associated with child survival in the context of a diagnosis of NS or other chronic health conditions and which warranted further research and possible action. These included:

1) *Sex*

Male child preference is well documented in Vietnam, and the proportion of male children surviving four or more years with NS was noted. It is reasonable to surmise that female children diagnosed with a chronic condition such as NS in Vietnam may be at increased risk of dying unless specific actions are taken to support families.

2) *Ethnicity*

Perhaps the most striking finding was the low number of families from ethnic minority groups who were represented in the needs assessment, and more specific efforts are required to consult with these families. Based on the literature and experience with consulting CAH families in Vietnam in the past, it is reasonable to assume children with NS from ethnic minority groups are not surviving (as opposed to not presenting for care or not equally affected by NS), and more targeted efforts to reverse this trend are required.

3) *Distance*

The distance (particularly as measured in time) families lived from quality providers of health care influenced child survival and, based on the evidence from this research project, it is reasonable to suggest children of families who live more than 100 km (3 hours) away from treating hospitals should be considered at especial risk of not surviving.

4) *Income and parental education*

These factors would seem inextricably linked. Family income is well established in the literature as linked to child survival, and NS families in both the survey and interview cohorts had higher monthly incomes than the national average (USD$2,827 versus USD$890; where 1 USD : 1 AUD : 21,220 VND as at 17 November 2011 [376]).

Parental education was associated with higher income levels and increased chance of survival in this consultation, with average parental education levels well above the national average; 35% of parents of children with NS had completed Year 12 (versus the national average of 20.8%) and 10% of fathers and 9% of mothers had completed university (versus the national average of 4.4%). Fewer families in the interview cohort had completed university education (2%) or had access to the internet (33% versus 54%), however, this may suggest families with the greatest need for information actively put themselves forward and self-selected to participate in the interviews when they saw what was happening on the day. This hypothesis fits with the observation that families desperate for more time with health professionals actively sought out the opportunity to participate in the pilot interviews. It also fits with the likely explanation that the more highly educated families were better able to travel and attend a non-essential event.

5) Family structure and support

Simple logic would suggest that children of single parent families are at especial risk of not surviving because of their family's reduced income and capacity to provide the time and resources needed to manage NS (including travel to tertiary referral centres). The data from the consultation supports this belief. Although the national divorce rate is low (1.8% in urban areas and 1.3% in rural areas), the proportion of single families in the survey cohort was double this (4%), and the proportion of single parent families in the interview cohort was more than five times higher than the national average (11%). This observation aligns with findings in the literature of a positive association between chronic conditions of childhood and single parent structures, and strong evidence for the cumulative impact of social disadvantage on child health [185]. Extended families are quite common in Vietnam, but household size in this consultation was above the national average (4.8 versus 3.8 persons). This was attributable to grandparents living in the family home rather than additional children. Grandparents featured significantly in the qualitative responses as being invaluable sources of practical and emotional support and material resources.

6) Health insurance

National statistics suggested that only 42% of the Vietnamese population had health insurance in 2010 [58], but the families consulted in this needs assessment had almost universal (93%) health insurance coverage. Despite its flaws (with only around 40% of families enjoying full coverage of costs), health insurance was clearly a protective factor, and indeed the poorest families spoke out about its benefits. School insurance appeared to have a particularly strong protective association (with 84% of children surviving more than four years being covered by school insurance), although this observation was confounded by the fact that children who were less ill were more likely to go to school and more likely to survive. Nevertheless, the effects of a vicious cycle that keeps a sick child home from school and requires a parent to leave the workforce, forgo an income and reduce their capacity to pay for healthcare for their child (or be eligible for school insurance, as is the case in Vietnam) should not be underestimated.

7) Child wellbeing

The type of NS children were living with (for instance steroid sensitive versus steroid resistant) was not a major feature in this needs assessment, but it would be a mistake to suggest the nature of NS itself was not important or influential in determining health outcomes. There are three main points to make in this regard:

- Firstly, most families consulted in the survey simply did not know enough about NS to share this type of information. This does not mean the information is not relevant or important, simply that it is missing.
- Secondly, a large proportion of both survey and interview cohorts was relatively newly diagnosed with NS (average duration two years), so in some cases it would be unreasonable to expect the exact diagnosis to have been made. The large number of

newly diagnosed children is also further indication that the true incidence of NS in Vietnam is likely quite significant and by extension, the loss of life associated with NS in Vietnam is also likely to be high. For this reason, it reasonable to assume that critical action to reduce the impact of NS on children and families in Vietnam will make an important contribution to child health in Vietnam.

- Finally, it has already been acknowledged that those children with the most severe forms of NS were systematically excluded from this needs assessment (not least because children requiring renal replacement therapy were not included), so the impact of more severe forms of NS on child wellbeing will be severely under-estimated by the findings of this research. The literature indicates children with multiple chronic conditions are at increased risk of poor health outcomes, and whilst this was not explored in this needs assessment, again it should be considered in the context of actions needed to support those living in the most vulnerable circumstances.

8) *Parental wellbeing and capacity to care for their children*

Whilst it was not possible to perform statistical analysis on data relating to the psychological impact of NS on the parents in the cohorts consulted, it was clear that NS took a toll on their wellbeing. Resilience, optimism and strong “spirit” are important strengths that were acknowledged by many parents and interviewers. Health literacy and confidence in the management of NS were highly valued by parents and strengthened when even minimal training and education opportunities were provided.

Limitations of the evidence

The most striking limitation of the data presented in Studies One and Two was the systematic exclusion of the most vulnerable children and families. Efforts were made during the planning stages of this research project to ensure the interview cohort was as representative as possible of the broader NS Community (as per the selection criteria for inclusion determined from a review of the literature). This approach was quite successful (as presented in Table 19) but it is important to acknowledge the limitations of this approach. Most notably, families who had lost a child to NS and families who were lost to follow-up from the three tertiary hospitals involved in this research project were systematically excluded. Because of this, study findings necessarily underestimate the true burdens and challenges faced by families and do not include recommendations these families may have been able to share.

One way of acknowledging and considering this systematic bias against and exclusion of families living in the most vulnerable circumstances was to consider the entire cohort of families consulted in this HNA as a “survivor cohort” (not just those families identified in Table 14) and through this lens actively seek to identify critical actions that could mitigate risk factors associated with vulnerability for other childhood NCD communities. Moving forward, rapid assessment of these “survival features” could potentially help doctors and other health professionals in resource-poor settings identify children least likely to survive and thrive following a diagnosis of NS or another chronic health condition, so they can target critical action to redress inequities. The Child Health Equity Checklist Count Scorecard (shown in CHEAR Toolkit, Appendix 1) is an example of a tool developed in light of findings from this research that could be used for this purpose.

The researcher acknowledges the heavy focus on biomedical stakeholders in the consultation process, and this approach excluded the broad range of multidisciplinary stakeholders working to support resource poor communities in Vietnam, such as farmer unions, other non-government organisations and broader government initiatives.

Summary of the key findings from Study One and Study Two

Findings are summarised as they related to:

a. Challenges, burdens and strengths
b. Determinants (health triangle)
c. Recommendations for change

a) Challenges, burdens and strengths

When analysing the challenges, burdens and strengths communicated by the families of children living with NS in Vietnam, it was important to the researcher always to consider critical action that could be taken in real time to redress inequities and improve health outcomes for the children based on the information being shared. The importance of considering families' feedback from a strengths-based perspective and not view families through a deficit lens was also vital to engaging with families as strong, powerful agents and not just victims in need of rescuing. This was key to sustainability of efforts over the longer term.

The potential for reductive analysis and reflection on the "causes of the causes" (similar to the "But Why?" approach informing CLAN's framework for action in 2006) to achieve both these goals informed the researcher's reflections on the challenges, burdens and strengths identified in Study One (the pilot interviews) and Study Two (surveys and interviews). The four planes of agency identified by Bhaskar in critical realism were trialled and found to provide a powerful framework in the context of thematic analysis, most particularly when it came to understanding the underlying determinants and potential recommendations for critical action. The four planes of agency were used to analyse all data (quantitative and qualitative) thematically relating to challenges, burdens and strengths emerging from the evidence of this HNA. These are shown in Appendix 8 and summarised as follows:

1) *Material transactions with nature* – those features of NS that are unique to NS and the potential impact NS has as a chronic condition on the bodies of young children. These features can be mitigated by optimal medical management. The very nature of NS, as a chronic, relapsing condition of childhood, is relevant to consider in the context of the burdens it places on families. Sub-themes identified included:

   a. The physical impact of NS and its treatment on children
   b. The potential impact of NS on the future of affected children

    c. Opportunities to prevent relapses of NS are being missed
    d. The voices and experiences of those most severely affected by NS are not being heard
    e. The broader impact of NS on children's lives (social, emotional, educational)
    f. Unaffordable access to essential medicines, equipment and healthcare

2) *Social interactions between people* – interpersonal, human-to-human connections have the potential to influence the impact of NS on children and families. The countless interactions families influence their experiences of life with NS every day. Sub-themes identified included:

    a. Social impact of NS
    b. Language and technology barriers to accessing quality information on NS
    c. Having both parents and extended family involved in the care of children with NS is protective
    d. Importance of support systems

3) *Social structures* – the organisational, governmental and systems-based factors that have the potential to influence positively or negatively the capacity of children and families to survive and thrive with NS. Families exist within broader social systems, and these have the capacity to support them on their journey with NS or make their journey more difficult. Sub-themes identified included:

    a. Interactions with the health system
    b. Interactions with the education system
    c. Burden of distance from tertiary referral centres and qualified health professionals
    d. Interconnectedness of time, money and health
    e. Bureaucratic burdens
    f. Impact of inequities
    g. Male child preferences
    h. Ethnic minority communities are under-represented
    i. Financial burdens (increased costs / reduced income)
    j. Entrenched poverty
    k. Data on NS in Vietnam are limited
    l. Health insurance (protective factor when universally available)

4) *Stratification of the embodied personality* – the intrinsic factors within every human being to respond to NS. Many families demonstrated significant resilience and strength in the face of hardship. Sub-themes identified included:

    a. Adverse psychological impact of NS (fear and anxiety)
    b. Coping mechanisms and resilience
    c. Families keen to learn about NS and how to optimally care for their children
    d. Families respect and trust health professionals at tertiary referral centres
    e. The impact of myths where information is absent or inaccurate
    f. Confidence and resilience of parents and children
    g. Lower parent education levels (associated with poorer health literacy, reduced confidence and reduced survival / worse health outcomes)

The use of this alternative framework to analyse data emerging from Studies One and Two was useful to the researcher, because it provided an opportunity to consider health determinants and potential critical actions to drive change through a fresh lens in Stage Four. These findings also facilitated an objective analysis of the effectiveness of CLAN's five pillars in enabling the researcher to pre-emptively identify and prioritise critical actions to improve health outcomes and redress inequities associated with NS in Vietnam.

b) Health determinants

Several factors were considered when determining which health determinants had the greatest impact on health functioning and should be given the highest priority for critical action (Table 28). Health determinants associated with NS were first ranked according to their potential for change. Interestingly, very few determinants were unchangeable. Exceptions included the type of NS a child has, finding a cure for NS and the education levels achieved by parents in their youth. Determinants considered potentially changeable were reviewed in the context of the capacity of the researcher, CLAN's resources and the broader participatory action research initiatives to influence them. Some potentially changeable determinants were not considered achievable in the short term, because they would require political will and multisectoral, multisystem commitment and were therefore beyond the scope of goals to aim for within the timeline of this HNA.

Consideration was also given to the capacity of CLAN's framework itself to assist the researcher in identifying critical actions that were sufficiently serious, sizeable and / or achievable and could therefore be included to some extent in the Action Plan developed and shared with stakeholders in early 2011. Predictably, some insights (such as the exclusion of ethnic minority groups and male child preference) were not sufficiently prioritised early in planning and so received less emphasis during the HNA, whilst other unexpected changes, such as the inclusion of medicines for NS in the national insurance scheme in August 2011, played a major role in redressing inequities.

Table 28 - Identifying health determinant priorities

Health determinants that impact health functioning and are relevant to Nephrotic Syndrome in Vietnam	Changeable?			Included in CLAN's Action Plan?
	Yes	Potentially	No	
Type of NS – impacts on prognosis (most types have a good prognosis with optimal care)			🟥	
Frequency of relapses	🟩			🟪
Financial safety nets in place		🟨		
Children and families empowered in their management of NS	🟩			🟪
Affordable access to quality health care to optimise health outcomes		🟨		
Children and families encouraged in their journey with NS	🟩			🟪
Children with chronic health conditions are supported to complete their education		🟨		🟪
Reduce social stigma associated with NS		🟨		🟪
Raise awareness nationally of NS; engage Ambassadors and celebrities	🟩			🟪
Strengths and successes are promoted, shared and celebrated	🟩			🟪
Translated quality educational resources and information on NS are widely and freely available	🟩			🟪
Single parent families and families with limited support networks (are at especial risk)		🟨		🟪
Disability inclusive messaging and actions at schools and within communities at local and national levels		🟨		
Platforms and opportunities available and accessible for NS Community networking and support	🟩			🟪
NS Community actively engaged and strengthened	🟩			🟪
Availability of efficient and effective inpatient and outpatient systems for NS		🟨		
Education systems have capacity to meet especial needs of children with NS		🟨		
Capacity of primary health care professionals / remote and regional centres to manage NS		🟨		🟪
Remote / rural families (those living more than 100km / 3 hours from tertiary centres are at especial risk)		🟨		🟪
Income generating capacity		🟨		
Poverty	🟩	🟨		🟪
Health literacy of parents / families	🟩	🟨		🟪
Sex (female children with NS are at increased risk of dying)		🟨		
Capacity of health system to provide culturally appropriate and safe health care (children with NS from ethnic minority communities are at increased risk of dying)		🟨		
Charitable / financial / practical support and resources are available to families and carers		🟨		🟪
Children with chronic conditions are supported to complete their education (even in hospitals)		🟨		🟪

Table 28 - Identifying health determinant priorities

Health determinants that impact health functioning and are relevant to Nephrotic Syndrome in Vietnam	Changeable?			Included in CLAN's Action Plan?
	Yes	Potentially	No	
Quality NS data are available		🟨		🟪
Universal health coverage (that covers all costs)		🟨		🟪
Psychological support available for children and families living with NS	🟩			🟪
Community awareness of NS / information available	🟩			🟪
NS Club Meetings / support / education training opportunities for families	🟩			🟪
Research to find a cure for NS			🟥	
Families keen to learn about NS	🟩			🟪
Families trust health professionals at tertiary centres	🟩			🟪
Myths and misconceptions	🟩			🟪
Families and children empowered to engage in finding solutions	🟩			🟪
Educational levels of parents (lower levels associated with increased risk of dying)			🟥	

c) Recommendations for change

Six key themes emerged from an analysis of data from the surveys and interviews regarding recommendations for change. Whilst the recommendations were not always practical or achievable (for example, “find a cure”), for transparency they are shared below:

1) Reduce financial burdens
    a. Provide financial support / income opportunities
    b. Especial support for poor families
    c. Connect families with systems that offer financial support
    d. Strengthen the existing insurance system
2) Optimise medical management (biomedical–social)
    a. Provide the necessary medicines
    b. Find a cure
    c. Help families to stay hopeful
    d. Increase access to qualified health professionals
3) Help families learn to manage NS
    a. Provide information on NS
    b. Empower parents to care for children at home
4) Special support for the most vulnerable families, with focus on:
    a. Poor families
    b. Remote families
    c. Those who have children with severe illness
5) Strengthen the health system
    a. Improve access to quality care
    b. Strengthen local health systems
    c. Provide support from government and hospitals
    d. Increase time with doctors
6) Focus on NS-specific activities to support families
    a. Support programs and organisations for NS
    b. Support for the most vulnerable families

The thematic analysis above aligned neatly with CLAN’s five pillars, with notable emphasis on a specific recommendation to target actions that would benefit families and children living in the most vulnerable circumstances, which aligns with Pillar Five. The recommendations highlight the recurring message shared by families that time is as important to them as money, and financial burdens can result from a range of factors, not just increased expenditure.

In the interests of objectively analysing the recommendations shared by experts consulted throughout this HNA (including hospital executives, health professionals, families and carers) the researcher sought to revisit the thematic categorisation of challenges, barriers and recommendations by grouping them according to the underlying causal mechanisms as guided by the four planes of agency. In this way the researcher was able later to reflect upon gaps and novel recommendations that emerged not so much from the HNA but from CLAN’s strategic framework for action. The acceptability and justification for any and all proposed recommendations were then assessed according to their accordance with the 54 articles of the United Nations’ Convention on the Rights of the Child (UNCRC [338]). This process is illustrated in Appendix 9.

4.12 Is NS an important child health priority?

A review of the evidence collected in this HNA suggests NS as it affected children in Vietnam at the time of this HNA was an important public health priority worthy of critical action (Table 29). In particular, the evidence gathered in this HNA contributed extensively to an understanding of the felt needs associated with NS in Vietnam. Achievable, justifiable, feasibly resourced opportunities were identified through the HNA that had the potential to improve health outcomes and redress inequalities if actioned.

Table 29 - Review the social needs associated with Nephrotic Syndrome in Vietnam

Evidence of need	Yes, definitely a priority	Maybe	No, not a priority
Normative need	Experts in Vietnam identified NS an important public health priority. Health professionals recommended action to help families with: - Health literacy - Financial burdens / transport needs - Access to quality medical care (including palliative care and management of ESKD) - Access to psychological support		
Comparative need	Key indicators (notably incidence and prevalence of NS in Vietnam; preventable morbidity and mortality) are higher in Vietnam than Australia and other high-income countries in the region (such as Taiwan), with opportunities identified to improve health outcomes and redress inequities. More data and research in Vietnam was identified as a need.		
Expressed need	Over-burdened inpatient and outpatient departments speak to the need for urgent and critical action. Workforce capacity building was identified as a need.		
Felt need	Representatives of the NS Community of Vietnam who were consulted in this HNA communicated the challenges and burdens experienced, as well as their recommendations for change. Key recommendations from families included: - Reduce financial burdens - Strengthen access to optimal health care - Help families learn about NS - Strengthen health and education systems - Support the most vulnerable families - Strengthen local health systems - Provide support from government and hospitals - Increase time with doctors		

4.13 Which health determinants should be priorities for action?

In the short term, the researcher focused on actions that could be achieved within the constraints of resource feasibility at the time. Moving forward, communication of the bigger picture and larger scale potential actions that will require whole of government approaches to effect change must be an important focus for attention.

It was clear from an examination of the evidence that the health determinants associated with the greatest vulnerability and risks to survival for children living with NS in Vietnam are relevant to all children in resource-poor settings diagnosed with any type of chronic health condition. Specific “survival determinants” should be prioritised for urgent identification by all health professionals in resource-poor settings who are caring for children living with chronic health conditions, and the CHECC Scorecard offers a simple tool for achieving this. A pilot trial of the CHECC Scorecard that helps health professionals identify children with a CHECC score above which governments, civil society and other organisations have a responsibility (in accordance with UNCRC) to do all they can to help those children survive and thrive. This number may vary across different countries, although the researcher estimates a score of “3” might reasonably be considered to indicate significant risk. UNCRC instructs all of society to work collaboratively to identify and implement urgent and specific actions that can be taken to optimise a child’s chances of survival if and when their rights to life and health are at risk, and the CHECC tool may well help focus collaborative efforts on those children in the most vulnerable circumstances.

In situations where a child’s survival is unquestionably improbable, health professionals must work with parents and carers, support them through their darkest days, provide information and facilitate access to appropriate and affordable palliative care to minimise suffering for all involved – but most especially of all, for the child.

4.14 Stage Three conclusion

In addition to showing priorities for action, identifying what can and should be done to drive change for children living with NS in Vietnam (Table 30), the analysis of evidence emerging from Study One and Study Two also highlighted the consequences of an *absence of action*. Death and suffering are the antithesis to “survive and thrive”. Indeed, all the recommendations that emerged during the HNA could be justified in light of the UNCRC’s 54 articles.

There can be no doubt that, at the time of this HNA, NS in Vietnam was a significant public health priority. The burdens, challenges, strengths and recommendations of all stakeholders were clearly identified through this HNA, and critical realism offered a useful framework for examining not just the challenges and burdens families of children with chronic conditions in resource-poor settings face, but also informed a systematic retroductive analysis of the underlying causes and structural mechanisms that promote inequities and contribute to poor health outcomes.

A range of low-cost critical actions were implemented in real time as a result of collaborative action guided by CLAN's framework to drive change, and these are presented in Chapter Five / Stage Four.

Survival as an immediate priority

The researcher acknowledges the children and families consulted in this HNA as strong and resilient survivors (Figure 72), and analysis of their feedback helped to identify a range of indicators (the CHECC Scorecard – see CHEAR Toolkit) that can inform rapid assessment of children diagnosed with NS and other chronic conditions in resource-poor settings, with the goal of identifying those most at risk of preventable morbidity and mortality so that critical and realistic actions can be implemented as a matter of urgency.

Moving forward, the researcher would recommend the CHECC Scorecard be shared with paediatricians in all resource-poor settings as a matter of urgency, and professional organisations be encouraged to work in-country with governments and other stakeholders to identify critical actions that can be taken to support those children least likely to survive their diagnosis of a chronic health condition. In situations where survival is extremely unlikely, or quality of life untenable, quality palliative care should be made freely available, assuming there are no other options or resources available.

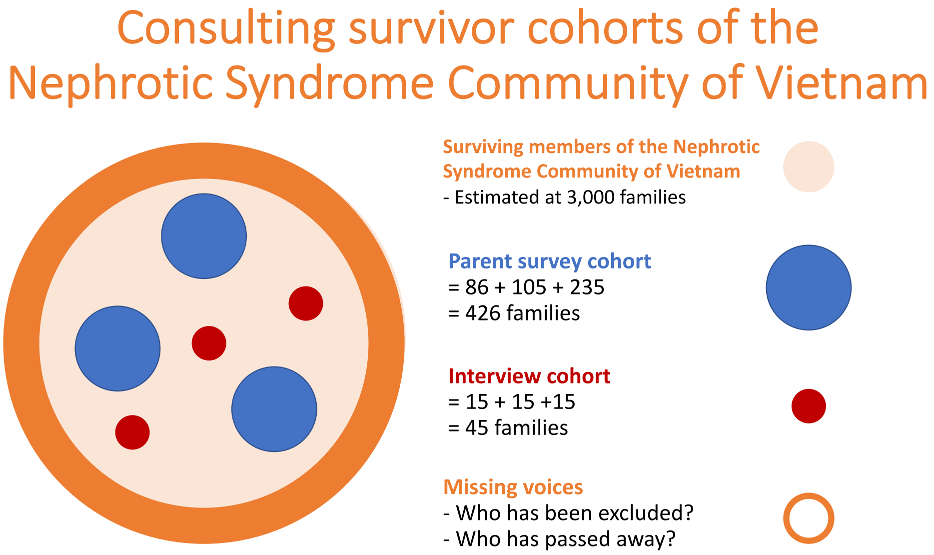


Figure 72 - Consulting a survivor cohort of the NS Community of Vietnam

Table 30 - Stage Three of the HNA: Conclusion

Case study notes: Stage Three of the HNA – Assessing a priority for action

What interventions were considered most effective and acceptable for this priority and what evidence informed your decision?	The evidence collated during the literature review, expert consultation process, Study One and Study Two informed Stage Three of the HNA. The cohorts of families consulted were identified as survivors, and survival was identified as a priority in this HNA. Specific details of the critical actions taken in response to the evidence during the HNA are outlined in Chapter Five / Stage Four. Recommendations identified by families and health professionals in advance of the inaugural NS Club Meetings in November 2011 were prioritised. Moving forward, the researcher would recommend use of the CHECC tool to identify children who have been newly diagnosed with any chronic health condition, with a view to identifying those children living in the most vulnerable circumstances so that critical actions can be implemented to protect their right to survive and thrive. Interventions that could be implemented at the individual, community and hospital level were found to be the most amenable to immediate action within the context of this HNA. This in part reflected the resources available to the stakeholders involved. Advocacy and reporting of findings helped escalate awareness of the need for other actions and encouraged other stakeholders to engage. The acceptability of all recommendations was assessed in light of the UNCRC’s 54 articles. No recommendations were found contrary to the articles in the Convention.
How were resource needs met?	Fundraising by CLAN and donations in-kind by participating partners and stakeholders made this HNA possible. Generous contribution of time, expertise and support by health professionals and hospitals in Vietnam were vital at every stage of the HNA.

CHAPTER 5 – TRANSLATION FINDINGS (HNA STAGES 4 & 5)

5.1 Introduction to Chapter Five

In Chapter Five, the translational activities that contributed to the HNA during the data collection phase of the thesis (that is, between September 2010 and February 2013) are described. Whilst the researcher, CLAN and other stakeholders continued to provide support to the NS Community of Vietnam after February 2013, these activities and findings do not inform the findings of Stage Four.

Several frameworks are used Chapter Five to inform its analysis and findings. First is the NICE HNA [6] used throughout this thesis (Table 1). In particular, Chapter Five reports on:

Stage Four – Action planning for change

Stage Five – Moving on / Project review

Secondly, the Knowledge To Action framework [340] (Figure 17) is used to inform an understanding of how the research project translated knowledge to action and action to knowledge throughout this thesis. The many translational knowledge tools, resources and products developed and tailored to NS during the research project are collated into the CHEAR Toolkit (Appendix 1)

Thirdly, CLAN's Strategic Framework for Action [180] (**Error! Reference source not found.**) informed the rights-based approach adopted to drive critical action across the life of the research project, and in particular, the use of five key pillars to inform the selection of interventions to benefit the NS Community of Vietnam:

- Pillar 1 – Affordable access to essential medicines and equipment
- Pillar 2 – Education, research and advocacy
- Pillar 3 – Optimal medical management
- Pillar 4 – Family Support Groups
- Pillar 5 - Promote financial independence

Finally, a program logic framework informed the project management approach to the planning, implementation, monitoring and evaluation of critical actions taken in this HNA to benefit the NS Community of Vietnam. The Action Plan developed in accordance with CLAN's strategic framework for action informed the development of a program logic framework by the researcher (in her dual role as President of CLAN) that facilitated consideration throughout the HNA of the following:

- Project timeline
- Risk management
- Project budgeting
- Project evaluation

<table>
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STAGE FOUR OF THE HNA - Planning for Change

Stage Four presents the key actions implemented through the HNA to improve health outcomes and redress inequities for the NS Community of Vietnam, as informed by CLAN's strategic framework for action and five pillars.

5.2 Translating knowledge to action

5.2.1 Identify the problem

In translating knowledge to action, a key challenge for the researcher was the fact that existing knowledge relating to the challenges and burdens facing children and families living with NS in Vietnam arose from an understanding of normative, comparative and expressed needs, rather than any meaningful insights into the felt needs of the NS Community of Vietnam. As the HNA progressed, the researcher came to better understand the felt needs of the NS Community and the recommendations for action identified by all stakeholders engaged in the project.

Insights from the literature review and initial consultations with experts

At first, there was very limited information regarding the felt needs of families living with NS in Vietnam, but consideration of the NS Community's normative, comparative and expressed needs identified a range of severe and sizeable problems. Paediatric nephrologists and hospital executives in Vietnam were concerned about the large numbers of children presenting with NS, and the overburdened inpatient and outpatient wards. Staff were overwhelmed by the sheer numbers of children needing care. There were insufficient human and hospital resources to provide the care needed, and preventable morbidity, mortality and loss to follow up was estimated to be high. Essential medicines were not affordable for most families, families had little understanding of NS and anecdotally children were not enjoying good quality of life nor achieving to their full potential. Comparison with the experiences of children and families living with NS in Australian confirmed the severity and scale of the inequities experienced by families in Vietnam. Children's basic rights to health and life were not being protected.

Review of existing evidence and gold standard approaches to the management of NS internationally confirmed there was a range of initiatives that could reasonably be taken to reduce the inequitable burden of NS in Vietnam. Vaccinations, home testing of urine, early management of relapses and empowerment of families to provide optimal care for their children were amongst the low-cost, potentially achievable options identified very early on, and these gave hope that critical actions taken in the short term could have a major impact on health outcomes.

The need for knowledge AND action

The definition of a HNA as "a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities" emphasises the fact that consultation alone is not sufficient. It was not ethical simply to learn more about the felt needs of the NS Community without incorporating action in real time to drive meaningful change that would benefit the Community.

Whilst the researcher had no personal lived experience of NS, nor any experience of using CLAN's strategic framework for action to tackle NS, translation of CLAN's model from CAH to diabetes in the past instilled confidence that a shift to NS would be achievable. Adapting CLAN's model to address NS in the context of this thesis and HNA would also offer the opportunity to examine objectively the capacity of CLAN's model to inform proactive critical action to redress inequities associated with childhood chronic conditions, through a comparison with the recommendations emerging from the research process. Critical realism theory acknowledged and reassured the researcher that whilst any actions taken using CLAN's framework would necessarily be imperfect, they were at least an improvement on a complete absence of action to redress inequities associated with a potentially important public health issue.

5.2.2 What was the proposed solution? (Aims and objectives)

In response to the requests by local health authorities for CLAN to adapt its strategic framework for action to drive change for the NS Community of Vietnam, the researcher requested support from CLAN's Committee to translate learnings to date from CAH and diabetes to NS. There was acknowledgement of the dual role the researcher would play as President of CLAN in leading action and discussions on processes that would minimise any potential conflict of interest for the researcher (such as the researcher reporting back to the Committee at each meeting on the progress of the research). There was also acknowledgement of the potential benefits to CLAN of this research project in translating the model to another chronic condition of childhood, with formal research processes strengthening procedures such as ethics submissions and possibly helping to disseminate CLAN's model in future.

CLAN's Committee agreed to the researcher's focus on NS and committed to raise funds to the best of its ability with the goal of supporting critical action to benefit the NS Community of Vietnam as part of a holistic HNA supported by the DrPH research process. Consultation with stakeholders in Vietnam informed the development of CLAN's Action Plan for NS in Vietnam, and agreement on the overall vision, aims and objectives. There were as follows:

Vision: To maximise quality of life for all children living with NS in resource-poor settings

Aims: To redress inequities for children living with NS in Vietnam, and facilitate the establishment of self-sustaining, locally embraced procedures and changes that could inform and inspire action for other chronic conditions of childhood in Vietnam and across the Asia Pacific region.

The **objectives** of CLAN's Action Plan centred on the five pillars:

1) Ensure affordable access to essential medicines and equipment
2) Promote education, research and advocacy

3) Optimise medical management
4) Encourage the NS Community in Vietnam
5) Reduce financial burdens and promote financial independence of NS families and

Under CLAN’s sixth pillar within the Action Plan the organisation was committed to ethical and transparent project management at all times, with a focus on promoting partnerships, identification of resources and mitigation of risks.

5.2.3 Adapt knowledge to local context

Study One outlined the participatory action research approach taken in the development of the information gathering tools and resources used to facilitate the consultation undertaken with key stakeholders within this HNA in Study Two. The consultation process sought to inform a holistic understanding of the challenges and burdens faced by the NS Community, and stakeholder recommendations for change, so information gathering templates included questions relating to:

- Demographic and epidemiological determinants
- School and social life
- Physical considerations
- Life with NS
- Access to quality health care
- Financial impact of NS
- Health literacy
- Specific felt needs
- Recommendations for change

Whilst detailed retroductive analysis of the findings of the surveys and interviews conducted in Study Two would inform a strong understanding of the challenges, burdens, strengths and recommendations, planning for critical action had to occur in advance of these findings becoming available. To facilitate this, the researcher worked with CLAN’s Committee and the other stakeholders to ensure all early insights emerging from the various consultation processes were shared with all stakeholders and rapidly informed the identification of critical, priority activities for inclusion in CLAN’s Action Plan for NS in Vietnam. Responsibilities for the various activities were considered and available resources allocated during this process. CLAN’s NS program logic framework supported the development of project timelines, fundraising strategies and risk management processes.

At an early stage, CLAN prioritised the identification and translation of several educational booklets on NS into Vietnamese language. Early consultation had confirmed there were no such resources available, so the team searched to identify the best resources internationally and sought permission to translate them for widespread dissemination in Vietnam. There was acknowledgement such resources would benefit health professionals as well as families. Two key booklets were identified, and the researcher engaged an experienced, qualified translator to commence work on these in early 2011 (Tool 5, CHEAR Toolkit, Appendix 1):

- *Nephrotic Syndrome: Information for Parents* (**Hội chứng Thận hư**) A booklet on NS produced by the Department of Nephrology at Royal Children's Hospital in Melbourne and

- *Nephrotic Syndrome in Children* (**Hội chứng Thận hư ở trẻ em**) A guide for parents on the management and treatment of Childhood NS (produced by Nottingham NHS)

5.2.4 Assess barriers to knowledge use

The pilot interviews in Study One and some of the parent and health professional interviews in Study Two helped to inform more detailed understanding of the barriers to knowledge use that would have to be overcome to improve health outcomes and redress inequities experienced by the NS Community of Vietnam.

For instance, some of the barriers identified early in the HNA included:

- Barriers to accessing the internet (very few families had access)
- Language barriers (most resources online were in English, but very few families spoke English, and online translation capacity was limited at that time)
- The high level of distrust families had for local health professionals
- Families' current inability to test urine at home for protein, and self-initiate early steroid therapy for relapses
- The severely limited time available to families when speaking with doctors
- The high financial burden on families of frequent outpatient and inpatient visits (through travel costs and lost income) and impact on schooling
- The complexity of health insurance systems and barriers to families' financial security
- The barriers imposed by myths and misconceptions on provision of optimal care for children (e.g. negative impact on schooling)
- Extreme financial and other burdens caused by unaffordable access to medicines
- Barriers to families connecting and communicating (e.g. distance, lack of capacity)
- Scale of the issue (huge numbers of children; overwhelmed health system)
- Opportunity to translate NS learnings to Systemic Lupus Erythematosus

These early insights led to the inclusion of additional actions in the final CLAN Action Plan for NS in Vietnam, such as:

- Training on urinalysis and provision of free urine strips to families
- Development of videos for families on NS
- Development of facts sheets dispelling commonly held myths

- Development of certified training sessions for doctors working in regional areas
- Consideration of changes to inpatient and outpatient review processes to minimise time and costs for families
- Awards for children doing well at school / positive messaging around school attendance
- Advocacy to improve affordable access to essential medicines and equipment
- Development of platforms to facilitate NS Community members to connect with one another
- Need for international partners and funders
- Permission given to hospital staff to use information gathering template developed in this thesis to benefit other NCD Communities.

5.2.5 Select, tailor, implement interventions

CLAN's strategic framework for action informed the development of CLAN's Action Plan for NS in Vietnam. The Action Plan was finalised with insights from parent interviews ahead of the inaugural NS Club Meeting in 2011 and was regularly updated and shared with key stakeholders to strengthen engagement and transparency. The Action Plan included an executive summary outlining the vision, aims and objectives. The plan identified key roles and responsibilities, action timelines and SMART indicators that could be used to inform evaluation and monitoring over time. The plan included a list of key stakeholders and partners that would ideally be engaged, as well as consideration of risks to the project.

Where possible, actions were planned to occur in advance of the inaugural NS Club Meetings. However, medium- and longer-term goals beyond the Club Meetings were included, in acknowledgement of CLAN's commitment to continue supporting the NS Community beyond the life of the data collection timeline of the thesis. CLAN's program logic framework captured these longer-term goals and helped to inform consideration of risk management planning throughout. The program logic framework covered a ten-year period (2010–2020) and included consideration of a pandemic in the risk assessment, and this likely reflects the fact it was developed in the immediate aftermath of the H1N1 Pandemic of 2009.

A summary of the actions undertaken by CLAN between September 2010 and February 2013 is provided in Table 31 and compared with the proposed actions. The unexpected and entirely welcome inclusion of essential medicines for NS in the national insurance scheme of Vietnam by the Ministry of Health in August 2011 was incredibly powerful and allowed the researcher and all stakeholders to focus on activities beyond advocacy for access to medicines. This seismic shift also facilitated positive and encouraging messaging to the NS Community at the 2011 and 2012 NS Club Meetings. With appropriate treatment more than 90% of children could reasonably expect to enter adulthood with normal renal function, so there was much for the NS Community to be hopeful and positive about. A brief conclusion to Stage 4 is shown in Table 33.

Table 31 - Translational actions proposed and undertaken between September 2010 and March 2013 (using CLAN's pillars and framework as a guide)

Priorities	Proposed activities	Actual activities
Pillar 1. Access to medicines and equipment	- identify any urgent access issues - determine if any humanitarian donations are required in short-term - Families able to affordably access urinalysis dipsticks to optimise medical management.	- Short-term initiatives – Discussions with hospital executives and health professionals in Vietnam regarding imperative of affordable access to medicines. In August 2011 the Vietnamese Ministry of Health legislated the inclusion of medicines for the management of SRNS within the national insurance list, so educational sessions with health professionals were prioritised to ensure staff felt confident in optimal use of medicines. - Families given free samples of urinalysis dipsticks at Club Meetings in 2011 / 2012 and lectures on how to use the sticks, interpret results and take appropriate action to manage relapses early. - Lectures on importance of vaccination to prevent infection and relapses.
	- registration of any NS drugs currently unavailable in Vietnam by 11/2014 - NS management policies and strategies shared with Provincial Hospitals in Vietnam	- Medium-term – ongoing education and training for families on use of dipsticks. - Promotion of vaccines. - Biopsy needles donated to hospitals in Vietnam by ANZPNA members to support diagnosis and management
	- Medication affordably available - Health insurance schemes effectively utilised by all NS families	- Long-Term – ongoing education and training for families on use of dipsticks. - Promotion of vaccines.
Pillar 2. Education, research and advocacy	- ensure quality translated educational resources on NS available (gold standard is that locally developed resources will be available) - lectures on relevant topics at NS Club meetings - NS Resource Nurses available at hospitals - NS videos and material available to NS community - Doctors, Nurses and Allied Professionals confident with current knowledge and access to latest evidence in literature - linked with international community of specialists - general treatment guidelines and management policies up to date - Vietnamese health professionals publishing results of own research and work - Media attend Club Meetings - Sharing advocacy Videos (in Vietnamese language)	- Translation of educational resources into Vietnamese language (two booklets on NS); - NS Factsheets developed in Vietnamese language tackling key myths; - NS Club video meeting developed - NS videos developed to share stories and advice from other countries; - NS Club Newsletter with information on NS distributed at NS Club Meetings - Paediatric nephrology educational sessions for Health Care Professionals (HCPs) from across Vietnam conducted in 2011, 2012 and 2013 in both Hanoi and HCMC - Educational sessions for families / youth at Club Meetings (led by local HCPs) - Collaboration on conference abstracts and oral presentations between CLAN, CHW and HCPs in Vietnam - Connections made with NephCure – information given to raise awareness of NS in Vietnam and activities underway

Table 31 - Translational actions proposed and undertaken between September 2010 and March 2013 (using CLAN's pillars and framework as a guide)		
Priorities	**Proposed activities**	**Actual activities**
	- Clear Disability discourse communicated to broader community, resulting in more acceptance and less stigma and isolation - Share stories and updates of Vietnamese NS community nationally and internationally to inspire and encourage all and raise awareness - Use international awareness days and forum to link communities internationally	
	- Health Needs Assessment informs future action - NS database available for ongoing research - Identify donors / sponsors able to support - link with others to help with monitoring / evaluation	Research – Health Needs Assessment completed and results shared with HCPs and NS Community at meetings in February 2013; - results of HNA presented in oral presentation at IPNA in China by colleague from Vietnam (International Pediatric Nephrology Association Conference) won $500 award for best abstract and covered travel costs - Vietnamese HCPs introduced to Australian HCPs (ANZPNA) to promote research collaboration - NephCure shared information on international NS registry for consideration for use in Vietnam
	- link with NephCure - Newsletters (include information on NS; other resources) - Use CLAN, NephCure and other web-sites to raise awareness - link with other groups (e.g. Rotary, local pharma / businesses)	Advocacy – Meetings with Vietnamese Ministry of Health and Health Insurance representatives to discuss challenges, burdens and recommendations from HNA - Media invited to NS Club Meetings - Club newsletters in Vietnamese (include FAQs; latest information on NS; messages of support from international community) and video of NS Club Meeting shared with key stakeholders to raise awareness - Club reports (English) shared with all key partners internationally - Success stories / videos shared internationally (CLAN website / social media) - Abstract at NCD Child Conference in Oakland in 2012 (Appendix 2)
Pillar 3. Optimisation of medical management	- Promote vaccination: - all children up to date with national schedule - promote additional vaccines free for children with chronic conditions)	Primary prevention – promotion of vaccinations to prevent infection and reduce relapses at all Club Meetings and in all HCP training sessions
	- Screening - urine dipstick testing - families taught how to manage early relapses	Secondary prevention – training on NS for paediatricians conducted in workshops in Hanoi and HCMC to promote awareness and capacity of paediatricians across Vietnam to diagnose and manage NS.

Table 31 - Translational actions proposed and undertaken between September 2010 and March 2013 (using CLAN's pillars and framework as a guide)

Priorities	Proposed activities	Actual activities
		- Lectures and practical demonstrations given to families at NS Club meetings to help families learn how to use dipsticks / diagnose relapses early and start treatment early
	- holistic approach (bio-psycho-social) to measuring QOL outcomes - families have access to optimal medical management - chronic disease management strategies guiding OPD care - families empowered to care for their children / understand NS	- Tertiary prevention – outpatient department policies revised and communicated to families at NS Club meetings by hospital staff. - Treatment guidelines updated to minimise duration of hospitalisation / number of outpatient visits necessary. - Paediatric nephrologists in Vietnam supported to come together nationally, meet with Australian paed nephrologists and discuss opportunities for future collaboration
	- address parent fears around NS and renal failure - address myths and misconceptions - regular Club meetings - Systems in place to support newly diagnosed families - psychological support available to families - translate positive stories of adults living with NS internationally	- Holistic care – outpatient department protocols developed and promoted; positive success stories shared from NS Communities internationally to emphasise opportunities for good health outcomes with NS. - Patients and family centred care promoted in lectures for HCPs. - Pivotal role of parents and their capacity to care for children included in lectures.
Pillar 4. Encourage Support Groups	- Executive members of Club identified - introduction of Club exec to international partners (e.g. NephCure) - NS Club introduced internationally to other NS forums - Survey at 2011 Club meeting to learn more / hear voices of families living with NS to better understand the key challenges and burdens they face - evaluation survey to determine how future NS Clubs might be improved - ensure Club aware of all resources and partners available to them - photos - newsletters - link with NephCure	- Support of annual Club meetings in Hanoi and HCMC; - NS Club Meetings held in Hue (Central Vietnam) and some provinces; - Evaluation surveys conducted at NS Clubs; - NS Club executive elected by NS Community; - Communication networks established (NS Club Facebook page) - Connections with international NS Networks facilitated (NephCure; IPNA; ANZPNA) - Training sessions facilitated for families and health professionals - Messages of support and success stories from international NS Communities shared to inspire; - Australian Ambassador invited to attend NS Club Meeting
Pillar 5. Reduce financial burdens	- all efforts in pillars 1-4 will help Pillar 5 - families more empowered to manage NS at home and so present to VHCP less frequently - all children with NS should be attending school, with a view to completing university - awards given to children at Club meeting for academic success	- Messaging to parents by health professionals encouraging children to attend school; - Awards given to children at NS Club Meetings for school performance; - Stipends paid to families to help them attend the NS Club Meetings (covered travel, food, accommodation, loss of income) Department of Education officials invited to NS Club Meetings;

Table 31 - Translational actions proposed and undertaken between September 2010 and March 2013 (using CLAN's pillars and framework as a guide)		
Priorities	**Proposed activities**	**Actual activities**
	- links with Education Department if needed (share information with teachers on NS / disability discourse) - survey families to better understand the financial burdens and challenges - work with Rotary and other NGOs to explore enterprise development programs (EDP) / microfinance (MF) and vocational training (VT) options - link with Grameen where possible	- Education on early management of relapses at home to reduce need to travel; - Medicine affordably available (on national insurance scheme); - Training for paediatricians and local health professionals; - Systematic outpatient care (reduce travel and unapproved expenses) - Opportunities for funding from external parties explored; ongoing fundraising conducted by CLAN (e.g. Jarvis Bay walk)
Pillar 6. Ethical & transparent management	- Regular CLAN Meetings - Routine processes of CLAN (e.g. Meeting minutes; external financial audits; information available on CLAN website; social media engagement; Annual Reports)	- Researcher reporting into CLAN Committee regularly, as well as hospital executives in Vietnam; - Ethical governance and accountability processes; - Multilateral engagement, reporting and accountability

5.3 Stage Four conclusion

Table 32 - Stage Four of the HNA: Conclusion	
Case study notes: Stage Four of the HNA – Assessing priority for action	
Summary of the action planning process	Stage Four presented the key actions implemented throughout the HNA to improve health outcomes and redress inequities for the NS Community of Vietnam, using CLAN’s strategic framework for action and the five pillars to inform the action planning and implementation process of this HNA. CLAN’s model allowed the researcher to engage confidently with a broad range of stakeholders, and clearly communicate a shared, multisectoral and collaborative approach to critical action in real time to benefit the NS Community of Vietnam. The five pillars prompted holistic action across a broad range of priorities. The action planning process of this HNA was strengthened by the participatory action research approach of Study One, and timely feedback from the insights arising during the interviews in Study Two, enabling felt needs to inform the critical actions taken. Strong engagement from hospital executives, local health professionals and Australian experts was invaluable. Fundraising by CLAN’s Committee made it possible for CLAN to commit to supporting the critical actions conducted in parallel to the research components of the HNA.

STAGE FIVE OF THE HNA – Moving On / Project Review

5.4 Translating action to knowledge

Stage Five ("Moving on / Project review") is the final stage of the HNA. In this section, the researcher reflects on how well the action plan was implemented (see Stage Four); analyses the extent to which CLAN's Strategic Framework for Action and five pillars were able to guide critical action in accordance with the recommendations arising from the more detailed consultations conducted within the HNA; and shares key learnings that emerged to sustain future action.

5.4.1 Monitor knowledge use

The outcomes and deliverables resulting from the translational activities undertaken throughout this HNA (from September 2010 to February 2013) as guided by CLAN's five pillars are provided in Table 33. The data and evidence informing these findings were drawn from CLAN annual reports, meeting minutes and handwritten notes recorded by the researcher during the February 2013 visit to Vietnam, where the final results of the HNA were reported to each of the participating hospital executives and NS Community Members at Club Meetings in Hanoi and HCMC.

In monitoring the outcomes and deliverables emerging from the critical actions taken by the many stakeholders involved in driving change for the NS Community of Vietnam, consideration was given to the following:

i. *Conceptual knowledge use* - including changes in levels of knowledge, understanding or attitudes. Anecdotal reports indicated families' understanding of NS and its management strengthened dramatically in the twelve months after the inaugural NS Club Meetings, and the queries shared by families in the question and answer sessions reflected much deeper levels of understanding, increased confidence and fewer myths and misconceptions. Whilst data were not available on changes in vaccination levels, there was a noticeable increase in the number of questions families asked about immunisations at the 2013 Club Meetings. Health professionals responded to insights relating to the burden of travel for families and established new protocols to minimise follow-up and streamline outpatient visits at tertiary centres and prioritised the training of health professionals in regional and remote areas so families could have greater confidence in their local health professionals.

ii. *Instrumental knowledge use* – such as changes in behaviour or practice that translate to improved health outcomes. The most notable examples of this resulted from the introduction of dipstick use for urinalysis testing by families in the home, and the inclusion of NS essential medicines in the national insurance list by the Vietnamese Ministry of Health in August 2011. These two changes had major impact on health outcomes. Most families indicated they were regularly testing their child’s urine for protein at the February 2013 NS Club Meeting, initiating steroid therapy earlier to prevent relapses. Health professionals reported not just a 50% reduction in the number of hospital admissions, but also less severe relapses resulting in shorter duration of admissions. In some cases, renal wards were now taking overflow patients from other wards because of the dramatic reduction in admission numbers.

iii. *Strategic knowledge use* – submissions of abstracts on the HNA findings to international conferences gave Vietnamese health professionals increased opportunities to network with peers and raise awareness of the challenges facing children living with NS in Vietnam. New collaborations with colleagues from the Australia New Zealand Paediatric Nephrology Association (ANZPNA) focused on opportunities to strengthen renal transplantation and replacement therapy options for children in Vietnam. The researcher likewise integrated key learnings from the NS Community into global advocacy efforts she was engaging in through the work of CLAN and NCD Child.

Table 33 - Translational activities undertaken between September 2010 and February 2013 to benefit the NS Community of Vietnam (using CLAN’s 5 pillars as a guide) with resultant outcomes and deliverables

Priorities	Translational activities (September 2010 to February 2013)	Outcomes and deliverables (as at February 2013)
Pillar 1. Access to medicines and equipment	- Short-term initiatives – Discussions with hospital executives and health professionals in Vietnam regarding imperative of affordable access to medicines. In August 2011 the Vietnamese Ministry of Health legislated the inclusion of medicines for the management of SRNS within the national insurance list, so educational sessions with health professionals were prioritised to ensure staff felt confident in optimal use of medicines. - Families given free samples of urinalysis dipsticks at Club Meetings in 2011 / 2012 and lectures on how to use the sticks, interpret results and take appropriate action to manage relapses early. - Lectures on importance of vaccination to prevent infection and relapses.	- August 2011 – Vietnamese Ministry of Health legislates inclusion of essential medicines for management of NS within national insurance scheme; - Lectures for HCPs on optimal management of NS and use of newly available NS medicines (>300 staff attend in 2012-13) and certificates issued for participation - Vaccinations promoted to all families and health professionals attending Club Meetings and training sessions - Free dipsticks given to all families attending NS Club Meetings in 2011 / 2012 / 2013 with educational sessions on use for management of NS / treatment of early relapses - Biopsy needles donated to Hue hospital by members of ANZPNA to support local diagnosis and management of SRNS
	- Medium-term – ongoing education and training for families on use of dipsticks. - Promotion of vaccines. - Biopsy needles donated to hospitals in Vietnam by ANZPNA members to support diagnosis and management	

Table 33 - Translational activities undertaken between September 2010 and February 2013 to benefit the NS Community of Vietnam (using CLAN's 5 pillars as a guide) with resultant outcomes and deliverables

Priorities	Translational activities (September 2010 to February 2013)	Outcomes and deliverables (as at February 2013)
	- Long-Term – ongoing education and training for families on use of dipsticks. - Promotion of vaccines.	
Pillar 2. Education, research and advocacy	- Translation of educational resources into Vietnamese language (two booklets on NS); - NS Factsheets developed in Vietnamese language tackling key myths; - NS Club video meeting developed - NS videos developed to share stories and advice from other countries; - NS Club Newsletter with information on NS distributed at NS Club Meetings - Paediatric nephrology educational sessions for Health Care Professionals (HCPs) from across Vietnam conducted in 2011, 2012 and 2013 in both Hanoi and HCMC - Educational sessions for families / youth at Club Meetings (led by local HCPs) - Collaboration on conference abstracts and oral presentations between the researcher, CHW and HCPs in Vietnam - Connections made with NephCure – information given to raise awareness of NS in Vietnam and activities underway	- Two booklets on NS translated, and 3000 copies were printed and available to be given free to all families and health professionals attending Club Meetings - NS Club factsheet and newsletters in Vietnamese printed and given free (contained information on myths and FAQs) to over the 400+ families attending meetings in 2011, 2012 and 2013; - Education sessions for HCPS on NS as above (workshops and case study sessions on wards); - NS Videos in Vietnamese sharing success stories / voices of children from NephCure - HCPs in Vietnam connected with colleagues in ANZPNA and IPNA
	- Research – Individual HNA reports developed for each participating hospital and their individual NS Communities, sharing local results and feedback - Conference presentations and abstracts / posters achieved collaboratively - Vietnamese HCPs introduced to Australian HCPs (ANZPNA) to promote research collaboration - NephCure shared information on international NS registry for consideration for use in Vietnam	- Results of HNA presented in written reports and face-to-face meetings with individual hospital executives at each of the participating hospitals - Results of HNA communicated back to NS Club participants at 2013 NS Club Meetings in Hanoi and HCMC - Results of HNA presented in oral presentation at IPNA in China by colleague from Vietnam (International Pediatric Nephrology Association Conference) won $500 award for best abstract and covered travel costs - Vietnamese HCPs self-publishing papers (genetic testing; and SRNS in 2018) - NCD Child poster (Oakland Conference in 2012) - NephCure shared information on NS register used internationally; Vietnam invited to participate (declined) - NS HNA templates adapted by staff in Hanoi to conduct a HNA to better understand situation for children living with Systemic Lupus Erythematosus in Vietnam.

Table 33 - Translational activities undertaken between September 2010 and February 2013 to benefit the NS Community of Vietnam (using CLAN's 5 pillars as a guide) with resultant outcomes and deliverables		
Priorities	**Translational activities (September 2010 to February 2013)**	**Outcomes and deliverables (as at February 2013)**
	- Advocacy – Meetings with Vietnamese Ministry of Health and Health Insurance representatives by the researcher to discuss challenges, burdens and recommendations from HNA - Media invited to NS Club Meetings - Club newsletters in Vietnamese (include FAQs; latest information on NS; messages of support from international community) and video of NS Club Meeting shared with key stakeholders to raise awareness - Club reports (English) shared with all key partners internationally - Success stories / videos shared internationally (CLAN website / social media) - Conference abstracts submitted	- Updates on Vietnam shared with NephCure - Vietnamese HCPs supported to attend IPNA Conference and present - the researcher participated in meetings with Ministry of Health and Health Insurance representatives to discuss HNA; - Media attended 2011–12 NS Club Meetings – footage on television in Vietnam - NS Club video developed and shared with key stakeholders to raise awareness - NS Club Newsletters contain key messaging on inclusion, the rights of children to health and life and work of NCD Child - NCD Child advocacy promoting voices of children and young people in the international NCD discourse - Poster at 2012 NCD Child Conference.
Pillar 3. Optimisation of medical management	- Primary prevention – promotion of vaccinations to prevent infection and reduce relapses at all Club Meetings and in all HCP training sessions	- Vaccination promoted at all NS Club Meetings and HCP training sessions
	- Secondary prevention – training on NS for paediatricians conducted in workshops in Hanoi and HCMC to promote awareness and capacity of paediatricians across Vietnam to diagnose and manage NS. - Lectures and practical demonstrations given to families at NS Club meetings to help families learn how to use dipsticks / diagnose relapses early and start treatment early	- Families taught how to test urine. At 2013 NS Club Meeting families asked for show of hand and overwhelming majority of families were now testing urine at home. - Families taught how to start prednisone at home early to prevent relapses progressing. - Hospital admissions for NS had reduced 50% by February 2013 at one participating hospital. Renal ward caring for overflow patients from other wards due to empty beds.
	- Tertiary prevention – outpatient department policies revised and communicated to families at NS Club meetings by hospital staff. Treatment guidelines updated to minimise duration of hospitalisation and number of outpatient visits - Paediatric nephrologists in Vietnam supported to come together nationally, meet with Australian paediatric nephrologists and discuss opportunities for future collaboration	- Nurses in renal wards providing educational support (using NS Booklets) to families during hospital admissions for NS by February 2013. - Situation for children requiring renal replacement therapy acknowledged as dire, and requests to connect with ANZPNA and IPNA colleagues to explore opportunities to support renal transplantation for children
	- Holistic care – outpatient department protocols developed and promoted; positive success stories shared from NS Communities internationally to emphasise opportunities for good health outcomes with NS. Patients and family centred care promoted in lectures for HCPs. Pivotal role of parents and their	- Videos of success stories shared from international NS Communities - NS Club Meetings supported annually in Vietnam by CLAN until 2017 - Families connecting using Facebook by 2013.

Table 33 - Translational activities undertaken between September 2010 and February 2013 to benefit the NS Community of Vietnam (using CLAN's 5 pillars as a guide) with resultant outcomes and deliverables		
Priorities	**Translational activities (September 2010 to February 2013)**	**Outcomes and deliverables (as at February 2013)**
	capacity to care for children included in lectures.	- questions at NS Club meetings in 2013 indicate much higher levels of understanding, fewer myths and increased positivity.
Pillar 4. Encourage Support Groups	- Support of annual Club meetings in Hanoi and HCMC; - NS Club Meetings held in Hue (Central Vietnam) and some provinces; - Evaluation surveys conducted at NS Clubs; - NS Club executive elected by Community; - Communication networks established (NS Club Facebook page) - Connections with international NS Networks facilitated (NephCure; IPNA; ANZPNA) - Training sessions facilitated for families and health professionals - Messages of support and success stories from international NS Communities shared to inspire; - Australian Ambassador invited to attend NS Club Meeting	- NS Club Executive working with local HCPs to plan and implement Club Meetings annually - NS Community using Facebook to connect - FAQs and feedback at 2013 NS Club Meetings demonstrate improved situation for NS Community of Vietnam - Evaluation at 2013 NS Club indicates high degree of satisfaction with Club Meeting; requests for more meetings; high engagement at all three participating hospitals (>400 families attended 3 Club Meetings) - local businesses supporting Club Meetings
Pillar 5. Reduce financial burdens	- Messaging to parents by health professionals encouraging children to attend school; - Awards given to children at NS Club Meetings for school performance; Stipends paid to families to help them attend the NS Club Meetings (covered travel, food, accommodation, loss of income) - Department of Education officials invited to NS Club Meetings; - Education on early management of relapses at home to reduce need to travel; Medicine affordably available (on national insurance scheme); - Training for paediatricians and local health professionals; - Systematic outpatient care (reduce travel and unapproved expenses) - Opportunities for funding from external parties explored; ongoing fundraising conducted by CLAN (e.g. Jarvis Bay walk)	- 50% reduction in hospital admissions to one hospital by Feb 2013 - medicines affordably available - fewer relapses - new OPD processes streamlining attendance - families required to attend OPD for f/u care less frequently - almost all families testing urine at home for protein by Feb 2013 - high attendance at NS Club Meetings by families (>400 families at Club Meetings in 2011-12 and in 2013)
Pillar 6. Ethical & transparent management	- Researcher reporting into CLAN Committee regularly, as well as hospital executives in Vietnam; - Ethical governance and accountability processes; - Multilateral engagement, reporting and accountability	- Final presentation on results of HNA shared with all three participating hospital executives in 2013; - CLAN maintains incorporation status as Non-Government Organisation in Australia; full signatory to ACFID Code of Conduct; Fundraising certification; External audit of CLAN finances annually – findings reported in CLAN's Annual Report

5.4.1 Evaluate outcomes

Evaluation of the processes and outcomes associated with the HNA and implementation of CLAN's strategic framework for action to drive critical action for the NS Community of Vietnam was facilitated by use of the RE-AIM framework that considered Reach; Efficacy; Adoption; Implementation; and Maintenance.

a) Reach

The HNA had strong support from the three largest children's hospitals in Vietnam and this was undoubtedly instrumental in the early decision by the Vietnamese Ministry of Health to include essential NS medications in the national insurance scheme. This single action made it possible for all children diagnosed with NS in Vietnam to afford access to the care needed to survive and thrive.

There was strong engagement from NS Community members in the HNA process, with response rates averaging 84%, and a conservative estimate of 20% of the entire NS Community involved in NS Club Meetings in 2011–2012. Whilst the researcher acknowledges the families consulted likely constituted a "survivor cohort", there were benefits to learning more about the strengths many families draw on to help their child with NS survive.

Future NS Club Meetings and HNAs would be advised to consider in advance the actions that might be taken to redress barriers to equitable engagement and participation. Specific efforts that deliberately seek out families known to live in the most vulnerable circumstances (perhaps using the CHECC tool) would allow these voices to be louder.

b) Efficacy

The parent surveys proved an effective way to survey large numbers of families in a cost-effective manner. With the recent advances in technology, the researcher would advise any future consultations make full use of digital tools and consultation processes, because the translation, collation, analysis and write up of large numbers of responses was undoubtedly the biggest impost on the researcher's time in this HNA.

With regard to the critical actions taken throughout the HNA, it is difficult to argue that they were not effective, efficient and feasibly resourced. The anecdotal reports of 50% reductions in hospital admission numbers, severity and duration are remarkable, and reflect the commitment of all stakeholders involved. CLAN's modest fundraising efforts were supplemented by the strong commitment by the Vietnamese government for this project, and whilst the cost–benefit of all investments has not been formally analysed, this would be a worthy focus of future research.

In the years since this HNA was conducted technology has advanced greatly, and the researcher would strongly encourage future groups keen to undertake a HNA to embrace technological options to facilitate consultation processes. Without doubt the handling and analysis of data was a major rate-limiting step for the researcher, and any opportunities to streamline this should be embraced in future!

c) Adoption

The HNA was supported by the three largest children's hospitals in Vietnam, and NS Club Meetings were later expanded to Hue Central Hospital and several provincial hospitals at the request of local health professionals and with the support of tertiary centre expertise. Translation of the NS HNA templates to SLE was driven by one of the tertiary centres, and the researcher and EH were pleased to attend and support the inaugural SLE Club Meeting held in Vietnam in 2013.

d) Implementation

This HNA was an opportunity to analyse the capacity of CLAN's strategic framework for action to guide the implementation of critical action to benefit the NS Community of Vietnam.

The retroductive approach to analysing the challenges, burdens, strengths and recommendations shared by families using the four planes of agency in Study Two helped inform a fresh consideration of the underlying structural causes and facilitated a comprehensive exploration of possible critical and *realistic* actions to drive change. These findings were then cross-checked against CLAN's five pillars (Table 33), and consideration given to actions identified in the HNA that were missing from CLAN's Action Plan (marked in red in Table 34), thereby identifying possible gaps in CLAN's model, and opportunities to strengthen future implementation plans.

Overall, CLAN's strategic framework for action proved very effective at identifying critical actions in line with the recommendations that ultimately emerged from families and other stakeholders consulted throughout the HNA. Suggestions that could not be implemented (such as "find a cure for NS") were, unsurprisingly, amongst the actions not included in CLAN's Action Plan. The vital importance of engaging and involving multisectoral stakeholders was highlighted by the comparison, and whilst CLAN's framework facilitates this, the pillars do not explicitly hold the implementation process accountable to ensuring these stakeholders are engaged. The importance of this becomes clear when considering recommendations relating to supporting children to stay in school, for example. If the Department of Education is not involved, it is reasonable to assume the school system will not change any barriers preventing children with NS (and other children in hospital for long periods because of chronic health conditions) from completing their education.

The other opportunity to strengthen CLAN's strategic framework would be to strengthen the focus on children living in the most vulnerable circumstances. CLAN's model is based on the assumption that all children with chronic health conditions in resource-poor settings are at risk, and yet, the reality is there are cohorts within cohorts. Children from ethnic minority groups, female children, children from single parent families, children from the most impoverished families, children who live long distances from quality health care services and children whose parents have very limited education are amongst the most vulnerable groups of children. At their time of their child's diagnosis with a complex chronic condition these families require especial support if the child's rights to life and health are to be respected and protected.

e) Maintenance

Whilst the data collection period of this HNA ended in March 2013, the researcher and CLAN were proud to continue supporting annual NS Club Meetings in Vietnam until 2017. Inclusion of essential medicines in the national insurance scheme contributed greatly to the capacity of all stakeholders to continue supporting the Community in a meaningful way. So too did the incredible generosity of Australia paediatric nephrologists who freely gave of their time and expertise to support colleagues and the NS Community in Vietnam. Recent correspondence with health professionals in Vietnam indicates challenges relating to NS are no longer a major issue, but rather supporting children with ESKD has become a critical priority.

Table 34 - Cross-checking the recommendations emerging from the HNA against CLAN's Strategic Framework for Action

Theme 1–Material transactions with nature		
Subthemes	**Examples of critical actions identified by the HNA**	**Fit with CLAN's Five Pillars**
Fears about the physical impact of NS and its treatment - Fear of complications - Fear of relapse - The chronic nature of NS	- strengthen access to essential, quality medication, equipment and investigations	Pillar One
	- communicate accurate messages around prognosis (based on international and national experience) - Information and education to reduce fear, misunderstanding, myths and misconceptions	Pillar Two
Fears about the future for children with NS - Fear of the unknown - Fear for future generations	- strengthen access to quality medical care - vaccination / immunisation to reduce infection and relapses - appropriate OPD care and management - Find a cure for NS and make available to all - reduce the physical impact of NS	Pillar Three
Fears about the broader impact of NS - Impact on health, life, school - Impact on the future	- Strengthen support networks	Pillar Four
	- Support children with NS to attend school / continue with their studies. Children may need additional support to continue education - Vocational training - UHC / insurance / social support networks and financial protection systems that prevent impoverishment	Pillar Five
Theme 2 – Social interactions between people		
Subthemes	**Examples of critical actions identified by the HNA**	**Fit with CLAN's Five Pillars**
Failure of children to fulfil their true potential in life		Pillar 1
		Pillar 2

Table 34 - Cross-checking the recommendations emerging from the HNA against CLAN's Strategic Framework for Action

The importance of support systems	- disseminate information to reduce myths (e.g. marriage, infertility, genetic counselling) - positive social dialogue / reduce stigma at national and community / and school levels	
	- acknowledge high regard families have for doctors / how can doctors play key role in sharing messages given resource restrictions / lack of time / busy OPDs? Need clever way to communicate with many - psychological support and counselling for families, children and health professionals	Pillar 3
	- promote social support networks (for families, parents and children) - promote opportunities for families to connect and share their experiences with one another	Pillar 4
	- support to maintain education level and vocational training	Pillar 5
Theme 3 – Social structure		
Subthemes	**Examples of critical actions identified by the HNA**	**Fit with CLAN's Five Pillars**
Reliance on the health system		Pillar 1
Bureaucratic burdens	- empower and educate families to help reduce strain on health system - provide detailed, quality educational materials and resources to families to strengthen their capacity to care for their children - find a cure for all (rich and poor) - translate / disseminate educational resources	Pillar 2
Financial burdens	- reduce the burden on health systems - find innovative solutions to increase the amount of time / access families have to qualified health professionals (e.g. strengthen local access; NS Club meetings; hotline) - reduce amount of hospitalisations / travel to hospitals / lost time at work for families / financial burden on families	Pillar 3
	- establish charitable organisations and funds to support NS Community	Pillar 4

Table 34 - Cross-checking the recommendations emerging from the HNA against CLAN's Strategic Framework for Action

Future earning capacity	- UHC / financial protection for families - strengthen health insurance system for chronic conditions - ensure safety nets are in place for those with severe illness – ensure palliative care available to those who are not expected to survive - facilitate targeted action to support the most vulnerable families (such as the poor, those living in remote areas, those with low education levels, single parent families etc) - strengthen local health systems - encourage families to maintain education of child as a priority from start / positive messages at time of diagnosis	Pillar 5
	- health and education systems in communication / shared goals - ensure all levels of government are engaged	Pillar 6 (process of multisectoral engagement)
Theme 4 – Stratification of the embodied personality		
Subthemes	**Examples of critical actions identified by the HNA**	**Fit with CLAN's Five Pillars**
Adverse psychological impact – anxiety, fear		Pillar 1
Coping mechanisms / resilience	- Provide educational resources - empower families / help them to feel effective and involved in care of their children - develop fact sheets and educational resources that debunk common myths and address misconceptions and knowledge gaps	Pillar 2
The role of myths where information is absent or inaccurate	- psychological counselling and support - find ways to reduce stress for families and young people	Pillar 3
Confidence	- connect families for support - offer families hope, encouragement and optimism (e.g. by sharing success stories and positive, hopeful messages)	Pillar 4
Stages of grieving and crisis		Pillar 5

5.4.3 Sustain knowledge use

The power of a committed and dedicated cohort of local health professionals in a country to improve health outcomes for entire communities of children living with chronic health conditions cannot be overstated. Whilst active involvement of families of children living with NS strengthens sustainability through community development, the very nature of NS when it is optimally managed (with 90% of children entering adulthood with normal renal function) means there will always be membership turnover in the NS Community, so the Community will always need support from committed health professionals and other organisations to achieve truly sustainable patient- and family-led initiatives.

The researcher, CLAN and other stakeholders played key supportive roles in this HNA, but it was the identification of NS as a public health priority by Vietnamese health professionals and the commitment from the Ministry of Health to make NS medications available to all families that made every achievement possible. Indeed, Vietnam is to be truly admired and congratulated on their genuine commitment to redressing inequities for the NS Community. Affordable access to essential medicines and equipment is too often overlooked as an imperative to helping children with chronic conditions survive and thrive, but this HNA demonstrates very clearly the change that is possible when all stakeholders come together with a shared goal of driving sustainable change. Every member State has the opportunity to review their national essential medicines lists, compare them against the WHO's Essential Medicines List for Children, identify local gaps and health priorities, and take action to redress inequalities for children. It is beyond the capacity of NGOs to sustain long-term access to affordable medicines for entire communities of children, and countries committed to equity for all must focus closely on the content and use of their national medicines lists for children.

Universal health coverage that protects the most vulnerable from catastrophic health expenses offers the greatest hope of sustainably redressing inequities for #EveryChild. Health systems that rapidly identify those children at greatest risk will have the greatest impact on child survival. Children from the most impoverished families; children from ethnic minority groups; children from single parent families; children whose parents have low educational levels; children who live long distances from quality health care services; and female children are all at especial risk. Special actions must be taken to support these children and their families at the time of diagnosis of any chronic health condition.

A strengths-based approach to supporting children and families living with chronic health conditions in resource-poor settings is an essential component of sustained knowledge use. Families are passionate about helping their own children, so investing in the capacity of parents and guardians to care for their children, and effectively manage their chronic health condition is perhaps the greatest investment any health system can make. Parents are strong, powerful, resilient and committed to their children. They are the best allies any child can have, and desperately keen to partner with others to ensure their children reach their full potential. Health systems must acknowledge the basic maxim that time is money, and the reality it holds for the parents of children living with chronic conditions in resource-poor settings. All actions that save families time will save money and save lives.

The researcher has developed a CHEAR (Child Health Equity Action Resource) Toolkit that contains the pivotal knowledge tools, products and resources developed throughout this HNA, and offers them freely to others to share and use for the benefit of children living with chronic health conditions everywhere (Appendix 1). In particular, the researcher would welcome collaboration with others to pilot use of the CHECC (Child Health Equity Count Check) Scorecard, to facilitate rapid identification of children at most risk of not surviving the diagnosis of a chronic health condition. Empowering families, young people and communities to optimally manage NS will inevitably benefit health systems and transform expressed needs.

At an international level, the researcher plans to continue advocating for the inclusion of children and young people in the global NCD discourse, and a human rights-based approach to ensuring all children in resource-poor settings have the best chance possible to survive and thrive. The key findings from this HNA (and the templates, tools and resources developed) are eminently transferrable to other chronic health conditions (as was demonstrated in Vietnam, with the use of the HNA templates translated to SLE). There are significant proportions of all children affected by chronic conditions in all countries. In 2017, more than 2.1 billion children were affected by NCDs [254] and UNICEF estimates that people under the age of 20 years account for 13% of all NCD-related mortality, with 1.2 million young people dying from treatable NCDs each year [319]. Hence, there is an opportunity and imperative for all Member States to engage with paediatricians and other health professionals in their own countries to identify those communities of children suffering the greatest inequities. We cannot allow perfectionism to paralyse us. Change is imperative and possible.

5.5 Stage Five conclusion

Table 35 - Stage Five of the HNA: Conclusion	
Case study notes: Stage Five of the HNA – Moving on / Project review	
How well was the action plan implemented?	CLAN Action Plan was implemented well, with completion of almost all proposed actions according to (and ahead of) plan. CLAN's Action Plan aligned well with the recommendations identified in the HNA.
What was achieved by the project?	Health outcomes of children living with NS in Vietnam were improved; hospital admissions were reduced and the severity of NS relapses reduced. Families continued to attend NS Club Meetings, and the Community's overall standard of health literacy improved – supported by the educational resources translated into Vietnamese and education and training provided by local health professionals. Essential NS medicines were included in the national insurance scheme in 2011, and urinalysis by families at home was undertaken by a majority of families.
How did it contribute to reducing inequalities?	Children living with NS in Vietnam now have the potential to enjoy a quality of life on par with that of children living with NS in Australia. They have access to the medicines, healthcare and support needed to survive and thrive life with NS.
What was learned through the project's successes and challenges?	There is a need to focus on children who are diagnosed with chronic conditions and living in the most vulnerable circumstances. This HNA led to the development of a CHECC list to help health professionals identify these children early. Member States and local health systems must take responsibility (as per UNCRC) to ensure the special actions needed to keep these children alive are implemented.
What needs to happen next?	Sharing of the CHECC list with paediatricians in the Asia Pacific region. Publishing the key learnings from this HNA and the experiences of the NS Community in Vietnam. Advocate for the active collaboration of education and health systems to benefit children living in vulnerable circumstances with chronic conditions.
What new priority was chosen for the population?	Children living with ESKD in Vietnam and other resource-poor settings are currently suffering enormously. Palliative care and other options to protect and promote the human rights of this community of children should be explored.
What main message from the last HNA will you take forward to the next?	Children living in the most vulnerable circumstances need especial action to ensure their basic human rights to survive and thrive are met.

CHAPTER 6 – THESIS CONCLUSION

Overall summary

This HNA was designed to strengthen an understanding of the challenges and burdens facing children and families who were living with NS in Vietnam; identify key recommendations for change; and where possible, facilitate critical action to redress inequities and improve health outcomes in real time. These goals were achieved. The HNA focused on NS because local hospital executives and health professionals identified NS as an urgent public health priority associated with unacceptable inequities and preventable burdens. Health professionals have a moral responsibility to identify and engage urgent support for communities of children whose basic human rights are at risk, and the Vietnamese health system has much to celebrate in the passion for and commitment to child health and wellbeing demonstrated daily by paediatricians across the country.

The NICE HNA framework informed a practical approach to gathering information and implementing realistic actions, and complemented CLAN's strategic framework for action. HNAs can take much time, energy and resources and, at worst, reporting burdens can make HNAs seem overwhelming and may even prevent well-meaning stakeholders from engaging in critical action. However, the benefits of formalised processes that involve appropriate ethics applications, strong governance processes, oversight by appropriate experts and authorities, and genuine multi-stakeholder commitment to critical, collaborative and participatory action justified such costs in this research project.

The literature review and consultation with health professionals and other health system officials offered strong foundational insights into the challenges and burdens facing the NS Community of Vietnam. Studies One and Two focused particularly on understanding the felt needs of the NS Community and their recommendations for change. Families identified five major concerns: financial burdens; the chronic, relapsing nature of NS; lack of knowledge about NS; psychosocial burdens and challenges accessing quality health care. Families consistently demonstrated a deep desire to care for their children to the best of their ability, but requested help finding the information, support and resources necessary to achieve this. Indeed, families demonstrated enormous resilience, commitment, fortitude and dedication to their children, and the researcher came to respect all members of the NS Community as members of a strong survivor cohort.

The many stakeholders consulted for this HNA identified recommendations for realistic actions that could be taken to improve health outcomes and redress inequities. These recommendations closely aligned with CLAN's five pillars: strengthen access to quality health care, equipment and targeted NS specific innovations; help families learn more about NS; optimise medical management; provide support for the most vulnerable families and help relieve families' financial burdens. CLAN's five pillars and strategic framework for action proved extremely effective guides to pre-emptive, comprehensive, critical action whilst more detailed insights from families and other stakeholders were still being obtained. CLAN's framework facilitated a broad range of rapid, cost-effective initiatives that were effective in saving lives and driving change for the NS Community at a national level, as indeed they had previously to benefit children living with CAH in Vietnam.

Strengths and limitations

Whilst lack of objectivity was a consistent risk to this research project because of the researcher's varied positionality, it was useful to reflect on the strengths and limitations of this body of work (as summarised in Table 36). Strengths and weaknesses were analysed with respect to the nature of NS as a chronic condition; the capacity of CLAN's strategic framework for action, experiences and existing resources to drive change; use of the NICE HNA framework and development of the CHEAR Toolkit; the role of the candidate and team that was built; engagement of all stakeholders and the translation of findings to address inequities associated with other chronic conditions of childhood nationally and internationally.

Some limitations were identified (notably the resource intensive approach to data collection, handling and analysis), but generally they were effectively mitigated and did not adversely impact the overall research project. Language barriers for the researcher (who does not read nor write Vietnamese), lack of patient registries and electronic medical records, and limited access to clinical databases were such examples, with the engagement of cultural mentors, and contributions of quality translators and dedicated local health professionals proving effective risk management strategies. The delay experienced by the researcher in finalising the write-up of the thesis was serendipitous in some ways, because it allowed for the independent research findings of local health professionals to be published first, allowing more objective insights into the real-world outcomes and sustainability of the program to inform a more detailed consideration of appropriate next steps.

Future directions

It is clear that key learnings from this HNA can and should now be transferred to driving change for children living with NS and other chronic health conditions in the most vulnerable circumstances around the world. This initiative had very modest funding, yet it has shown that a strategic, collaborative approach, when endorsed and supported at the highest level of a health system, can effect transformative change within a generation. Whilst anecdotal and published data emerging since this research project suggest children living with NS in Vietnam are experiencing greatly improved health outcomes, there remains much to do for children who are diagnosed with ESKD in Vietnam and beyond. Humane approaches to palliative care where renal replacement therapies are unavailable or unaffordable must be a priority for us all.

On that note, the CHECC Scorecard is perhaps the most exciting and innovative tool to emerge from this research project. The researcher looks forward to working with others to pilot and refine the CHECC tool in a range of settings with a view to empowering health professionals and systems to rapidly identify and instigate especial and urgent support for children who are newly diagnosed with chronic conditions, living in the most vulnerable circumstances and therefore at greatest risk of failing to survive and thrive. Whilst the other purpose-built information gathering templates developed in this HNA were very effective, the researcher would caution against a one-size-fits-all approach to implementation and would suggest future HNAs ensure all tools emerging from this HNA are tailored to local context, culture and circumstances before use. The researcher would also recommend that future HNAs harness more efficient, automated, digital methods to streamline data collection, analysis and reporting.

Beyond the conduct of HNAs, this research project has clearly demonstrated that CLAN’s strategic framework for action and collaborative approach to community development offers hope for those seeking to drive critical action to improve health outcomes and redress inequities for children living with chronic conditions in resource-poor settings. Use of CLAN’s model in this HNA demonstrated the broad range of stakeholders that needed to be involved, and indeed their engagement was contributory to the positive and sustainable project outcomes. Efforts must be comprehensive, holistic and multisectoral.

Whilst it is imperative for health professionals to identify and support individuals and families at especial risk rapidly, health systems can also learn from the actions of health authorities in Vietnam and consider entire communities of children living with chronic health conditions that might be inequitably burdened by preventable morbidity and mortality. Just as health authorities in Vietnam identified the NS Community as requiring especial support to redress health inequities in 2010, there is opportunity to consider other communities in need of urgent action. There is scope to develop and implement rapid equity indicators to identify other NCD communities internationally living in the most perilous and heartbreaking of circumstances. Use of the CHECC tool in newborn screening programmes offers one such opportunity. Professional societies offer another platform for collaborative action, and the indicators trialled by CLAN and in the 2015 Asia Pacific Snapshot Survey of Paediatric Endocrinologists (APPES) demonstrated the effectiveness of identifying communities of children at immediate risk of dying through a focus on incidence; prevalence; morbidity / quality of life; mortality / loss to follow up; access to essential medicines, equipment and quality health care; existence of family support groups and health information resources in local languages; and other perceptions of specific barriers to survival [377].

Rapid assessments such as these that inform critical, cost-effective action, advocacy and engagement of civil society and government agencies alike, have the potential to drive real change. By analysing and comparing indicators between nations we can identify those cohorts of children who are living in the most vulnerable situations, and prioritise the critical actions required to redress the greatest inequities children in our region face. In this way, we can systematically, equitably and transparently advance action until the challenges and burdens facing all of the most vulnerable childhood communities have been addressed. Only in this way do we stand a chance of achieving that most lofty goal: #LeaveNoChildBehind.

Table 36 - Overview of thesis strengths and limitations		
Factors	**Strengths**	**Limitations**
Nature of Nephrotic Syndrome (NS)	- NS is a common condition of childhood - There is enormous inequity associated with NS globally - NS has a good prognosis when managed appropriately	- Because NS resolves spontaneously in most children as they grow older (similar to asthma, for example), the Community of people living with NS changes over time. This affects the sustainability of community development approaches (compared with type 1 diabetes or CAH Communities, for example, where Community members live with the condition their entire lives)
CLAN experiences, Strategic Framework for Action and five pillars	- CLAN's model translated effectively from CAH and diabetes to NS - Existing tools and resources previously used by CLAN to support CAH, diabetes and autism were rapidly adapted to NS - Fundraising efforts enabled critical actions for the NS Community of Vietnam to be implemented in real time - Focus on felt needs offered fresh insights into challenges and burdens that informed critical action and had positive effect on health outcomes	- CLAN's model had not previously been used to address Nephrotic Syndrome - Whilst CLAN's model has been successfully translated to address inequities associated with other NCDs of childhood in countries other than Vietnam, the model had not yet been replicated to support another NS Community internationally.
Use of the HNA and development of the CHEAR Toolkit	- The tools and resources developed in this HNA are now available in the CHEAR Toolkit - The Participatory Action Research approach to the development of information gathering tools proved effective, as did the HNA framework - Technical and digital achievements in recent years offer new ways of working into the future	- Manual collection, handling and analysis of the data was time consuming and labour intensive and not ideal for use with larger communities - The absence of an NS specific register and electronic database limited the nature and quality of information collected from 2011–13.
Candidate	- The candidate brought several strengths (medical, child health and public health qualifications; insider knowledge of a mother caring for a child with a chronic condition; capacity and commitment to working collaboratively and cross-culturally) - The candidate engaged a cultural mentor to guide and strengthen efforts	- The candidate had no prior knowledge or experience supporting children living with NS in Australia or Vietnam. In hindsight, this perhaps demonstrates even more clearly the effectiveness of the CLAN model - The candidate did not read, speak or write Vietnamese

		- The candidate was the President and Founder of CLAN, so there was a constant risk to objectivity.
Team	- A broad range of partners and stakeholders was engaged to make this research project a success - Support from the Vietnamese government strengthened sustainability and systems approaches - Dedicated health professionals from Vietnam and Australia were actively engaged and provided in-kind support - The NS Community identified and elected executive leadership - CLAN's Committee provided strong support and long-standing commitment to the NS Community - The cultural mentor strengthened the project	- Limited resources and funding led to a reliance on generosity of spirit and in-kind resources but limited the capacity of the researcher and CLAN to translate findings to other NS Communities in other resource-poor settings. This was overcome through dedicated fundraising by CLAN, strong support from the Vietnamese government and health system and in-kind contributions of many other stakeholders
Engagement	- Involvement of multiple centres (the three largest children's hospitals in Vietnam, representing Hanoi and Ho Chi Minh City) suggests results and findings are relevant to the national NS Community of Vietnam - High response rates to surveys and high engagement with interview process suggests families found approach culturally safe and appropriate - Strong support by the Vietnamese government and health system and legislative change that made medication affordable had major impact on the success of the HNA - Ongoing engagement and contact between the researcher, Australian experts and local health professionals since the project ended has facilitated longer-term, sustainable change	- Over-burdened health professionals and systems limited the nature and quality of clinical data that was available to the researcher. This was overcome by involving health professionals in the collation of clinical data in a dedicated section of the interview process. - Whilst nationwide data was not available, rollout of NS Club Meetings to regional centres after the research project finished has facilitated ongoing learning and change, with local health professionals since publishing research data and findings independently on NS in Vietnam.
Translation to other conditions	- Adaptation of the information gathering tools to facilitate consultation with the SLE Community of Vietnam in 2014 indicates local stakeholders found the approach effective and appropriate. - CLAN has since translated the information gathering tools to support consultation with the Nodding Syndrome Community of Uganda	- The research findings have not yet been translated to support change for another NS Community internationally. - The qualitative data were collected from 2011-12 so the findings are not completely translatable – particularly with regards technological advances.

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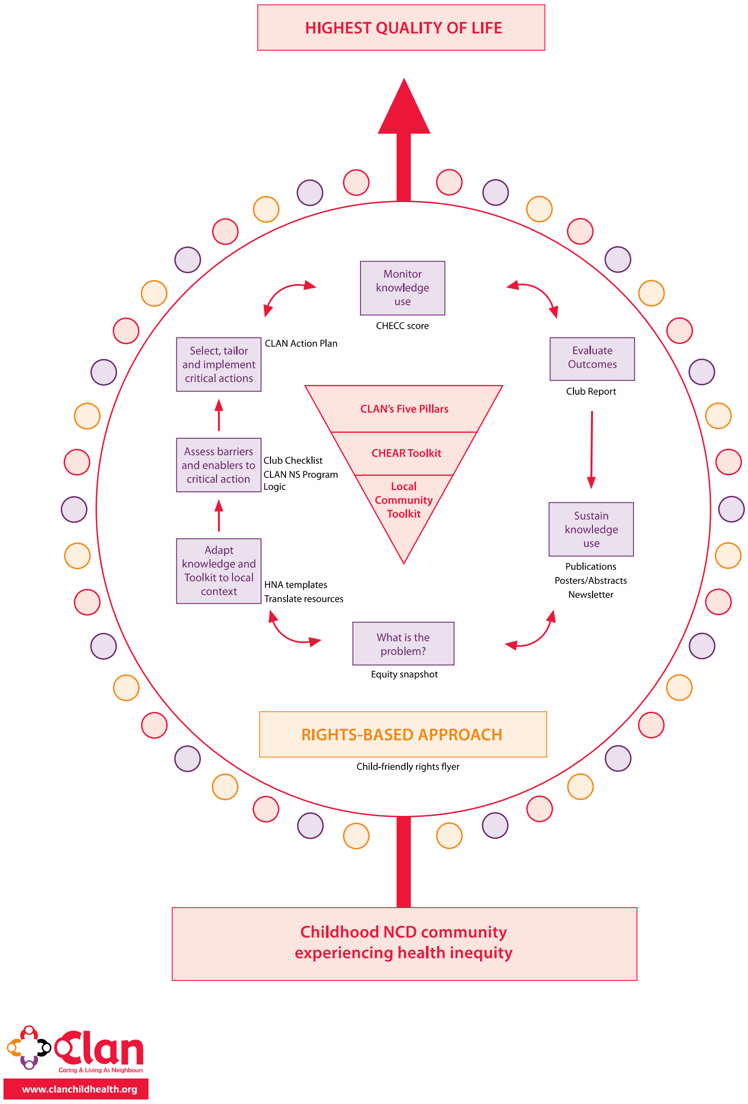
APPENDICES

Appendix 1: CHEAR Toolkit

In the Child Health Equity Action Resources (CHEAR) Toolkit key tools and resources developed during this HNA are collated one place for easy use by others interested in considering critical action to support others. In the diagram below, the interplay between CLAN's strategic framework for action and the Knowledge To Action framework is shown, to illustrate when and how the seven key tools developed during this HNA can be used to support critical action to benefit children living with NS (and other chronic health conditions of childhood) in resource-poor settings.

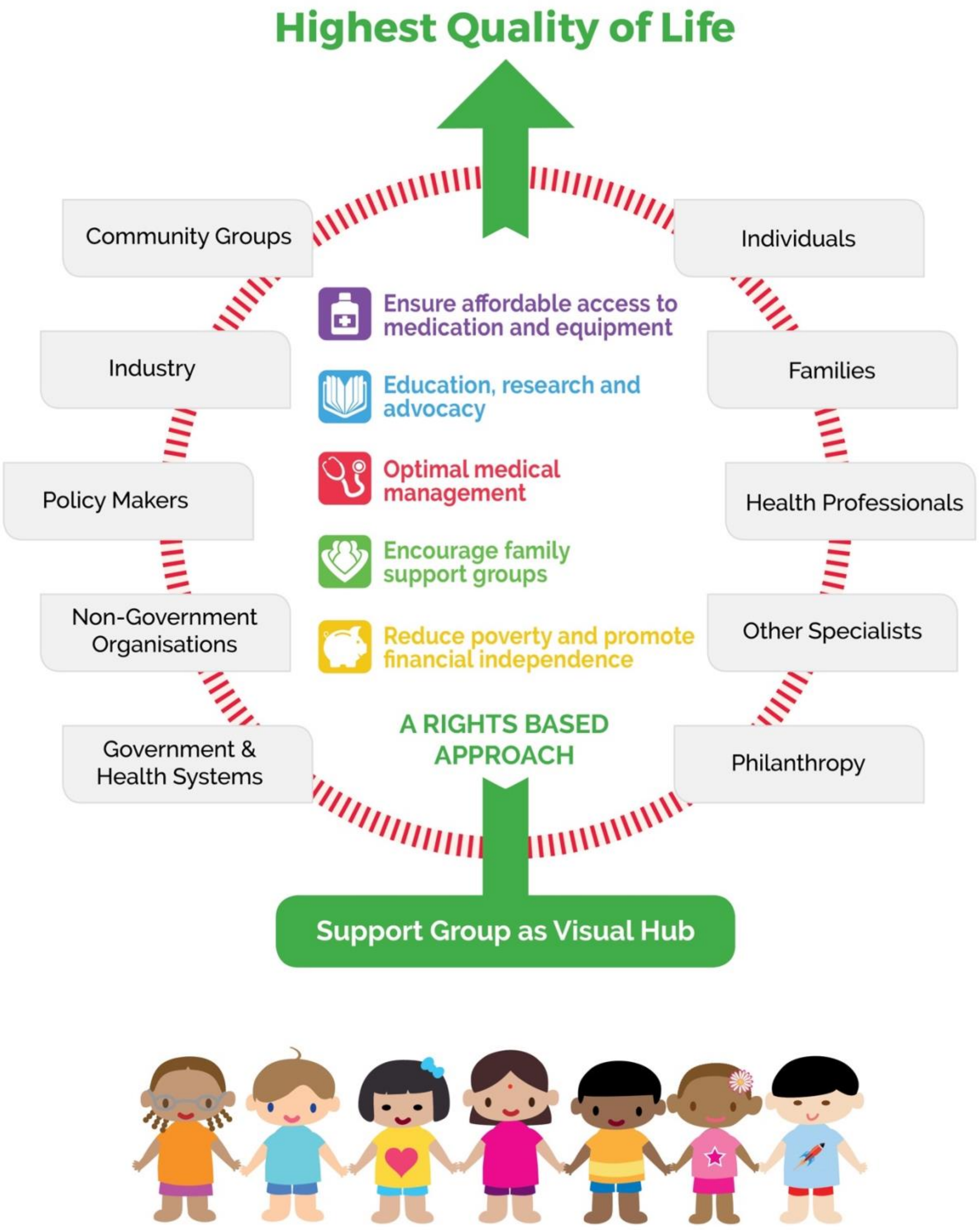


Interplay between CLAN's strategic framework for action, the knowledge to action framework and CHEAR Toolkit and other resources developed during this HNA to benefit the NS Community of Vietnam

The CHEAR Toolkit has been designed as a starting point to assist others as they develop their own local tools and resources. Tools included in the kit are:

- Tool 1 - CLAN’s Five Pillars and Strategic Framework for Action
- Tool 2 - CLAN Action Plan for NS in Vietnam
- Tool 3 - NS Program Logic Framework (2010–2020)
- Tool 4 - CLAN’s Club Planning Checklist
- Tool 5 - HNA TEMPLATES
- Tool 6 - NS Education and Awareness Resources
- Tool 7 - CHECC Scorecard

Tool 1 - CLAN’s Five Pillars and Strategic Framework for Action



CLAN's Strategic Framework for Action (Child-Friendly version)

Clan

(Caring & Living As Neighbours)

www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.

THE PLAN FOR
NEPHROTIC SYNDROME (NS)
CLAN

Table of Contents

Executive Summary

There is a glaring global inequity in health care and health outcomes for children living with chronic health conditions in resource-poor countries, and this requires urgent humanitarian attention. **CLAN (Caring & Living As Neighbours** – www.clanchildhealth.org) is committed to addressing this crisis, and does so from a rights-based perspective: it is not acceptable that our neighbours' children suffer so terribly from preventable disability and death.

CLAN is an Australian-based charitable organisation, and is accredited with AusAID for Overseas Aid Gift Deductibility Status (OAGDS) and the Australian Taxation Office for Tax Deductibility Status (TDS); formally associated with the United Nations Department of Public Information for Non-Government Organisations (UNDPI/NGO); and a Signatory to the Australian Council for International Development (ACFID) Code of Conduct. Since 2004, CLAN has collaborated with a broad range of partners to demonstrate that not only is change possible, but that adoption of a strategic framework for action has the potential to literally transform the landscape for children living with chronic health conditions in resource-poor countries.

This Strategic Plan offers a framework that is specifically focused on redressing inequities experienced by children living with Nephrotic Syndrome (NS) in Vietnam. There are striking similarities between NS and other chronic health conditions (such as Diabetes, Congenital Adrenal Hyperplasia, Autism and more recently Osteogenesis Imperfecta) that affect children, and which CLAN has worked on in the past. These conditions:

- are complex, chronic (lasting more than 6 months)
- require medication and access to quality health care on an ongoing basis not only to survive but also to thrive
- have an unacceptably high morbidity and mortality associated with under treatment
- consistently reduce families in resource-poor settings to abject poverty as they struggle year on year to provide the care so desperately needed for their child
- have the potential for excellent outcomes and prognosis when well managed and families are empowered to care for their children.

CLAN believes that through effective partnerships and collaboration, everything that has been achieved for children living with other chronic conditions in Vietnam can be easily replicated for children with NS, and this document proposes a roadmap to addressing this inequity once and for all. In the tradition of “see one, do one, teach one”, the objective is that at the end of this project, sufficiently self-sustaining, locally embraced procedures and changes will have occurred that local health care professionals and families will not only continue independently, but also use to inspire progress in a similar way for children with other chronic conditions. Moreover, a key goal is for this project to be an inspiration for other NS projects in the Asia Pacific region.

Vision Statement for NS CLAN

**TO MAXIMISE QUALITY OF LIFE FOR ALL CHILDREN
LIVING WITH NEPHROTIC SYNDROME (NS)
IN RESOURCE-POOR SETTINGS**

OVERVIEW OF PLAN FOR NS CLAN IN VIETNAM

1) Ensure Affordable Access to Essential Medicine & Equipment
    a. Access to essential medicine
        i. Short-term
        ii. Medium Term
        iii. Long-term
    b. Access to essential equipment

2) Education, Research & Advocacy
    a. Educate children with NS and their families
    b. Educate health care professionals, policy makers, government officials
    c. Educate national & international communities
    d. Promote research on NS in Vietnam, with communication of results to local NS community
    e. National & international advocacy efforts to effect change for children living with NS in Vietnam

3) Optimal Medical Management (Primary, Secondary & Tertiary Prevention with holistic approach to care)
    a. Primary prevention
    b. Secondary prevention
    c. Tertiary prevention
    d. Psychological support

4) Encourage the NS Community in Vietnam
    a. Empower and support the local NS Club
    b. Link community with international NS members and support

5) Reduce the Financial Burden of NS that leads to poverty and promote financial independence of families
    a. Micro-Finance; Vocational Training; Enterprise development opportunities
    b. Health insurance

CLAN ACTION PLAN FOR ADDRESSING PRIORITIES IDENTIFIED BY THE FIVE PILLARS

1. AFFORDABLE ACCESS TO ESSENTIAL MEDICINE & EQUIPMENT

PRIORITIES	PROPOSED ACTIONS	WHO	WHEN	EVALUATION
Medx - Short-term solutions	- identify any urgent access issues - determine if any humanitarian donations are required in short-term	- Vietnamese Health Care Professionals (VHCPs) - CLAN	ASAP / ? donations or policies rq'd in Nov	- outstanding gaps identified during interviews and Inaugural Club Meeting Nov 2011 (surveys)
- Medium-term solutions	- registration of any NS drugs currently unavailable in Vietnam by 11/2014 - NS management policies and strategies shared with Provincial Hospitals in Vietnam	- MOH - VHCP	- 2014	- all NS drugs available locally by 2014 - VHCP training provinces in NS mgmt
- Long-term solutions	- Medication affordably available - Health insurance schemes effectively utilised by all NS families	- MOH	- 2015	- NS families less financially stressed on f/u survey markers
Access to Equipment	Families able to affordably access urinalysis dipsticks to optimise medical management.	- donors - VHCP / MOH - business	- needs identified	- improvement in access to equipment on survey f/u

2. EDUCATION, RESEARCH & ADVOCACY

PRIORITIES	PROPOSED ACTIONS	WHO	WHEN	EVALUATION
Educate children and their families	- ensure quality translated educational resources on NS available (gold standard is that locally developed resources will be available) - lectures on relevant topics at NS Club meetings - NS Resource Nurses available at hospitals - NS videos and material available to NS community	- VHCP - CHW - Nephcure - CLAN	- some resources ready by inaugural clubs	- improved confidence and access to resources by survey f/u
Educate Health-Care Professionals (HCPs)	- Doctors, Nurses and Allied Professionals confident with current knowledge and access to latest evidence in literature - linked with international community of specialists - general treatment guidelines and management policies up to date - VHCPs publishing results of own research and work	- VHCP - CHW - CLAN	- 2011 to 2014	- national and international publications - HCP self-report - NS Club survey
Educate policy makers	- Media attend Club Meetings - Sharing advocacy Videos (in Vietnamese language) - Clear Disability discourse communicated to broader community, resulting in more acceptance and less stigma and isolation	- Media - VHCP - CHW - CLAN	- Nov 2011	- Disability related item in newsletters - media at Club - NS video in Vietnamese

Educate national and international communities	- Share stories and updates of Vietnamese NS community nationally and internationally to inspire and encourage all and raise awareness - Use international awareness days and forum to link communities internationally	- items in international NS forums	ASAP	- increased reports of NS in Vietnam in int'l NS forums
Research	- Health Needs Assessment informs future action - NS database available for ongoing research - Identify donors / sponsors able to support - link with others to help with monitoring / evaluation	- VHCP, CHW, WBD CLAN	ASAP Nov Club - Database by 2012	- Surveys of families and HCPs evaluated
Advocacy	- link with NephCure - Newsletters (include information on NS; other resources) - Use CLAN, NephCure and other web-sites to raise awareness - link with other groups (e.g. Rotary, local pharma / businesses)	- Rotary - CLAN, Nephcure	ASAP Nov Club	- content on Vietnam in international forums

3. OPTIMAL MEDICAL MANAGEMENT				
PRIORITIES	**PROPOSED ACTIONS**	**WHO**	**WHEN**	**EVALUATION**
Primary prevention	- Promote vaccination - all children up to date with national schedule - promote additional vaccines free for children with chronic conditions	- VHCP - CHW	- 2011	- Club survey – families aware of resources available to them
Secondary prevention	- Screening - urine dipstick testing - families taught how to manage early relapses	- VHCP - CHW - MOH	- by 2013	- Database and surveys / HNA informing understanding of late diagnosis
Tertiary prevention	- holistic approach (bio-psycho-social) to measuring QOL outcomes - families have access to optimal medical management - chronic disease management strategies guiding OPD care - families empowered to care for their children / understand NS	- VHCP - CHW - Nephcure - Hoc Mai	- by 2013	- OPD strategies used across multiple chronic conditions (CAH, DM, NS) - surveys at Clubs / of HCPs
Psychological support	- address parent fears around NS and renal failure - address myths and misconceptions - regular Club meetings - Systems in place to support newly diagnosed families - psychological support available to families - translate positive stories of adults living with NS internationally	- VHCP - CHW - NephCure - CLAN	- by 2013	- referral strategies to psych in place - translated stories available - Annual Clubs

4. ENCOURAGE THE NS COMMUNITY IN VIETNAM				
PRIORITIES	**PROPOSED ACTIONS**	**WHO**	**WHEN**	**EVALUATION**
Empower and support the local NS Club	- Executive members of Club identified - introduction of Club exec to international partners (e.g. NephCure) - NS Club introduced internationally to other NS forums - Survey at 2011 Club meeting to learn more / hear voices of families living with NS to better understand the key challenges and burdens they face - evaluation survey to determine how future NS Clubs might be improved - ensure Club aware of all resources and partners available to them	- VHCP - CLAN - NephCure	ASAP - need ethics approval of surveys from VHCP	- Club Nov 2011 / 2012 held - evaluation survey - family survey - Club exec identified - number of families at Club
Link the local NS Club in Vietnam to the broader international NS community	- photos - newsletters - link with NephCure	- CLAN - NephCure	- Nov 2011	- presence of Club in Vietnam on NephCure and CLAN site - link with international partners grows

5. REDUCE FINANCIAL BURDEN & PROMOTE FINANCIAL INDEPENDENCE				
PRIORITIES	**PROPOSED ACTIONS**	**WHO**	**WHEN**	**EVALUATION**
Reduce the financial burden of NS on families	- all efforts in pillars 1-4 will help Pillar 5 - families more empowered to manage NS at home and so present to VHCP less frequently - all children with NS should be attending school, with a view to completing university - awards given to children at Club meeting for academic success - links with Education Department if needed (share information with teachers on NS / disability discourse) - survey families to better understand the financial burdens and challenges	- All - Club meeting - Education Dept	2011	- less admissions to VHCP - track % of children with NS of school age who attend & aim for reduction over time - survey 2011
Promote financial independence of NS families	- work with Rotary and other NGOs to explore EDP / MF / VT options - link with Grameen where possible	- CLAN - Rotary - Grameen	Oct 11 meet with Rotary	- Survey families over time to assess change - reduction in financial stress families experience

APPENDIX 1 – IDENTIFICATION OF POTENTIAL RESOURCES & PARTNERS

PHARMACEUTICAL INDUSTRY

INTERNATIONAL NGOs
- Rotary

VHCP & VIETNAMESE MOH

AUSTRALIAN HOSPITALS & INDIVIDUALS
- CHW
- Elisabeth Hodson, Allison Tong

TRANSLATORS

INTERNATIONAL NS ORGANISATIONS
- Nephcure

OTHERS

APPENDIX 2 – IDENTIFICATION OF RISKS (Detailed risk management strategy in development)

Risks to ensuring medication affordable and available

Risks to Education, Research & Advocacy Strategies

Risks to Optimisation of Medical Management

Risks to Growth of NS Club

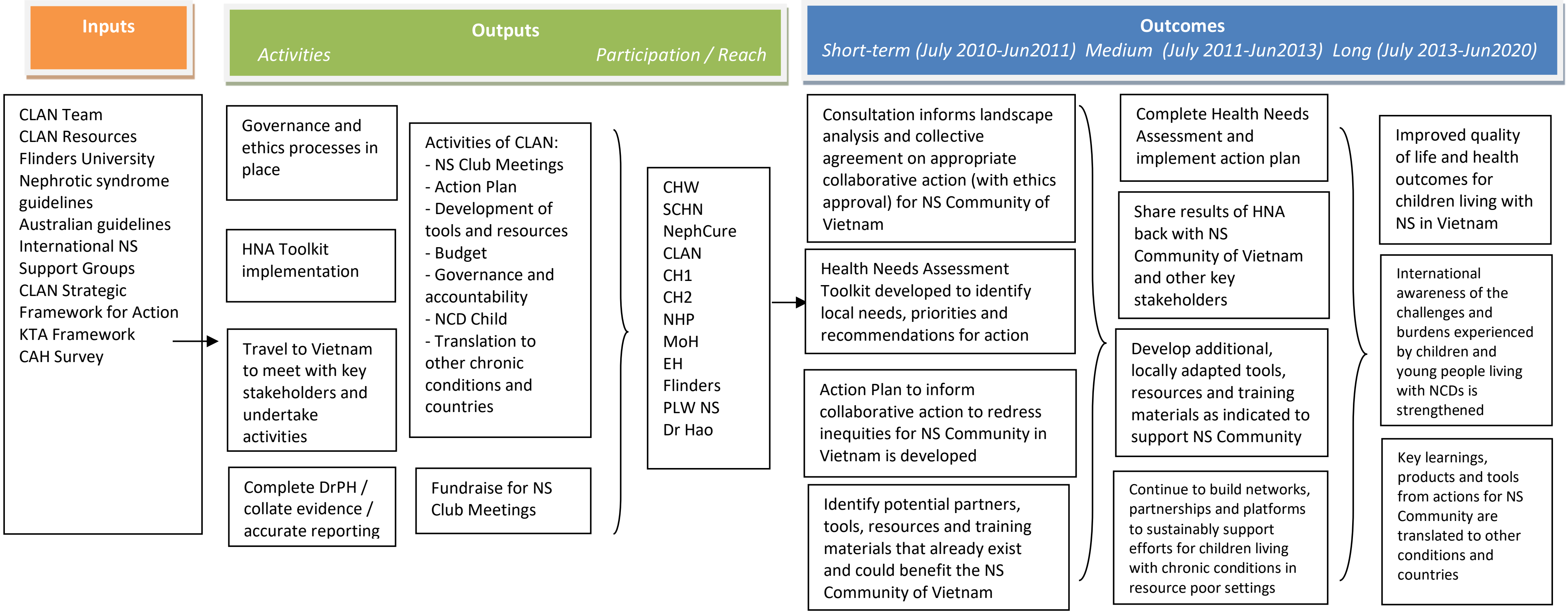
Risks to Reducing the Financial Burden of NS that lead to poverty

Other General Risks

Tool 3 - NS Program Logic Framework (2010 - 2020)

Redressing inequities for children and young people living with Nephrotic Syndrome in resource-poor settings (2010 - 2020)

Situation summary: Anecdotally, children and young people living with NS in Vietnam in 2010 experience an inequitable burden of preventable morbidity and mortality. CLAN is committed to a strategic framework for action that addresses this humanitarian crisis from a rights-based perspective, and believes through effective partnerships and collaboration achievements seen for children living with other chronic conditions in resource-poor countries (e.g. CAH, Diabetes, Osteogenesis Imperfecta) can be replicated to NS. **Ultimate goal:** To maximise quality of life for all children living with Nephrotic Syndrome (NS) in resource-poor settings



Inputs

CLAN Team
CLAN Resources
Flinders University
Nephrotic syndrome guidelines
Australian guidelines
International NS Support Groups
CLAN Strategic Framework for Action
KTA Framework
CAH Survey

Outputs

Activities

Governance and ethics processes in place

HNA Toolkit implementation

Travel to Vietnam to meet with key stakeholders and undertake activities

Complete DrPH / collate evidence / accurate reporting

Activities of CLAN:
- NS Club Meetings
- Action Plan
- Development of tools and resources
- Budget
- Governance and accountability
- NCD Child
- Translation to other chronic conditions and countries

Fundraise for NS Club Meetings

Participation / Reach

CHW
SCHN
NephCure
CLAN
CH1
CH2
NHP
MoH
EH
Flinders
PLW NS
Dr Hao

Outcomes

Short-term (July 2010-Jun2011)

Consultation informs landscape analysis and collective agreement on appropriate collaborative action (with ethics approval) for NS Community of Vietnam

Health Needs Assessment Toolkit developed to identify local needs, priorities and recommendations for action

Action Plan to inform collaborative action to redress inequities for NS Community in Vietnam is developed

Identify potential partners, tools, resources and training materials that already exist and could benefit the NS Community of Vietnam

Medium (July 2011-Jun2013)

Complete Health Needs Assessment and implement action plan

Share results of HNA back with NS Community of Vietnam and other key stakeholders

Develop additional, locally adapted tools, resources and training materials as indicated to support NS Community

Continue to build networks, partnerships and platforms to sustainably support efforts for children living with chronic conditions in resource poor settings

Long (July 2013-Jun2020)

Improved quality of life and health outcomes for children living with NS in Vietnam

International awareness of the challenges and burdens experienced by children and young people living with NCDs is strengthened

Key learnings, products and tools from actions for NS Community are translated to other conditions and countries

Assumptions (internal risks)

- KA has capacity to complete DrPH
- CLAN continues to operate
- CLAN's model can be translated from CAH / Endocrine to NS / other conditions
- Financial barriers are too great / impossible to make a difference

External Factors (potential risks)

- Medication can't be secured for NS
- Vietnamese government approves activities
- Pandemic
- Global audience is not interested / able to be engaged
- NS Community is not engaged / does not see value in activities

Tool 4 - CLAN’s Club Planning Checklist

Clan

(Caring & Living As Neighbours)

www.clanchildhealth.org

Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.

Please notify CLAN of any additional tips you have found useful and we will add it to the list to help prepare future meetings.

Pillar	To Do CHECK LIST to prepare for CLAN Club Meetings for Chronic Health Condition XYZ	Measure of success	Person Responsible
Pillar 1 - Access to essential medicines and equipment	Consider if access to medicine or equipment is a major issue for the community having the Club meeting. If it is: - if families can’t access medicines / equipment, be prepared for fact that ALL questions at Club meeting will focus on access to medicines / equipment, so do as much as possible in advance to secure access - work with the community and other key stakeholders to develop an strategy and advocacy plan to guide ongoing efforts to drive change CLAN has found it most effective to work with the community and other key stakeholders to put in place short, medium and long-term solutions:	Should be: S - specific M - measurable A - achievable R - relevant T – time bound	

	<u>a) Short-term solutions</u> - if affordable access to medicines or equipment is a challenge for families, consider organising humanitarian donation beforehand so they can be given out at Club meeting (e.g. CLAN used to give free Hysone and Florinef at start of CAH work, before drugs were registered in-country; arranged donation of urine dipsticks for NS Club and BGL testing strips for Diabetes; bisphosphonates were sent to Fiji prior to OI Wishbone Day celebrations). Discuss distribution plans for day with hospital staff; distribute through hospital pharmacy where possible. Include any associated costs in Club meeting budget. <u>b) Medium-term solutions</u> – consider sustainability options. Where possible, work towards registration of drugs in-country to ensure longer-term access <u>c) Long-term solutions</u> - consider options to improve affordability (e.g. inclusion of drugs on national health insurance list; innovative income generation for families; children attending school)		
Pillar 2 - Education Research & Advocacy	<u>a) Education</u> - consider educational needs of ALL stakeholders, viz children, families, health professionals, policy makers, national and international community - Translate the “bible” on condition XYZ into local language and arrange printing and distribution so booklets can be given free to all families at the Club meeting. This booklet surreptitiously educates health professionals, the media and politicians alike		

	- All presentations from visiting speakers to be translated into local language; printed copies of powerpoint slides to be given to families on the day (they will forget most of what they hear otherwise) - After Club meeting ensure translated educational resources also available online for families (e.g. pdf) with brief report (including group photos) of meeting - Newsletter provided for all families at the Club meeting. Should include articles and information about the particular condition; letters of encouragement from other international community groups; encouraging stories about individuals living with the condition; FAQs; key messages from the hospital etc - In the absence of quality information all communities develop myths to fill the void. Identify key myths held by the community in advance (e.g. hydrocortisone given for CAH weakens the bones so children shouldn't play games) and ensure educational materials contain content to dispel the myths. <u>b) Research</u> - take opportunity to consult with the families at the Club meeting to conduct a community health needs assessment (CLAN has proforma easily altered for each Club). This information should guide advocacy efforts and planning prior to next annual Club meeting. - consider publishing results of survey in journal (arrange Ethics in advance if you plan to do this) - ensure formal evaluation conducted at end of Club meeting to help improve future meetings (CLAN has proforma)		

	c) Advocacy - Invite media to the Club meeting (help raise awareness) - use social media platform for connecting nationally & internationally - consider setting up fundraising page online and promote to international community (helps connect others) - consider inviting politicians / MOH if access to medicine an issue - if international guests attending, consider inviting Embassy officials from their country		
Pillar 3 - Optimal Medical Managem’t	Consider a range of options to optimise medical management: a) Guidelines - consider translation of treatment guidelines / protocols into local language to streamline future management at hospital. Disseminate nationally. Let families know the guidelines exist (so they know standard of care to expect when they attend a health facility) - ensure guidelines and Club activities encompass holistic approach to care (bio-psycho-social with focus on prevention) and prevention - establish systems to support newly diagnosed children / families b) Professional development and capacity building - promote inter-disciplinary approach to health care; engage range of health professionals in Club planning, implementation and evaluation - run educational training sessions for local health professionals by visiting experts the day BEFORE the Club meeting (in this way all health professionals answer families’ questions the same, and there is no loss of face). Consider acknowledgement certificates for participants		

	- establish a national professional society (e.g. Paediatric Endocrinology Society) to promote high standards of care - encourage health professionals to engage in international conferences <u>c) Health system strengthening</u> – consider range of options, including - development of a patient register (local and national) to support ongoing care and monitoring of health outcomes, as well as strengthening local, national and international research - presentations at Club to help families understand best processes to follow for OPD care / routine review / care during emergencies etc		

Pillar 4 - Encourage Support Group	<u>a) Club structure</u> – ensure there is sufficient time set aside in the Club meeting to vote for the Club executive / to hold elections / introduce leaders / exchange mobile phone numbers / speak about problems etc. The Club Executive should be involved (take leading role) in planning future Club meetings. Note – this is hard if condition is a disease of poverty (e.g. RHD); community will require support for much longer in this instance - Help Club execs learn how to fundraise and connect internationally for support (build sustainability and independence) <u>b) Strengthen partnerships</u> - as per CLAN’s strategic framework, consider which partners / stakeholders should be engaged and invited to attend the Club; this will depend on community process and cultural factors. Who are leading organisations locally, nationally and internationally? Identify leading international support groups in HICs; update them on upcoming Club meeting; invite them to be involved, present at Club / health		

	professional meetings, support activities, or at a minimum, share letter of encouragement - Identify sponsorship opportunities (local, national, international) c) Build community - take photos and possible video footage at the Club meetings to promote Clubs in future - identify and establish platforms to best support community (e.g. Facebook page / Watts App / Twitter / web-site, mobile apps) - consider development of novel mobile phone app (CLAN has sample) - use lunch break to promote socializing between families - share report of meeting with international partners / online / help with awareness - work with Club Executive to determine name of Club (e.g. should NOT be called the “CLAN Club” – should have a name that families identify with and feel sense of belonging to). Examples of names other communities have come up with include: CAHSAPI (CAH, Philippines); IKAHAK and KAHAKI (Indonesia); CLIP (CAH, Pakistan) etc. Also work with Club over time to develop a logo, communication platform (e.g. Whats App or Facebook) and website		

Pillar 5 - Reduce Financial Burdens	a) Reduce financial burdens - integrate questions within community survey to help identify key burdens and costs to families and ways to reduce financial burdens - are there any government financial support mechanisms available to families? If so, provide families with simple written summary in local language outlining how to access same. Also give to newly diagnosed.		

	<u>b) Promote financial independence</u> - provide information to families on full range of financial support options available (e.g. government support; health insurance; local NGOs; ethical and established enterprise development schemes; other) - consider income generation activities community could engage in. CLAN has examples of this; potentially risky, so must be done very carefully. Ensure “above all do no harm”; separate doctors from financials dealings so families don’t lose face with health care providers <u>b) Schooling and education</u> - monitor percentage of school-aged children attending school as marker of success and change over time - Ensure recognition of importance of schooling is built into the meeting. Acknowledge students doing well at school; Find sponsors to support this		

General Admin	<u>a) Planning</u> - Complete “CLAN Plan for (condition XYZ)” in consultation with key stakeholders and partners, to ensure clear strategic plan - Maintain community development focus at all times (rights-based) - engagement and involvement of multisectoral range of partners bodes well. The less partners and sectors involved, the less likely the chances of success. - Families and children must remain the visual hub of all action - identify as broad a group of stakeholders as possible (share CLAN’s strategic framework for action with potential partners to communicate overall goal) - Community and local health professionals decide they want a Club meeting and complete application papers for CLAN if needed (include budget, Club program and evaluation format as well as other details).		

	- Date is set for Club meeting in consultation with CLAN (to organise any international attendees) - determine key goals for Club meeting (based on community priority) and develop evaluation strategy (and identify indicators) at start of planning - Contact families through hospital if the Club is new and through the club executive if an established club - Develop budget for event. Budget must protect families from financial burden associated with attending Club meeting. CLAN generally budgets on amount per family (budget to cover cost of meals and snacks for families, loss of income, cost of travel – families should not be out of pocket) - Consider topics families will want to know about and speakers they would learn most from. Invite speakers - consider specific topics of importance (e.g. adolescent issues; transitional care) - Social media strategy in place – engage partners; consider hashtags - longer term fundraising strategy / partnership management plan - ensure those planning Club activities and Club Executive members are aware that the CLAN Online Policy Handbook (including our Complaints Policy) are online at www.clanchildhealth.org in the Contact Us section. Club Executive are asked to communicate to Club members that this information is available and where it is available. To this end, CLAN would ask that our web address be widely disseminated at Club meetings and in any newsletters or communications to families. <u>b) Implementation</u> – Follow agenda for meeting. Should include timeline, speakers and topics, Q&A sessions, surveys of families; lunch and snack breaks		

	- consider fun activities and volunteers to help entertain the children whilst parents concentrate on lectures (children should recall happy days). CLAN can share previous examples <u>c) Evaluation and reporting</u> - give evaluation survey to families and key people involved to learn how to improve future meetings - Report on Club to be prepared after the meeting (include photos, number of attendees, activities undertaken, media reports, evaluation outcomes etc) - ask families at start of day if they give permission for any photos to be used in reports. Explain purpose of photos and reports (to raise awareness; assist with advocacy and fundraising). Invite any families who do not want photos take to indicate to staff member and ensure they are not included in any photos <u>d) Child and Family wellbeing</u> - Consider child protection issues; ensure all children are safe and protected during the day; take precautions to ensure no children are at risk during the day in any way - consider psychological aspects of event and steps that can be taken to protect and support families (e.g. sensitivities around discussions on ambiguous genitalia in CAH meetings should be considered deeply in advance and managed professionally and empathetically; children should never be made to feel embarrassed or ashamed; consider having psychological support at meetings in case families become upset)		

Tool 5 - HNA TEMPLATES

The following templates are shared below:

A. Survey template to consult with of parents / guardians of children and young people living with NS in Vietnam

B. Semi-structured interview template to guide consultation with parents / guardians of children and young people living with NS in Vietnam

C. Survey template for health professionals who interviewed families

D. Interview / survey template to facilitate consultation with health professionals caring for children living with NS in Vietnam

E. Interview / survey template to facilitate consultation with other key stakeholders relevant to redressing inequities for children living with NS in Vietnam

TEMPLATE A. SURVEY FOR CONSULTING FAMILIES ATTENDING NS CLUB MEETINGS

Please fill out the blanks or circle the equivalent items. When you choose the option "other", please specify.

1. Introduction

Child's name : _________________________	DOB:____/____/____ Age: ________________	Ethnic group: ____________

Gender: ☐ Male ☐ Female

Information about your family home:

☐ Rural Area ☐ Urban Area Name of Province: ________________________

Distance from home to this hospital: ____________________ kms

Time to travel from home to this hospital: ________________________

Most usual mode of transport to this hospital family uses: ________________________

Do you have access to the internet? (please tick all that apply)

☐ Yes, on my mobile ☐ Yes, at home ☐ Yes, in my village ☐ No, never

Do you speak English? No Yes

Family's insurance status:

- ☐ Insurance for children under 6 years old
- ☐ School health insurance
- ☐ Insurance for poor family
- ☐ Don't have any insurance for our child

If you don't have any insurance please explain why:

If you do have insurance, have you been able to reimburse all costs?

Yes / No

If not, please explain why.

School life:

Does your child go to school now? ☐ No ☐ Yes

NO - **<u>If no, your child does not go to school now:</u>**

What is the reason your child is not attending school?

____

____

Do you feel your child would still be at school now if they had never developed NS?

☐ No ☐ Yes

How long ago did your child stop attending school? ___________________

YES - **<u>If yes, your child does go to school now:</u>**

What grade is the child in now? _____________

How many days of school did your child miss in the last 12 months? ______

What was the reason for missing school? _____________________________

Do you have any concerns with how your child is coping socially at school?

Using a score from 1 to 10, how is your child doing with their studies at school? (please circle)

(very bad) 1 2 3 4 5 6 7 8 9 10 (very good)

Do you have any other general concerns relating to your child's schooling?

2. Health details (you may need help from your doctor or nurse to answer these questions)

What type of Nephrotic Syndrome (NS) does your child have?

If your child's Nephrotic Syndrome Steroid Sensitive? ☐ No ☐ Yes

When was the diagnosis of NS made?	Where was the diagnosis of NS made?

When did your child first come to this hospital for treatment of NS?

In the last 12 months, how many times has your child needed treatment for swelling?

____

Approximately how many times has the swelling come back and needed treatment in your child's lifetime?

____

Is your child up to date with the national vaccination programme? ☐ No ☐ Yes

Has your child had any extra vaccinations? (tick if had vaccine + date given):
☐ No, has not had any extra vaccinations
☐ Pneumococcus – date ________________
☐ H. influenzae – date __________________
☐ Varicella – date __________________
☐ Hepatitis B – date __________________
☐ Other - date __________________

List of all Medicines Used	**Please tick all the medicines your child has ever used to treat their Nephrotic Syndrome and then tick which ones your child is using currently.**	
	TICK IF EVER USED	TICK IF USING NOW
	☐ Prednisone	☐ Using now
	☐ Cyclophosphamide	☐ Using now
	☐ Cyclosporin	☐ Using now
	☐ Mycophenalate	☐ Using now
	☐ Levamisole	☐ Using now
	☐ Albumin	☐ Using now
	☐ Other:	☐ Using now
	☐ Other:	☐ Using now
	☐ Not sure which medicines my child has ever used	☐ Not sure which medicines my child is using now

3. Your child's health in the last 12 months

How many times has your child been admitted to hospital for inpatient care in their life?	____________________times
How many of these admissions were for NS?	
How long was each admission for NS?	

Has your child ever used Traditional Medicines to treat their NS?
☐ Yes / ☐ No

If yes →

Is your child still receiving traditional medicines currently?
☐ Yes / ☐ No

How much money would you estimate that you have spent on traditional medicines in the last 6 months?

Have you ever stopped prescribed treatment against medical advice? If yes, what was the reason (including cost)?

Using a score from 1 to 10, how would you rate your child's health in general ONE YEAR AGO?

(very bad) 1 2 3 4 5 6 7 8 9 10 (very good)

Using a score from 1 to 10, how would you rate your child's health in general NOW?

(very bad) 1 2 3 4 5 6 7 8 9 10 (very good)

4. Understanding of NS

How confident do you feel about your understanding of why your child sometimes gets swelling of the face, arms or legs? (please circle)

(not at all confident) 1 2 3 4 5 6 7 8 9 10 (very confident)

Do you have access to any educational resources or information on NS?
☐ No ☐ Yes

If yes, please describe + indicate where you get your information:

Do you feel you would like to learn more about your child's condition and how to care for your child the best way?

☐ Yes, I would like more information ☐ No, I have enough information

How confident do you feel about what to do when your child gets swelling? (please circle)

(not at all confident) 1 2 3 4 5 6 7 8 9 10 (very confident)

Have you learned how to test your child's urine for protein at home?

☐ Yes ☐ No ☐ Not sure

Do you test your child's urine for protein at home?

☐ Yes ☐ No ☐ Not sure

If yes, how often do you test?

Do you have a health professional in your local home town / area that you go to for help to manage your child's NS?

☐ Yes ☐ No

How confident do you feel that your local health professional can safely manage your child's NS? (please circle)

(not at all confident) 1 2 3 4 5 6 7 8 9 10 (very confident)

How far from your home is the nearest health care professional that you can access to help manage your child's NS?

________________________ (kms)

________________________ (time it takes to travel to this health professional)

5. Burdens and challenges:

What is the hardest thing for your family about living with NS?

What is the hardest thing for your child about living with NS?

What are your greatest worries regarding your child with NS?

Sometimes the worries, stress and burdens of NS have an impact on parents' own mental health and wellbeing, and can make them feel anxious and depressed. What impact has there been on you personally?

(rarely feel depressed) 1 2 3 4 5 6 7 8 9 10 (always feel depressed)
(rarely feel anxious) 1 2 3 4 5 6 7 8 9 10 (always feel anxious)
(rarely feel sad) 1 2 3 4 5 6 7 8 9 10 (always feel sad)
(rarely feel worried) 1 2 3 4 5 6 7 8 9 10 (always feel worried)
(rarely feel hopeful) 1 2 3 4 5 6 7 8 9 10 (always feel hopeful)
(rarely feel optimistic) 1 2 3 4 5 6 7 8 9 10 (always feel optimistic)
(rarely feel in control) 1 2 3 4 5 6 7 8 9 10 (always feel in control)

Do you have any specific worries about your child's social life?

Where does your family get support from to help you manage life with NS?

During the **past 4 weeks**, to what extent has your child's physical health or emotional problems interfered with normal social activities with family, friends, neighbours, or other community groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐Quite a bit ☐Extremely

During the **past 4 weeks**, to what extent has your child's physical health or emotional problems interfered with their ability to attend school?

☐ Not at all ☐ Slightly ☐ Moderately ☐Quite a bit ☐Extremely

6. Demographics

Who is living in your house? (please tick all that apply):

☐ Father ☐ Mother ☐ Grandparent/s (how many? ________)
☐ Siblings (how many?____________)
☐ Other_________ (how many? ________________)

Father's education level:__________ Father's career:__________________	Mother's education level:_____________ Mother's career:_____________________

Who is the primary caregiver :

☐ Father ☐ Mother ☐ Both of you ☐ Grandparent
☐ Other__________________

Household income in a month : _________________VND

What percentage of your household income would you estimate that you lose when your child is hospitalised with a relapse of NS? __________%

Source of household income :

☐Father working ☐Mother working ☐Relative's support

☐ Other______________

Using the **last** relapse of NS as an example, what was the total amount of money that your family had to spend to make your child well again?

_________ VND (If this is the first admission write 1st time please)

Using the last month (prior to this relapse) as an example, how much money do you usually pay in one month to manage your child's NS?:

________________ VND

Where do you access your medicines?

Does NS cause financial strain for your family? (please circle)
(No strain at all) 1 2 3 4 5 6 7 8 9 10 (Yes, extreme strain)

If answer is > 6 strain AND the child was diagnosed with NS more than a year ago, please describe the financial impact of a chronic health condition on your family budget over time.

Has anyone in your family ever had NS?
☐ No ☐ Yes ➔ Who (sibling or other relative)? ________________________
Age and gender now ___________________________

You who completed this questionnaire are:
☐ Father ☐ Mother ☐ Both of you ☐ Grandparent
☐ Other______________ →your education level _______________

7. Recommendations for change:

What do you think needs to be done to help children and families who are living with NS in Vietnam to enjoy better lives?

How useful have you found the NS Club Meeting today?

(Yes, very much) 1 2 3 4 5 6 7 (No, not at all)

What were the three best things about the Club Meeting today?

What three things should we do differently at the next Club meeting to make it better?

If we had another NS Club Meeting next year would you attend?

☐ Yes I would attend
☐ I might attend
☐ I might not attend
☐ No, I definitely would not attend

Please give your reason for your response:

Do you have any questions / comments you would like to share?

FOR STUDY USE ONLY
ID: ____________________Date of collection: __________________

Site: CH1/CH2/NHP

TEMPLATE B. INTERVIEW GUIDE FOR CONSULTING WITH FAMILIES OF CHILDREN LIVING WITH NS (QUALITATIVE FOCUS)

Please fill out the blanks or circle the equivalent items. When you choose the option “other”, please specify.

1. Introduction

Child’s name : ________________________	DOB:____/____/____ Age: _______________	Ethnic group: ____________

Gender: ☐ Male ☐ Female

Information about your family home:
☐ Rural Area ☐ Urban Area Name of Province: _______________________

Distance from home to this hospital: ___________________ kms

Time to travel from home to this hospital: ______________________

Most usual mode of transport to this hospital family uses: ______________________

Do you have access to the internet? (please tick all that apply)
☐ Yes, on my mobile ☐ Yes, at home ☐ Yes, in my village ☐ No, never

Family’s insurance status:

- ☐ Insurance for children under 6 years old
- ☐ School health insurance
- ☐ Insurance for poor family
- ☐ Don’t have any insurance for our child

If you don’t have any insurance please explain why:

If you do have insurance, have you been able to reimburse all costs?

Yes / No (please circle)

If not, please explain why.

Does your child with NS go to school now? ☐ No ☐ Yes

<u>If no, your child does not go to school now:</u>
- What is the reason your child is not attending school?

____

____

- Do you feel your child would still be at school now if they had never developed NS?
Yes / No (please circle)

- How long ago did your child stop attending school? __________________

If yes, your child does go to school now:

What grade is the child in now? _____________
How many days of school did your child miss in the last 12 months? ______
What was the reason for missing school?

Do you have any concerns about your child’s academic progress at school?

Do you have any concerns about how your child is doing socially at school?

1. Introduction (continued)

Note to interviewer – please review Section 2 (should be completed already by the health professionals).

When was your child diagnosed with NS?

Please share the story of how the diagnosis of NS was made.

What was the most stressful thing about this experience for you and your family?

Were there any factors that especially helped you and your family during this experience, and made it less stressful for you?

What factors might help future families to find the experience of a new diagnosis of NS less stressful in your opinion?

2. Health details (you may need help from your doctor or nurse to answer these questions)

What type of Nephrotic Syndrome (NS) does your child have?

Is your child's Nephrotic Syndrome Steroid Sensitive? ☐ No ☐ Yes
(Does prednisone make the swelling go away?)

When was the diagnosis of NS made?

Where was the diagnosis of NS made?

When did your child first come to this hospital for treatment of NS?

In the last 12 months, how many times has your child needed treatment for swelling?

____

Approximately how many times has the swelling come back and needed treatment in your child's lifetime?

____

What is your child's height? ______ cm
(to 1 decimal place)

Weight: ______ kg
(to 1 decimal place)

Is your child up to date with the national vaccination programme? ☐ No ☐ Yes

Has your child had any extra vaccinations? (tick if had vaccine + date given):
☐ No, has not had any extra vaccinations
☐ Pneumococcus – date __________________
☐ H. influenzae – date ____________________
☐ Varicella – date ____________________
☐ Hepatitis B – date ____________________
☐ Other - date ____________________

Does your child have Dialysis?
☐ No ☐ Yes If Yes → when did they start? __________________________

List of all Medicines Used	**Please tick all the medicines your child has ever used to treat their Nephrotic Syndrome and then tick which ones your child is using currently.**	
	TICK IF EVER USED	TICK IF USING NOW
	☐ Prednisone	☐ Using now
	☐ Cyclophosphamide	☐ Using now
	☐ Cyclosporin	☐ Using now
	☐ Mycophenalate	☐ Using now
	☐ Levamisole	☐ Using now
	☐ Albumin	☐ Using now
	☐ Other:	☐ Using now
	☐ Other:	☐ Using now

3. Your child’s health in the last 12 months

How many times has your child been admitted to hospital for inpatient care in their life?	_________________times
How many of these admissions were for NS?	
How long was each admission for NS?	
What were the reasons for the other hospital admissions (not NS)?	
How many times has your child attended the Outpatient Department for treatment of NS?	_________________times
How many times has your child attended the Outpatient Department for treatment of other health problems (not NS)?	_________________times
How many times has your child visited the hospital Emergency Department for NS care?	_________________times
How many times has your child visited the hospital Emergency Department for other health problems (not NS)?	_________________times

Has your child ever used Traditional Medicines to treat their NS?
☐ Yes / ☐ No

If yes →

Is your child still receiving traditional medicines currently?
☐ Yes / ☐ No

How much money would you estimate that you have spent on traditional medicines in the last 6 months?

Have you ever stopped prescribed treatment against medical advice? If yes, what was the reason for doing so (including cost)?

Using a score from 1 to 10, how would you rate your child’s health in general ONE YEAR AGO? (very bad) 1 2 3 4 5 6 7 8 9 10 (very good) Using a score from 1 to 10, how would you rate your child’s health in general NOW? (very bad) 1 2 3 4 5 6 7 8 9 10 (very good)

4. Understanding of NS

How confident do you feel about your understanding of why your child sometimes gets swelling of the face, arms or legs? (please circle) (Yes, very confident) 1 2 3 4 5 6 7 8 9 10 (No, not at all confident)
Please describe in your own words what your child’s health problem is and why they get swelling:
Please describe in your own words what you understand regarding the longer term outcomes for your child with NS:
Do you have access to any educational resources or information on NS? ☐ No ☐ Yes If yes, please describe + indicate where you get your information:
Do you feel you would like to learn more about your child’s condition and how to care for your child the best way? ☐ Yes, I would like more information ☐ No, I have enough information
Please describe in your own words what you do when your child gets swelling of the face, arms, legs or other body parts.

How confident do you feel about what to do when your child gets swelling? (please circle)

(Yes, very confident) 1 2 3 4 5 6 7 (No, not at all confident)

Have you learned how to test your child's urine for protein using dipsticks?

☐ Yes ☐ No ☐ Not sure

Do you test your child's urine for protein at home?
☐ Yes ☐ No ☐ Not sure
If yes, how often do you test? ______________________

Do you have a health professional in your local home town / area that you go to for help to manage your child's NS?
☐ Yes ☐ No

How confident do you feel that your local health professional can safely manage your child's NS? (please circle)
(not at all confident) 1 2 3 4 5 6 7 8 9 10 (very confident)

How far from your home is the nearest health care professional that you can access that you feel confident can safely manage your child's NS?
________________________ (kms)
________________________ (time it takes to travel to this health professional)

5. Burdens and challenges:

What is the hardest thing for your family about living with NS?

What is the hardest thing for your child about living with NS?

What are your greatest worries regarding your child's health with NS?

Sometimes the worries, stress and burdens of NS have an impact on parents' own mental health and wellbeing, and can make them feel anxious and depressed. What impact has there been on you personally?

(rarely feel depressed) 1 2 3 4 5 6 7 8 9 10 (always feel depressed)
(rarely feel anxious) 1 2 3 4 5 6 7 8 9 10 (always feel anxious)
(rarely feel sad) 1 2 3 4 5 6 7 8 9 10 (always feel sad)
(rarely feel worried) 1 2 3 4 5 6 7 8 9 10 (always feel worried)
(rarely feel hopeful) 1 2 3 4 5 6 7 8 9 10 (always feel hopeful)
(rarely feel optimistic) 1 2 3 4 5 6 7 8 9 10 (always feel optimistic)
(rarely feel in control) 1 2 3 4 5 6 7 8 9 10 (always feel in control)

Do you have any specific worries about your child's schooling?

Do you have any specific worries about your child's social life?

Where does your family get support from to help you cope with life with NS?

During the **past 4 weeks**, to what extent has your child's physical health or emotional problems interfered with normal social activities with family, friends, neighbours, or other community groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐Quite a bit ☐Extremely

During the **past 4 weeks**, to what extent has your child's physical health or emotional problems interfered with their ability to attend school?

☐ Not at all ☐ Slightly ☐ Moderately ☐Quite a bit ☐Extremely

6. Demographics

Who is living in your house? (please tick all that apply):
☐ Father ☐ Mother ☐ Grandparent/s (how many? _______)
☐ Siblings (how many?___________)
☐ Other________ (how many? _______________) TOTAL = _____

Father's education level:_________	Mother's education level:____________

Father's career:________________ Mother's career:____________________

Who is the primary caregiver :
☐ Father ☐ Mother ☐ Both of you ☐ Grandparent
☐ Other_________________

Household income in a month : ________________VND

What percentage of your household income would you estimate that you lose when your child is hospitalised with a relapse of NS? _________%

Source of household income :
☐Father working ☐Mother working ☐Relative's support

☐ Other_____________

How much money do you pay for one month treatment:
Medicine: ______________________VND
Travel: ________________________VND
Accommodation: ____________________VND
Loss of income: ________________________ VND
Special Diet: ____________________________ VND
Doctor's fees: ______________________VND
Investigations: _______________________VND
Hospital fees: ______________________VND
Pagoda donations: ___________________ VND
☐ Other (please list below + estimate of cost)

TOTAL = _________________ VND

Using the **last** relapse of NS as an example, what was the total amount of money that your family had to spend to make your child well again?

________ VND (If this is the first admission write 1st time please)

Using the last month (prior to this relapse) as an example, how much money do you usually pay in one month to manage your child's NS?:

_______________ VND

Where do you access your medicine?

What are the greatest difficulties for you in accessing medicine or health care?

Does NS cause financial strain for your family? (please circle)
(No strain at all) 1 2 3 4 5 6 7 8 9 10 (Yes, extreme strain)

Has anyone in your family ever had NS?

☐ No ☐ Yes ➔ Who (sibling or other relative)? ________________________

Age and gender now ___________________________

You who completed this questionnaire are:
☐ Father ☐ Mother ☐ Both of you ☐ Grandparent
☐ Other_______________ →your education level ________________

7. Recommendations for change:

What do you think needs to be done to help children and families who are living with NS in Vietnam to enjoy better lives?

In Vietnam there have been Clubs to help children who are living with other chronic conditions (PLEASE DESCRIBE TO FAMILY). Do you feel a NS Club would be useful?

☐ Yes ☐ No ☐ Unsure

If there was a NS Club at this hospital, would you attend?

☐ Yes ☐ No ☐ Unsure

If no, or not sure, what would be the main reasons why you would not attend?

____

We plan to have a NS Club meeting in November. What would your suggestions be about how to make the meeting most helpful for your family?

Do you have any questions / comments you would like to share?
(PLEASE RECORD QUESTIONS)

TEMPLATE C. SURVEY FOR HEALTH PROFESSIONALS AFTER INTERVIEWING FAMILIES (QUALITATIVE FOCUS)

8. Input from the Interviewer

1. **Please share your general reflections on the interview:**

2. **What were your key impressions of this family?**

3. **What are your thoughts on the best way to improve quality of life for children with NS from this interview?**

4. **Other comments:**

FOR STUDY USE ONLY
ID: ____________________Date of collection: ______________

Site: CH1 / CH2 / NHP

Time taken to translate survey:

TEMPLATE D. EMAIL / INTERVIEW GUIDE FOR CONSULTING HEALTHCARE PROFESSIONALS

Please fill out the blanks or circle the equivalent items. When you choose the option “other”, please specify.

1. General Information

Name:	
Name of hospital you work at:	Department you work in:
Email address:	
Phone:	
Please outline your formal qualifications:	
Do you speak English?: ☐ Yes, advanced ☐ Yes, intermediate ☐ Yes, beginner ☐ No	

2. Background Information - Numbers of children with Nephrotic Syndrome

How many children do you estimate presented to your hospital for management of Nephrotic Syndrome in the years listed?	2010
	2005 - 2009
	2000 – 2004
	1995 – 1999
	1990 – 1994
How many children do you estimate died of NS in the years listed?	2010
	2005 - 2009
	2000 – 2004
	1995 – 1999
	1990 – 1994

3. Current profile of children with NS at your hospital

How many children do you estimate are currently living with NS and present to your hospital for their care?	________________ (number of children)
Of the total number of children managed at your hospital with NS: - how many do you estimate have steroid sensitive NS (SSNS)?	________________ (number of children)
Of the children with SSNS: - how many would you estimate to be frequently relapsing?	________________ (number of children)
Of the children with SSNS: - how many would you estimate to be steroid dependent?	________________ (number of children)
Of the total number of children managed at your hospital with NS: - how many do you estimate have steroid resistant NS?	________________ (number of children)
Which group of children with NS present the greatest challenges to your department? Please explain your reason for this.	________________________________ ________________________________ ________________________________ ________________________________ ________________________________ ________________________________ ________________________________

4. Access to medicine and equipment for NS

Are the following medicines available for use, and if so, what is the cost?	**Name of medicine (please tick)**	**Cost / item (please clarify)**
	☐ Prednisone	
	☐ Cyclophosphamide	
	☐ Cyclosporin	
	☐ Mycophenalate	
	☐ Levamisole	
	☐ Albumin	
	☐ Rituximab	
	☐ Tacrolimus	
	☐ Oral frusemide	
	☐ ACE Inhibitors	
	☐ Statins	
	☐ Amlodipine	
	☐ Other:	
Is the following equipment available for use, and if so, what is the cost?	☐ Urinary Dipstick Do most nurses in your department know how to use urinary dispticks? ☐ Yes ☐ No	
Are the following vaccinations available, and if so, what is their cost?	☐ Pneumococcus	
	☐ H. influenzae	
	☐ Varicella	
	☐ Hepatitis B	

5. Does your hospital use any Clinical Guidelines to manage children with NS?

☐ No

☐ Yes → If yes:

Are the guidelines available in Vietnamese language? Yes / No

Please describe the guidelines:

6. Please describe any educational resources that you use to help educate families about the best ways to care for their child with NS (if there are none available, please just state this).

7. In your opinion, what are the greatest burdens for children and families living with NS who come to your hospital for care?

8. In your opinion, what are the main complications that children at your hospital with NS experience?

9. Please give estimates of the main costs associated with the treatment of NS for children:

a) when acutely unwell:

Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
☐ Other_________________	Cost - ___________________VND

b) for maintenance treatment over a one month period:

Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
Item - ___________________	Cost - ___________________VND
☐ Other_________________	Cost - ___________________VND

10. What would your recommendations be for the best ways to improve health outcomes for children who are living with NS in Vietnam?

11. What would your recommendations be for the best ways to improve the quality of life of children who are living with NS in Vietnam?

FOR STUDY USE ONLY

ID: ___________________Date of collection: _________________

Site: CH1/CH2/NHP ____________

TEMPLATE E. INTERVIEW GUIDE FOR CONSULTING POLICY MAKERS & OTHER KEY STAKEHOLDERS

1. To your knowledge, how many children are living with Chronic Kidney Disease (CKD) in Vietnam?

2. To your knowledge, how many of these children with Chronic Kidney Disease in Vietnam have Nephrotic Syndrome?

3. In your opinion, what are the main challenges and burdens facing children who are living with Nephrotic Syndrome (or CKD) in Vietnam?

4. What are your key recommendations on the best ways to improve health outcomes and improve quality of life for children living with CKD and NS in Vietnam?

FOR STUDY USE ONLY
ID: ____________________Date of collection: __________________

Site: CH1/CH2/NHP ________

Tool 6 - NS Education and Awareness Resources

Nephrotic Syndrome educational resources in Vietnamese language

- NS Booklets for families
    - **Nephrotic Syndrome: Information for Parents** (**Hội chứng Thận hư**) - a booklet on NS produced by the Department of Nephrology at Royal Children's Hospital in Melbourne and
    - **Nephrotic Syndrome in Children** (**Hội chứng Thận hư ở trẻ em**) – a guide for parents on the management and treatment of Childhood NS (produced by Nottingham NHS)

NS Club Newsletter (in Vietnamese – shared with all families at Club Meetings)

Hội Chứng Thận Hư

Bản tin Câu lạc bộ

Clan
www.clanchildhealth.org

Tháng 02 năm 2013-Phần 2

Chúc mừng tất cả các bạn!

Hân hoan chào đón các bạn đến với buổi trò chuyện của câu lạc bộ dành cho trẻ em có Hội Chứng Thận Hư và gia đình tại Việt Nam. Chúng tôi mong rằng bản tin này sẽ có thông tin bổ ích để hỗ trợ cho những nỗ lực của các bạn trong việc giúp trẻ em có Hội Chứng Thận Hư tại Việt Nam có thể tận hưởng cuộc sống với chất lượng tối ưu.

Thông điệp từ tổ chức CLAN

CLAN (Quan tâm và chung sống như những người láng giềng) là một tổ chức Phi Chính Phủ tại nước Úc với mong muốn giúp trẻ em bệnh mạn tính có thể có cuộc sống với chất lượng tốt nhất. Rất nhiều trẻ em tại Việt Nam bị ảnh hưởng bởi Hội Chứng Thận Hư (HCTH), và CLAN lấy làm vinh hạnh khi được chung tay cùng với nhiều đối tác ở nước Úc, Việt Nam cũng như các đối tác quốc tế khác để giúp sự hỗ trợ cộng đồng trẻ em HCTH tại Việt Nam được phát triển vững mạnh, như thế trẻ em HCTH có cơ may được tận hưởng cuộc sống khỏe mạnh và hạnh phúc.

CLAN tin rằng những trẻ em bệnh mạn tính như HCTH cần 5 yếu tố chủ chốt để có được cuộc sống chất lượng nhất có thể có được. Những yếu tố ấy là:

1. Tiếp cận thuốc điều trị bệnh và dụng cụ Y tế với giá thích hợp
2. Giáo dục (cho trẻ em, gia đình, nhân viên Y tế, những chuyên gia chính sách và cộng đồng quốc tế), Nghiên cứu và Kêu gọi sự hưởng ứng
3. Kiểm soát bệnh tật một cách tối ưu (phòng ngừa cấp 1, cấp 2 và phòng ngừa cấp 3, với sự tập trung vào khía cạnh sinh học-yếu tố tâm lý-đời sống xã hội)
4. Cổ vũ mạng lưới nhóm hỗ trợ gia đình
5. Giảm sự nghèo đói bằng cách giảm các gánh nặng tài chính do bệnh và giúp các gia đình tìm cách để có được sự độc lập về tài chính.

CLAN thấy tự hào vì cùng với chuyên viên y tế và gia đình tổ chức các buổi họp mặt Câu lạc bộ Hội chứng thận hư cho trẻ em Việt Nam trong năm 2011 và 2012. Chúng tôi rất biết ơn sự giúp đỡ của các bạn để thực hiện dự án nghiên cứu và xin chia sẻ thành quả cũng như những bức ảnh nổi bật ghi được từ các buổi họp mặt Câu lạc bộ trong bản tin này!

Chúng tôi mong các bạn thấy vui thích khi tham gia câu lạc bộ HCTH hôm nay và nhận được sự cổ vũ tinh thần từ những gia đình khác. Chúng tôi mong những thắc mắc của các bạn được giải đáp một cách thỏa đáng và bạn tự tin hơn để chăm sóc con mình một cách tốt nhất.

Trên hết, chúng tôi tha thiết hy vọng sự hỗ trợ cộng đồng trẻ em HCTH được phát triển vững mạnh, và các bạn có thể nhận thấy rằng bạn bè quốc tế quan tâm đến con bạn, những bé đang trong hoàn cảnh khó khăn vì một bệnh mạn tính. Bạn cũng đang giúp cải thiện cho tình trạng bệnh của con mình bằng cách làm thành viên của cộng đồng HCTH tại địa phương mình và tham gia câu lạc bộ HCTH.

Trân trọng,

Kate Armstrong
(Chủ tịch tổ chức CLAN)

NS Club video resources – shared at the NS Club Meetings with all families

NS Club Meeting Hanoi 2012

- Developed to assist with advocacy, awareness, encouragement of the NS Community, fundraising and reporting to donors

Tyler talks about his life with Nephrotic Syndrome (Vietnamese)

- Developed to assist with family education, encouragement and support.

Child-friendly Rights Flyer for the NS Community

Developed to assist with awareness, education and advocacy.

What are the Rights of the Child Living with Nephrotic Syndrome (NS)?

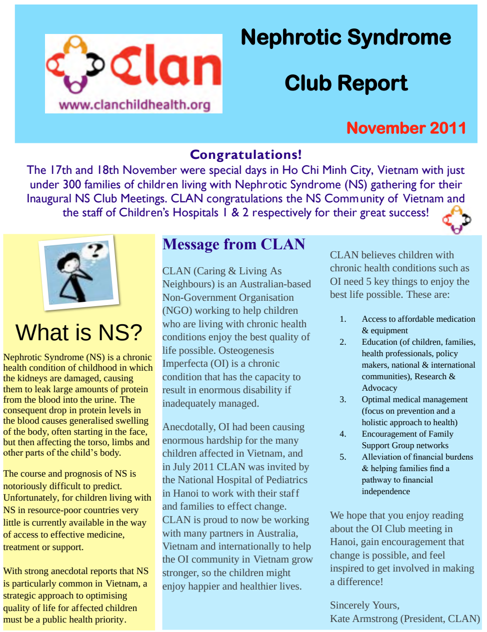
All children around the world should have, or be able to have the same rights. These rights are provided for by the United Nations Convention on the Rights of the Child (UNCRC) 1989.

The United Nations recognises that as a child you should be fully prepared to live an individual life in society and be brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality and solidarity.

NS is one of the most common kidney conditions of childhood. As a child living with NS, you have the right "to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". It is the responsibility of the international community to ensure that countries "strive to ensure that no child is deprived of his or her right of access to such health care services".

Children, young people and their families living with NS and other chronic health conditions in low- and middle-income countries ask for help with five key action areas (CLAN's Five Pillars). Fortunately, UNCRC recognises these needs as the rights of children.

NS Club reports - November 2011 and February 2012 (in English, to assist with advocacy, raising awareness and reporting back to donors)



Clan
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Nephrotic Syndrome

Club Report

November 2011

Congratulations!

The 17th and 18th November were special days in Ho Chi Minh City, Vietnam with just under 300 families of children living with Nephrotic Syndrome (NS) gathering for their Inaugural NS Club Meetings. CLAN congratulations the NS Community of Vietnam and the staff of Children's Hospitals 1 & 2 respectively for their great success!

What is NS?

Nephrotic Syndrome (NS) is a chronic health condition of childhood in which the kidneys are damaged, causing them to leak large amounts of protein from the blood into the urine. The consequent drop in protein levels in the blood causes generalised swelling of the body, often starting in the face, but then affecting the torso, limbs and other parts of the child's body.

The course and prognosis of NS is notoriously difficult to predict. Unfortunately, for children living with NS in resource-poor countries very little is currently available in the way of access to effective medicine, treatment or support.

With strong anecdotal reports that NS is particularly common in Vietnam, a strategic approach to optimising quality of life for affected children must be a public health priority.

Message from CLAN

CLAN (Caring & Living As Neighbours) is an Australian-based Non-Government Organisation (NGO) working to help children who are living with chronic health conditions enjoy the best quality of life possible. Osteogenesis Imperfecta (OI) is a chronic condition that has the capacity to result in enormous disability if inadequately managed.

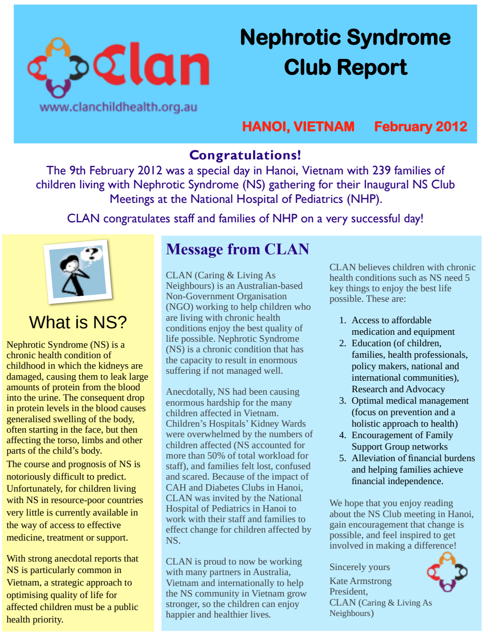
Anecdotally, OI had been causing enormous hardship for the many children affected in Vietnam, and in July 2011 CLAN was invited by the National Hospital of Pediatrics in Hanoi to work with their staff and families to effect change. CLAN is proud to now be working with many partners in Australia, Vietnam and internationally to help the OI community in Vietnam grow stronger, so the children might enjoy happier and healthier lives.

CLAN believes children with chronic health conditions such as OI need 5 key things to enjoy the best life possible. These are:

1. Access to affordable medication & equipment
2. Education (of children, families, health professionals, policy makers, national & international communities), Research & Advocacy
3. Optimal medical management (focus on prevention and a holistic approach to health)
4. Encouragement of Family Support Group networks
5. Alleviation of financial burdens & helping families find a pathway to financial independence

We hope that you enjoy reading about the OI Club meeting in Hanoi, gain encouragement that change is possible, and feel inspired to get involved in making a difference!

Sincerely Yours,
Kate Armstrong (President, CLAN)



Clan
www.clanchildhealth.org.au

Nephrotic Syndrome
Club Report

HANOI, VIETNAM February 2012

Congratulations!

The 9th February 2012 was a special day in Hanoi, Vietnam with 239 families of children living with Nephrotic Syndrome (NS) gathering for their Inaugural NS Club Meetings at the National Hospital of Pediatrics (NHP).

CLAN congratulates staff and families of NHP on a very successful day!

What is NS?

Nephrotic Syndrome (NS) is a chronic health condition of childhood in which the kidneys are damaged, causing them to leak large amounts of protein from the blood into the urine. The consequent drop in protein levels in the blood causes generalised swelling of the body, often starting in the face, but then affecting the torso, limbs and other parts of the child's body.

The course and prognosis of NS is notoriously difficult to predict. Unfortunately, for children living with NS in resource-poor countries very little is currently available in the way of access to effective medicine, treatment or support.

With strong anecdotal reports that NS is particularly common in Vietnam, a strategic approach to optimising quality of life for affected children must be a public health priority.

Message from CLAN

CLAN (Caring & Living As Neighbours) is an Australian-based Non-Government Organisation (NGO) working to help children who are living with chronic health conditions enjoy the best quality of life possible. Nephrotic Syndrome (NS) is a chronic condition that has the capacity to result in enormous suffering if not managed well.

Anecdotally, NS had been causing enormous hardship for the many children affected in Vietnam. Children's Hospitals' Kidney Wards were overwhelmed by the numbers of children affected (NS accounted for more than 50% of total workload for staff), and families felt lost, confused and scared. Because of the impact of CAH and Diabetes Clubs in Hanoi, CLAN was invited by the National Hospital of Pediatrics in Hanoi to work with their staff and families to effect change for children affected by NS.

CLAN is proud to now be working with many partners in Australia, Vietnam and internationally to help the NS community in Vietnam grow stronger, so the children can enjoy happier and healthier lives.

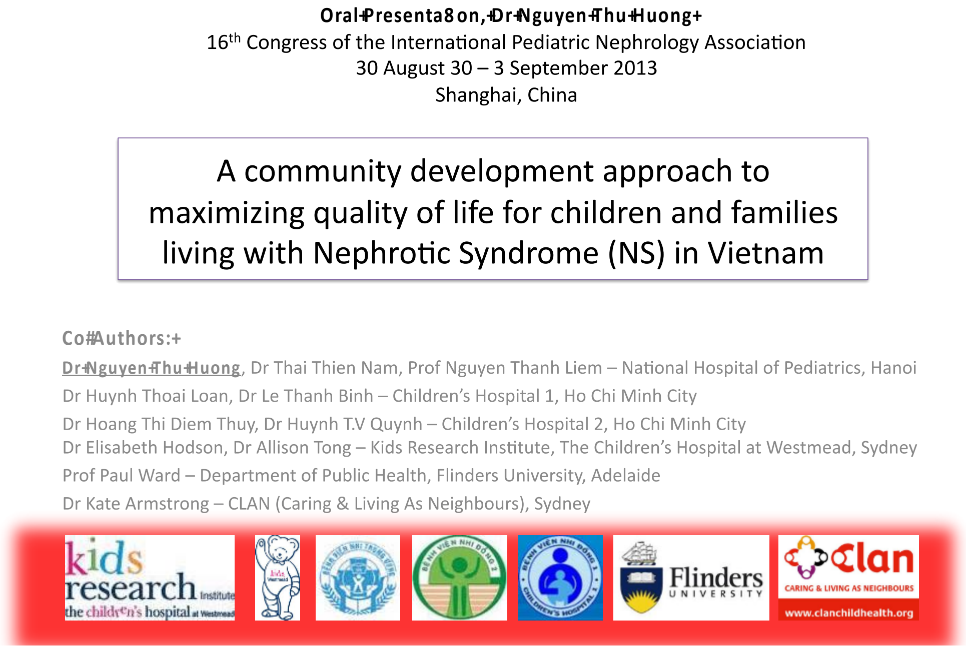
CLAN believes children with chronic health conditions such as NS need 5 key things to enjoy the best life possible. These are:

1. Access to affordable medication and equipment
2. Education (of children, families, health professionals, policy makers, national and international communities), Research and Advocacy
3. Optimal medical management (focus on prevention and a holistic approach to health)
4. Encouragement of Family Support Group networks
5. Alleviation of financial burdens and helping families achieve financial independence.

We hope that you enjoy reading about the NS Club meeting in Hanoi, gain encouragement that change is possible, and feel inspired to get involved in making a difference!

Sincerely yours
Kate Armstrong
President,
CLAN (Caring & Living As Neighbours)

Conference presentations - IPNA Oral 2013



Oral+Presenta8on,+Dr+Nguyen+Thu+Huong+
16th Congress of the International Pediatric Nephrology Association
30 August 30 – 3 September 2013
Shanghai, China

A community development approach to maximizing quality of life for children and families living with Nephrotic Syndrome (NS) in Vietnam

Co#Authors:+
Dr+Nguyen+Thu+Huong, Dr Thai Thien Nam, Prof Nguyen Thanh Liem – National Hospital of Pediatrics, Hanoi
Dr Huynh Thoai Loan, Dr Le Thanh Binh – Children's Hospital 1, Ho Chi Minh City
Dr Hoang Thi Diem Thuy, Dr Huynh T.V Quynh – Children's Hospital 2, Ho Chi Minh City
Dr Elisabeth Hodson, Dr Allison Tong – Kids Research Institute, The Children's Hospital at Westmead, Sydney
Prof Paul Ward – Department of Public Health, Flinders University, Adelaide
Dr Kate Armstrong – CLAN (Caring & Living As Neighbours), Sydney

Health professional educational lectures – available on request

Tool 7 - CHECC (Child Health Equity Checklist Count) Scorecard

Will a child survive & thrive with a chronic health condition in a resource-poor setting?
Make sure you CHECC risks to survival for EVERY child diagnosed with a chronic health condition so we #LeaveNoChildBehind!

#	Indicator	Criteria	Evidence base / rationale	Score/10
1	Gender	Score 1 if child is female	Some cultures give priority to male children	1*
2	Distance of home from quality health care	Score 1 if child lives more than 3 hours (or 100km) from qualified and trusted health professional	There is decreased access to quality care in remote and rural locations. Travel costs money and time.	1
3	Ethnicity	Score 1 if child is Indigenous or from an Ethnic Minority Group	Indigenous and ethnic minority families experience racism and systemic disadvantage	1
4	Monthly income	Score 1 if out-of-pocket costs of caring for child will be greater than 10% of family's monthly income OR a parent income has been lost as carer	Poverty reduces survival and health outcomes Consider costs of medicine, equipment, health care and travel	1
5	Family structure	Score 1 if child is from a single parent family	Children with chronic conditions from single parent families have poorer health outcomes	1
6	Parent education level	Score 1 if either parent's education is less than Grade 9 level	Health outcomes increase when parental educational levels are higher	1
7	Parental health literacy	Score 1 if parents cannot access culturally appropriate educational resources on child's chronic condition in their own local language	If family do not understand what chronic condition is, nor how to manage it, child health outcomes are likely to be worse	1
8	Parental support and wellbeing	Score 1 if parents have no extended family or local community support to assist with caring for their child OR they report feeling stressed, depressed and unable to cope	Family support (e.g. grandparents, wider family to assist) is associated with better outcomes; social isolation, stigma and parental stress are associated with worse outcomes.	1
9	Child wellbeing	Score 1 if the child is unable to attend school (either now or not expected to attend once older) AND/OR child has more than one chronic condition	Health outcomes are reduced with comorbidities. Children with chronic health conditions should be screened for mental health conditions	1
10	Family support networks	Score 1 point if the family has no access to a support group or network of other people living with the same condition	Support groups can provide people living with chronic conditions with valuable support and information	1
			Total score	10

Child has best chance to thrive

If the CHECC is >3 the child's rights to health and life are at serious risk.
Special action is urgently required if the child is to SURVIVE and THRIVE.
See the CHEAR Toolkit for more information
*Note: Local review of indicators and scores

Survival at risk

Appendix 2: Poster submitted to the International NCD Child Conference, Oakland, CA, USA in 2012

The Power of a Community Development Approach to Population-Wide Change for Children Living with Nephrotic Syndrome (NS) In Vietnam

Armstrong, Kate[1]; Nguyen Thanh Liem[2]; Nguyen Thu Huong[2]; Tran Thi Mong Hiep[3]; Huynh Thoai Loan[4]; Le Van Hao5; Hodson, E[6]; Tong, A[6,7]
CLAN (Caring & Living As Neighbours)[1]; National Hospital of Pediatrics (Hanoi)[2]; Children's Hospital 2 (Ho Chi Minh City)[3]; Children's Hospital 1 (HCMC)[4]; Vietnam Academy of Social Science (VASS)[5]; Centre for Kidney Research, The Children's Hospital Westmead (CHW, Sydney)[6]; Sydney School of Public Health, University of Sydney[7]

What is Nephrotic Syndrome (NS)? NS is a chronic health condition of childhood in which the kidneys intermittently leak large amounts of protein from the blood into the urine, resulting in generalised swelling of the body. The course and prognosis of NS is notoriously difficult to predict and underlying aetiology poorly understood. Unfortunately, for children living with NS in most resource-poor countries, access to effective medicine, treatment or support is very limited.

1. Parents gather for a group photo after a successful inaugural NS Club meeting at Children's Hospital 1, HCMC, Vietnam (November 2011).
2. Two hundred and thirty nine (239) families of children with Nephrotic Syndrome attend the Inaugural NS Club meeting at the National Hospital of Pediatrics, Hanoi, Vietnam, February 2012.
3. President of the NS Club in Hanoi, Vietnam addresses 239 attending families at their inaugural meeting, February 2012.
4. Comprehensive educational resources on Nephrotic Syndrome and its management have been translated into Vietnamese and shared free of charge with all families in the country.
5. Visiting kidney specialists from Australia attending NS Club meetings have taken the opportunity to also conduct training days for more than 100 Vietnamese doctors from a broad number of provinces, providing updates on Nephrotic Syndrome and other kidney disease.
6. Vietnamese media interview Professor Tran Dinh Long, Head of the Pediatric Nephrology and Urology Society of Vietnam. The NS Club Meeting is an opportunity to raise local, national and international awareness of the challenges families face.
7. Nephrotic Syndrome Club meetings provide the perfect opportunity to survey families and ask what THEIR burdens and challenges are and what THEY recommend should change to help the children.
8. Club Meetings are an opportunity for the children to come along, have fun, meet other children living with the same chronic condition, and realise they are not alone.

Nephrotic Syndrome in Vietnam Estimates from the three largest children's hospitals in Vietnam suggest there are 3,000 children currently affected by NS, and anecdotally, NS accounts for more than 50% of the workload of the renal departments at these tertiary referral centres. Overcrowded outpatient departments mean families rarely see a doctor for more than 5 to 10 minutes at a time, and high bed occupancy rates (often more than one child per bed) impact patient care.

CLAN's Strategic Framework for Action Since 2004, CLAN (Caring & Living As Neighbours) has collaborated with a wide range of partners to initiate community development-based change to maximize quality of life and health outcomes for children living with chronic health conditions in Vietnam. Identifying all children affected by NS as members of an "NS Community" since 2010, multi-stakeholder action has utilised a strategic framework for action that focuses on five key pillars:

1. Affordable access to essential medicine and medical equipment
2. Education (of children, families, health professionals, national and international organisations policy makers), research and advocacy
3. Optimisation of medical management
4. Encouragement of family support networks
5. Overcoming financial burdens and promoting financial independence for families.

Achievements Since 2010

- Establishment of NS Clubs at all 3 children's hospitals in Vietnam (over 500 families attended educational meetings so far)
- Identification of NS community leaders
- Conduct of health needs analysis to identify key recommendations for change
- Decisive action by Vietnamese Ministry of Health to ensure essential NS drugs are included on the National Insurance Scheme (August 2011)
- Translation of key educational resources into Vietnamese language
- Development of a documentary and presence of Vietnamese media at NS Club meetings to raise awareness
- Educational training days for over 100 health professionals in Vietnam on renal conditions
- International collaboration to initiate development of patient registers and future options for genetic analysis.

Clan

Conclusion Nation-wide change is occurring at a rapid pace in Vietnam for children living with NS thanks to collaborative, health-system strengthening action focused on the NS community itself.

www.clanchildhealth.org.au

Appendix 3: Poster presented at IPNA Conference 2016

Caring & Living As Neighbours

www.clanchildhealth.org

Key Recommendations from a Community Development Approach to Nephrotic Syndrome in Vietnam:

Opportunities to Redress Inequities at a Regional and International Level

K. ARMSTRONG(1,2), H.T. NGUYEN(3), H.T.D. THUY(4), H.T. LOAN(5), C.D. NGUYEN(6), A. LE PAGE(7), F. MACKIE(8), E. HODSON(9)

(1) CLAN (Caring & Living As Neighbours), Sydney, AUSTRALIA; (2) Flinders University, Adelaide, AUSTRALIA; (3) National Hospital of Pediatrics, Hanoi, VIETNAM; (4) Children's Hospital 2, Ho Chi Minh City, VIETNAM; (5) Children's Hospital 1, Ho Chi Minh City, VIETNAM; (6) Hue Central Hospital, Hue, VIETNAM; (7) Monash Children's Hospital, Melbourne, AUSTRALIA; (8) Sydney Children's Hospital, Randwick, AUSTRALIA; (9) Children's Hospital Westmead, Sydney, AUSTRALIA.

Acknowledgements: Prof Paul Ward (Flinders University); Dr Mac Yen Thanh (CLAN); Dr Thanh Le Binh (CH1, HCMC); Dr Huynh Thi Vu Quynh (CH2, HCMC); Children & Young People's Kidney Unity at the City Hospital, Nottingham, England ("Green Booklet"); Royal Children's Hospital, Melbourne, Australia ("Blue Booklet").

A. Objectives

A person- and community-centred approach to collaborative action to improve quality of life for children living with Nephrotic Syndrome (NS) in Vietnam since 2010 has improved health outcomes and reduced burdens on the national health system. Review of key achievements and ongoing challenges informs recommendations for future action at local, national, regional and international levels.

B. Methods

Utilisation of CLAN's strategic framework for action focused international collaborative action for NS in Vietnam on five pillars: access to medicines and equipment; education, research and advocacy; optimisation of medical management; encouragement of family support groups; and reducing financial burdens on families. Benchmarking change against these pillars since 2010 allows stakeholders to track progress.

Highest Quality of Life

Community Groups

Individuals

Industry

Families

Policy Makers

Health Professionals

Non-Government Organisations

Other Specialists

Government & Health Systems

Philanthropy

Education, research and advocacy

Optimal medical management

Encourage family support groups

Ensure affordable access to medication and equipment

Reduce poverty and promote financial independence

A RIGHTS BASED APPROACH

Support Group as Visual Hub

C. Results

Key achievements for children living with NS in Vietnam since 2010 include:

- improved access to medicines (cyclosporine, mycophenolate mofetil) on national insurance scheme;
- translation of educational resources, with free distribution to families;
- families trained on use of urinary dipsticks, with approximately 80% of families now testing for proteinuria at home;
- reduced relapse (number and severity) and admission rates;
- clinical seminars for provincial doctors (14 seminars between 2011–2015; estimate attendance by more than 500 doctors);
- NS community surveys to clarify priorities for action;
- drastically reduced loss to follow up, with very few families now electing not to return for care as recommended;
- regular NS Club meetings (13 meetings from 2011–2015; more than 1,000 families have attended; on evaluation, 98% families "would attend again");
- recent establishment of the Vietnamese Pediatric Nephrology Association; and
- promotion of school attendance, with awards given to children for good performance at Club meetings.

<< Key educational resources on NS translated into the Vietnamese languange

Ongoing opportunities include:

- tailoring insurance processes to address chronic conditions;
- sustainable and humanitarian approaches to ESRF and SRNS;
- development of a national register and ongoing research agenda;
- strengthening national capacity in the field of pediatric nephrology through local, regional and international support of the Vietnamese Pediatric Nephrology Association, its activities and initiatives.

D. Conclusions

Engagement of national and regional paediatric nephrology societies in collaborative activities using a shared strategic framework offers sustainable opportunities for scaling efforts internationally. Recent engagement with ANZPNA and ongoing involvement of IPNA and other regional groups will facilitate translation of key achievements and insights across borders and fast-track efforts to redress inequities for all children living with NS.

Appendix 4: Extract from Final Resolution, *UN High Level Meeting on Non-Communicable Diseases*

> *24. Note with concern the rising levels of obesity in different regions, particularly among children and youth, and note that obesity, an unhealthy diet and physical inactivity have strong linkages with the four main non-communicable diseases and are associated with higher health costs and reduced productivity*
>
> *26. Note also with concern that maternal and child health is inextricably linked with non-communicable diseases and their risk factors, specifically as prenatal malnutrition and low birth weight create a predisposition to obesity, high blood pressure, heart disease and diabetes later in life, and that pregnancy conditions, such as maternal obesity and gestational diabetes, are associated with similar risks in both the mother and her offspring;*
>
> *28. Recognize that smoke exposure from the use of inefficient cooking stoves for indoor cooking or heating contributes to and may exacerbate lung and respiratory conditions, with a disproportionate effect on women and children in poor populations whose households may be dependant on such fuels;*
>
> *(f) Promote the implementation of the World Health Organization Set of Recommendations on the Marketing of Foods and Non-alcoholic Beverages to Children, including foods that are high in saturated fats, trans-fatty acids, free sugars or salt, recognizing that research shows that food advertising geared to children is extensive, that a significant amount of the marketing is for foods with a high content of fat, sugar or salt and that television advertising influences children's food preferences, purchase requests and consumption patterns, while taking into account existing legislation and national policies, as appropriate;*
>
> *(i) Promote, protect and support breastfeeding, including exclusive breastfeeding for about six months from birth, as appropriate, as breastfeeding reduces susceptibility to infections and the risk of undernutrition, promotes the growth and development of infants and young children and helps to reduce the risk of developing conditions such as obesity and non-communicable diseases later in life, and in this regard strengthen the implementation of the International Code of Marketing of Breast-milk Substitutes and subsequent relevant World Health Assembly resolutions;*
>
> *(a) Take measures to implement the World Health Organization set of recommendations to reduce the impact of the marketing of unhealthy foods and non- alcoholic beverages to children, while taking into account existing national legislation and policies;*
>
> *(f) Promote multisectoral and multi-stakeholder engagement in order to reverse, stop and decrease the rising trends of obesity in child, youth and adult populations, respectively;*
>
> *(o) Promote the inclusion of non-communicable disease prevention and control within sexual and reproductive health and maternal and child health programmes, especially at the primary health-care level, as well as other programmes, as appropriate, and also integrate interventions in these areas into non-communicable disease prevention programmes*

Appendix 5: Health Needs Assessment Tools (Drafts 1, 2 and 3 from Study One)

Health Needs Assessment Template **Draft One** (Study One, PAR Cycle One)

Study 1 - HNA
Draft 1 - submitted

Health Needs Assessment Template **Draft Two** (Study One, PAR Cycle Two)

Study 1 - HNA
Draft 2 - as at

Health Needs Assessment Template **Draft Three** (Study One, PAR Cycle Three)

Study 1 - HNA
Draft 3 - FINAL

The final version of the tool used in this HNA is provided as Tool 5 of the CHEAR Toolkit (Appendix 1).

Appendix 6: Challenges, burdens and strengths as shared in the parent surveys

Theme	**Sub-themes**	**Illustrative quotes**
Burden of NS on children	Physical burden of NS on children's bodies	*"He is thinner and shorter than other children"* *"Headache… breathless… gastritis…"* *"He got tired sometime when he went to school"*
	Emotional / psychological burdens	*"The child usually felt upset, sad, unconfident due to having NS"* *"Always worried… sad… not confident"* *"Afraid of death"* *"He was not confident in interactions with friends when he had oedema"*
	Social / educational burdens	*"Can't eat and play as usual… can't play with others"* *"Had to miss classes to see doctors"* *"He had to miss classes during hospitalisation"* *"It is difficult for him to join his friends"* *"He does not enjoy his life, has to be on diet and faces difficulties in adaption with friends"* *"Diet. He can't join activities at school, such as swimming, because we are afraid the water is not clean"*
	Barrier to children achieving their full potential in life	*"Will NS be cured? Can she have children?* *"Can my child get married? Will his NS pass to his son?"* *"Afraid my child will not have a good future… Afraid NS will last a long time and have complications… He may suffer dialysis… Afraid of death"* *"NS will affect his career and productivity"* *"Afraid that he may suffer life threatening condition if we can't take him to the hospital on time once he has relapse"*
	Side effects of medicines on children's behaviour	*"Aggressive"* *"Naughty"* *"Gets angry quickly"*
	The adverse impact of myths / non-evidence based approaches	*"My child is so naughty. We could not make him less active"* *"My child had to leave school. Had to be on diet and take medicine as per doctor's advice"* *"Was not accepted into kindergarten school because of need for a less salty diet"* *"He had to be on diet, physical activity was limited"* *"He must on diet, he can't play normally like his friend do, hence he can't enjoy his life"*
Burden on families	Financial burdens	*"I was worried about financial issues, worried that my child's health will become worse"* *"Spending a lot of money made the economy of our family go down"*

Theme	Sub-themes	Illustrative quotes
		"Transportation (especially as we have financial difficulties)"
	The inter-connectedness of time, money and health	*"Finance, time, health"* *"We had to spend much time to take care my child, it affected our works; also we faced difficulties in finance"* *"Our family had to spend time and money to take him for follow up"* *"We're always worried about financial difficulties… I've had to stop working to take care of him"* *"I am worried about his health, treatment costs and arranging time"* *"Finance because I have to quit my work, stay home"* *"When my child was admitted to the hospital, we were so worried during hospitalisation, our income was reduced because we had to take work leave to take care our child"* *"I had to take leave from work to take care my child whenever he got sick"*
	The chronicity of NS	*"NS lasts so long and affects family's economy…"*
	Psycho-social burdens	*"Very depressed… sad and worried…"* *"I'm always worried… nervous that I can't work"* *"The mother could not concentrate on work because she is so worried for the child at home, about his diet and taking medicine"* *"I am so worried about my child's NS relapsed many times, I'm not sure if it will be cure or not"* *"…we are also sad about my child's disease"* *"Health and future of our child"* *"All of our family members are worried about his health"* *"I am so worried. I wish my child will recover so that he will be like other children"* *"I lost my confidence while my child got a chronic disease"* *"I'm afraid"* *"I'm worried. My mood is not stable due to my child's health condition"*
	Adverse impact of myths / non-evidence based approaches	*"It is hard for me (the mother) go to work because I have to pay attention on his diet. He has to eat less salty food. Getting full before taking medicine, avoid sugar…"* *"We had to ask our child to follow less salty diet. Spend so much time and money"* *"It is hard for me (the mother) to go to work because I have to pay attention to his diet. He has to eat less salty food"*

Theme	Sub-themes	Illustrative quotes
	Fears for the future	*"(I'm worried…) NS would relapse many times and his "future" will be impacted." "Medicine may cause kidney insufficiency, osteopenia, delayed bone growth, early puberty"* *"NS will relapse… recurrence and complications"* *"We are always worried that he will not have a cure"* *"Health, memory and productive ability"* *"Afraid that he may suffer life threatening condition if we can't take him to the hospital on time once he has relapse"* *"NS may lead to kidney failure"* *"Can my child get marriage? Will his NS pass to his son?"*
Strengths of children and families	Resilience of children (and importance of encouraging them)	*"At the beginning, he usually felt unconfident due to having NS but after getting encouragement from family, he did not have that feeling anymore. He had normal activities as other children."* *"He felt pressed due to NS but he can bear when NS relapse as we encouraged him. He studied well and take medicine as prescriptions"*
	Resilience of parents and families	*"Although we are farmers, we learn that we have to try our best to help our child face with NS and we believe in doctors"* *"We are farmers. We are trying our best to manage his NS"*
	Commitment of parents to acting in the best interests of their children (even at great personal cost)	*"Although we don't have money and live far from hospital, we took our child go directly to NHP because the procedure is very complicated if we visited local hospital and the NS would not be cure soon. He is not as healthy as others. But he is getting better with treatment"* *"My family was very worried and spent much time for the child. Whenever he got fever, we were so afraid of recurrence, hence we took him to the (Local) Hospital at that time."* *"We need to stay home to take care him, hence our income reduced. We are afraid of having another baby"*

Appendix 7: Key recommendations for action emerging from parent surveys

Theme	Subtheme	Illustrative quotes
Reduce financial burdens	Prioritise financial support for families	*"Children and family need care and treatment from doctors as well as support financially"*
	Especial support for poor families	*"I'm afraid our finance can't afford when he is 6 years old (changing insurance policy)".*
	Collaborative action to relieve financial burdens on families	*"I only wish that everyone will work together to help children with NS to recover soon in order to reduce financial burdens. If it is possible I would like to ask everyone in this society to give a hand to help those families who are facing many difficulties."*
	Connect families with systems that offer financial support	*"Organisations would help to build a foundation to support families having children with NS in order to reduce their burden"*
		"I think the government and organisations should have fund for families in order to help their lives less stressful and better"
		"I wish he can have insurance (at the children's hospital). He needs help and support from organisations"
	Strengthen the existing insurance system	*"We would like to suggest that insurance cover 100% even though we don't have referral letter because the quality of care given by local health professionals is not as good as that at centralised hospitals. The chance of relapse of NS is high, almost every month. It is so difficult for us to take leave to take care of him. In addition, we need to manage other fees such as transportation, treatment cost. Burdens follow burdens, and the chance for us to get fired is high because we need to get permission from our employer to care for our child. We would like to ask for help from the Government".*
		"The paperwork of examination for children less than 6 years old was complicated"
		"He had to ask referral letter from district hospital, after that asking at the hospital of province. I would like to ask the government and community help us have less procedure. Thank you"
		"I hope insurance will cover even though we don't have referral letter"
		"It took a lot of time to have referral letter from local hospital, it made my child's health condition get worse

Theme	Subtheme	Illustrative quotes
		(when NS relapsed), hence we sometime took her directly to (hospital X) without a referral letter. So, we had to pay all expenses. I would like to ask help from the government and community care and support families with NS children in order to help their NS recover and they can adapt to life."
		"Less paperwork for inpatient care."
Optimise medical management (bio-medical-social)	Provide the necessary medicines	*"Specific medications for NS so that NS will not relapse and they don't need to suffer dialysis-they can have normal life"*
		"How to help NS children recover as soon as possible so that they will not be disability"
	Find a cure	*"Scientists and doctors must find the best way of treatment and medicine in order to help children with NS be cure as much as possible. Hence, families will not be worried about their children's health."*
		"I would like to ask your help for the cure of NS for my child, so that my child can go to school, other family members can go to work to earn money"
	Provide psychological support for children	*"My child was so shocked when doctors informed that NS is a chronic health conditions which he has whole life. I hope doctors would pay more attention about children's feeling because he is 14 years old, it really made him down and upset. We have coped with this issue slowly"*
		"Help children enjoy their life"
	Help families stay more hopeful	*"I think families and children should be encouraged and helped in order not to get depressed"*
		"Families have children with NS are very worried because it may lead to kidney failure. We would like to suggest that government and organisations should raise concern so that children can achieve optimal quality of life. With those families are so poor, government should give them priority so that they will be more optimistic"
	Increase access to qualified health professionals	*"The hospital should have support and consultant service through the internet. Improving primary health care so that NS can be managed at local levels"*
		"Health professionals should spend more time for children"
Help families learn about NS	Provide information on NS	*"I wish health education program of NS will be broadcasted on Television channel so that all families can access information"*
		"There should be health educators guide families about NS."

Theme	**Subtheme**	**Illustrative quotes**
	Raise community awareness	*"I hope there will be knowledge of NS be broadcasted on television, hence all families can approach updated information"*
		"Television should broadcast meetings and health education about NS, the way of management NS. I hope we can get financial support"
	Empower parents to care for children at home	*"Fortunately, club meetings were held. I wish club meetings can happen more frequently, hence families will understand more about NS (on behalf of other families I gave my voice)"*
		"We wish we will have more knowledge and skill to take care our children at home and we can attend NS club meetings, so that we will have opportunity to meet other families who have the same voice"
	NS Support Clubs	*"There should be regular and more often meetings to evaluate and help knowledge of families updated. Ask help from supporters"*
		"…building NS club meetings so that families can share and exchange knowledge, help each other to have a better life"),
		"Families of NS children has faced many troubles and worriedness, but visiting hospital also caused problems to us. Doctors did not have enough time to explain us about NS because of the overwhelmed work. Fortunately, club meetings were held. I wish club meetings can happen more frequently, hence families will understand more about NS"
Special support for the most vulnerable families	Poor families	*"Families with financial burden need help from other supporters in order to help children with NS adapt to communities"*
	Families with multiple members who are unwell	*"My husband has mental illness. My child has NS. I'm a farmer with very low income. I would like ask help from community to be concerned about my child"*
Strengthen the health and education systems	Improve access	*"He is not confident. Local government should hold group support to have a better outcome for their psychological aspects."*
	Help children stay in school	*"Helping them at school (they had to do strong physical activities at school)."*
		"Let him go to school and play with classmates"
		"Helping them at school (they had to do strong physical activities at school)."
		"Working together to help children go to school so that they will have better life"

Theme	Subtheme	Illustrative quotes
	Collaborative action	*"(We are all) working together to help children go to school so that they will have better life".*
		"Families need help from local governments and Ministry of Health"
		"We hope domestic and international charitable organisations help us"
		"I would like to ask help from WHO so that children with NS will have a better life"
		"We hope domestic and international charitable organisations help us"
		"Living in a healthy environment, having balanced physical activities. NS children need to change "environment" as well as diet"
	Strengthen local health systems	*"If local hospitals, clinics were equipped well and there were specialists, my child would have been taken care better at local levels. If it happened, we would not spend a lot of money on transportation"*
		"Treatment guideline should be trained at province hospitals and community clinics to reduce travelling cost"
		"Helping patients can visit hospitals near their houses, so that we can reduce a lot of costs"
		"Arrange good doctors to local medical setting so that our children can be managed better and families have less burden"
	Support from government and hospitals	*"The Government should open more hospitals and care more about children having diseases, so that their health can be stable"*
		"I suggest government should raise concerns on health care system and NS"
	Increase time with doctors	*"Families of NS children face many troubles and worries, but visiting hospital also causes problems for us. Doctors do not have enough time to explain NS to us because of the overwhelming work conditions.*

Appendix 8: Challenges, burdens and strengths emerging from HNA evidence collected in Study One and Two analysed according to the four planes of agency

Theme (according to the four planes of agency)	Sub-themes (relating to challenges, burdens and strengths)	Illustrative quotes / evidence	Determinants of health functioning
Plane 1. **Material transactions with nature**	The physical impact of NS and its treatment on children - Fear of complications - Fear of relapse - Barrier to children fulfilling their true potential in life - Side effect of medications - The prognosis for NS with optimal treatment is excellent	"I'm so worried my child will have a high risk of kidney failure" "I'm so worried when he gets cough and fever in case his NS relapses" With optimal care 90% of children diagnosed with NS can expect to enter adulthood with normal renal function	Affordable access to quality health care to optimise health outcomes Frequency of relapses Financial safety nets in place Children and families encouraged in their journey with NS Children and families empowered in their management of NS
	The chronic, relapsing nature of NS	"Time spent caring for our child and finances will be impacted if NS relapses many times" "We don't have enough money for long-term treatment" The impact of chronic, complex health conditions on all aspects of family wellbeing	Type of NS – impacts on prognosis (most types have a good prognosis with optimal care)
	The potential impact of NS on the future of affected children - Fear of the unknown - Fear for future generations	"I'm not sure when NS will be cured, and worry about complications of NS as well as side effects of the medicine" "Can my child have children?"	Health literacy Access to quality information on NS (to optimise care and dispel myths)
	Opportunities to prevent relapses of NS are being missed	Vaccination rates are suboptimal (only 66% of children were up to date with the national immunisation scheme; a minority had been given any additional vaccines Families unable to test urine at home Families unable to self-initiate prednisone early to treat relapses at home	Vaccination Families empowered to test urine Families empowered to manage relapses early
	The voices and experiences of those most severely affected by NS are not being heard	Systematic exclusion bias in this study (children who have died / receiving renal replacement therapy so families were not consulted). Current findings and understandings are an under-estimate of the true burden	Determinants associated with death and loss to follow-up can be assumed but remain unknown.

Theme (according to the four planes of agency)	**Sub-themes (relating to challenges, burdens and strengths)**	**Illustrative quotes / evidence**	**Determinants of health functioning**
	The broader impact of NS - Emotional and psychological impact - Impact on health, life, school - Impact on the future	"I'm so worried that NS will not be cured, and my child will have limitations on his study and his career in the future" "He is not healthy; sometimes has to skip classes to visit doctors" "I worry my child can't grow up normally (physically)"	Children with chronic health conditions are supported to complete their education (even in hospitals) Optimise and minimise outpatient and inpatient visits Need for holistic health care
	Unaffordable access to essential medicines, equipment and health care	Despite 94% of families having health insurance, less than half of these families (41%) report insurance covers all costs. Families in the survivor cohort have a higher monthly income than the national average ($300 USD versus $74) Prednisone is relatively cheap Dipsticks are relatively cheap but not included on insurance scheme All other drugs required for quality care of NS were included in national insurance scheme in August 2011	Affordable access to medicine, equipment and healthcare
Plane 2. **Social interactions between people**	Social impact of NS	"Can't catch up with studies… can't play normally… can't communicate with others…" "Can my child get married?" "My child had to leave school, had to be on diet and take medicine as doctor's advice"	Empower and encourage children and families Children are supported to complete their education
	Societal and stigmas and cultural considerations	*"In long term I worry if she will get older and be able to have her own family. It's harder to get a husband because people in our community know and so she is less wanted by males. Are there problems having children?"* *"She is not good looking (because of short height / which might) influence her carrier / ability to have babies in the future"* *"Worried about how she looks: fat and short… will it influence her social life?"*	Reduce social stigma associated with NS Raise awareness nationally of NS; engage Ambassadors and celebrities Strengths and successes are promoted, shared and celebrated

Theme (according to the four planes of agency)	**Sub-themes (relating to challenges, burdens and strengths)**	**Illustrative quotes / evidence**	**Determinants of health functioning**
	Language and technology barriers to accessing quality information on NS	Only 7% of families speak English; only about half have access to the internet	Translated quality educational resources and information on NS are widely and freely available
	Having both parents and extended families involved in the care of children with NS is protective	Children from single parent families are at increased risk of poor health outcomes Household size in survivor cohort is greater than the national average Grandparents provide significant support to NS families Actively involved fathers play a protective role - in 54% of families both parents were involved in the care of their child	Children from single parent and families with limited support networks are at increased risk
	Impact of support systems	"I hope my child can enjoy his social life with friends and neighbours" "Attending the meeting made me feel less worried" Families appreciated Club Meetings Strong response rates (average 84%) / engagement in consultation processes	Disability inclusive messaging and actions at schools and within communities at local and national levels Platforms and opportunities available and accessible for NS Community networking and support NS Community actively engaged and strengthened
Plane 3. **Social structures**	Interactions with the health system	"My family was very worried and spent much time caring for the child. Whenever he got a fever we were so afraid of recurrence that we took him to (the local) Hospital straight away." "We visit (hospital) many times" "We don't have medical knowledge; the hospital is overloaded; it is so difficult to see doctors or get doctors' advice; we don't speak English…"	Availability of efficient and effective inpatient and outpatient systems for NS Empower families to optimally manage NS and prevent relapses
	Interactions with the education system	Children and families want to attend school Attendance at school has a protective effect (perhaps confounded by link to school insurance and severity of illness)	Education systems have capacity to meet especial needs of children with NS
	Burden of distance from tertiary referral centres and qualified health professionals	Average distance to tertiary centres is 95km Confidence in local health professionals is low (average 5/10)	Capacity of primary health care professionals / remote and regional centres to manage NS

Theme (according to the four planes of agency)	**Sub-themes (relating to challenges, burdens and strengths)**	**Illustrative quotes / evidence**	**Determinants of health functioning**
		Some provinces are under-represented in the cohorts consulted	Remote / rural families (those living more than 100km (3 hours) from tertiary centres are at especial risk)
	The interconnectedness of time, money and health	"We had to spend much time to take care of my child; it affected our work; also we faced financial difficulties" "my wife does not work to care for our son"	Income generating capacity
	Bureaucratic burdens restrict access to health insurance (a protective factor when universally available)	"We did not follow the insurance policy guidelines because we are not satisfied with the local medical services" "When my child started having symptoms we brought him to the local hospital, but his health worsened, so we took him to (tertiary hospital) without a referral letter (and were ineligible for insurance)" Very poor families are supported by health insurance for the poor Families prioritise insurance if they can afford it	Universal health coverage (that covers all costs)
	Impact of inequities	"We are so poor. Finance is our biggest problem. We love our son, but we can't do anything because we don't have enough money (cry)" "Transportation (especially as we have financial difficulties)" "We have no trust in provincial system (especially lower levels)"	Specific action to support families in the most vulnerable circumstances (poor, remote, illiterate, single parent families)
	Male child preference	Male children with NS are more likely to survive	Sex (female children with NS are at increased risk of dying)
	Ethnic minority communities are under-represented	Only 3% of the NS cohort families identified as belonging to ethnic minority groups	Capacity of health system to provide culturally appropriate and safe health care (children with NS from ethnic minority communities are at increased risk of dying)
	Financial burdens (increased costs / reduced income)	"I am worried about his health, treatment cost and arranging time to care for him" "Treatment and medicine cost is so expensive for our family"	Charitable / financial / practical support and resources available to families and carers

Theme (according to the four planes of agency)	**Sub-themes (relating to challenges, burdens and strengths)**	**Illustrative quotes / evidence**	**Determinants of health functioning**
	Entrenched poverty (future earning capacity of children with NS in peril)	"Impact of NS on his study, productive ability, career" "I'm not sure if my child can go to school"	Children with chronic conditions are supported to complete their education
	Data on NS in Vietnam is limited	Estimates of incidence, prevalence and mortality available only No patient registers No electronic databases Limited research capacity	Quality NS data are available
Plane 4. **Stratification of the embodied personality**	Adverse psychological impact – anxiety, fear	"I'm just so worried… always worried" "Since he got sick, he did not communicate or play with friends like he did before. He got tired very easily, that's why he communicates less. In summary, I am very worried"	Psychological support available for children and families living with NS Community awareness of NS / information available
	Coping mechanisms / resilience	"Attending this meeting made me feel less worried" "We always take care of him well, hence he can be cured soon" "We had to work harder to help my child"	NS Club Meetings / support / education training opportunities for families Research to find a cure for NS
	Families keen to learn about NS and how to optimally care for their children	100% of respondents wanted to learn more about NS	Families keen to learn about NS
	Families respect and trust health professionals at tertiary referral centres	Very few families stopped prescribed treatment, and even then only because of financial / access barriers	Families trust health professionals at tertiary centres
	The impact of myths where information is absent or inaccurate	"NS relapsed when weather changed" "He can't join physical education like others" "He has to be on a special diet" Families are less likely to use traditional medicines were affordable access to quality medicines, healthcare and information is available	Myths and misconceptions
	Confidence and resilience of parents and children	"At the beginning he lacked confidence due to NS, but after getting encouragement from family, he did not have that feeling anymore. He had normal activities like other children"	Families and children empowered to engage in finding solutions Psychological support

Theme (according to the four planes of agency)	Sub-themes (relating to challenges, burdens and strengths)	Illustrative quotes / evidence	Determinants of health functioning
		Families and children are incredibly resilient and powerful agents. Parents will go to great extremes to act in the best interests of their children. "He felt depressed due to NS, but he can bear when NS relapsed because we encouraged him. He studied well and takes medicines as prescriptions instruct"	
	Lower parent education levels are associated with poorer health literacy, reduced confidence and poorer health outcomes	Average education levels of parents in NS survivor cohorts are higher than the national average	Children from parents with lower educational levels are at increased risk of dying

Appendix 9: Key recommendations emerging from the evidence in the HNA

In the table, a blank space left next to a challenge indicates no specific recommendation was made. Recommendations for challenges not considered potentially changeable were crossed out and left in place for transparency. All recommendations provided by families were ranked using a traffic light score according to:

- Acceptability / justifiability - in light of the UNCRC
- Feasibility – in light of available resources

Themes	**Key challenges**	**Key recommendations (illustrative quotes)**	**Justifiable (according to UNCRC)**			**Resource feasibility?**
(Planes 1-4)			**Yes**	**No**	**Article Number**	**Yes/ ?/ No**
Plane 1. Material transactions with nature	The physical impact of NS and its treatment on children - Fear of complications - Fear of relapse - Barrier to children fulfilling their true potential in life - Side effect of medications - The prognosis for NS with optimal treatment is excellent	Provide good health services and medications; Having a better way to treat the child with corticosteroid resistant NS	🟩		Article 6 – right to life Article 23 – right to decent life Article 24 – right to best treatment	🟨
		~~They should have one special medicine to cure this. There are too many kinds of medicine right now. Do they have one special / powerful medicine?~~	Not changeable			
		Families request deeper level of knowledge and understanding Need more resources *"Help families improve care of their children in the home"*	🟩		Article 17 – right to information Article 24 – right to education and health literacy Article 29 – right to self development	🟩
	The chronic, relapsing nature of NS	There should be support programs for child with special condition, long-term treatment (medicine, finance support)	🟩		Article 6 – right to life Article 23 – right to decent life Article 24 – right to best treatment	🟨
	The potential impact of NS on the future of affected children - Fear of the unknown - Fear for future generations	See doctors and do the treatment well and always hope for good result You need to be supported to be able to get over this. Cured or not, it's just fate, we can just try to do our best.	🟩		Article 5 – responsibility to learn to exercise rights Article 31 – right to rest, leisure, play and recreation	🟩
	Opportunities to prevent relapses of NS	Lectures for families Training on how to test urine and diagnose relapse early	🟩		Article 17 – right to information	🟩

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
	are being missed	Families WANT to be independent	🟩		Article 24 – right to education and health literacy Article 24 – right to best treatment	🟩
	The voices and experiences of those most severely affected by NS are not being heard	Charity foundation for poor families. Insurance for all parents, esp poor families;	🟩		Article 6 – right to life Article 23 – right to decent life Article 24 – right to best treatment	🟩
	The broader impact of NS - Emotional and psychological impact - Impact on health, life, school - Impact on the future	provision of information of current state of children in more regular (predictable) way so families are less anxious.	🟩		Article 23 – right to dignity, self-reliance and special care as needed Article 27 – right to standard of living adequate for your physical, mental, spiritual, moral and social development	🟩
	Unaffordable access to essential medicines and equipment and health care	For poor families like me, support from charities is very much needed (100% insurance and other support).	🟩		Article 6 – right to life Article 23 – right to decent life Article 24 – right to best treatment	🟩
Plane 2. Social interactions between people	Societal and stigmas and cultural considerations					
	Social impact of NS					
	Language and technology barriers to accessing quality information on NS					
	Having both parents and extended families involved in the care of children with NS is protective	"Normally the parents are the best care takers, but in this case and in other extended families the grandparents also need information and support. If they get that, they would be very helpful"	🟩		Article 14 – rights of families and guardians to provide direction to you in the exercise of your rights Article 17 – right to information	🟩

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
	Impact of support systems	Club meeting a good idea Community to nominate Club Presidents Connect families via facebook / SMS Organizing the meeting clubs Experience Establishing the families club which help the new family and each other; support from health staffs, give more Information; Improvement the local health system sharing between families; Provide enough knowledge; share experiences together between parents	🟩		Article 15 – right to freedom of association Article 5 – responsibility of parents to help child learn to exercise their rights Article 31 – right to rest, leisure, play and recreation Article 23 – right to special support	🟩
Plane 3. Social structures	Poverty / financial stress / lack of strong support from insurance system	Help us escape poverty Loss of work very hard for farming families Help treatment and help with finances Financial support for patients and families Support from the sponsors Charity foundation for poor families. Organisations and the community should support the child financially so they can have a better life. Provide more information about NS, prevention, policies for poor families. There are too many people who are so poor, for me this hasn't affected me much. Insurance for all parents, esp poor families; Financial support for poor patients For poor families like me, support from charities is very much needed (100% insurance and other support). The question is how to get the money to save the children. Don't fall into debt. Many families here have sold everything they have but still don't get enough money Provide more information about NS, prevention, policies for poor	🟩		Article 4 – right to legislative, administrative and other measures for implementation of rights Article 26 – right to benefit from social security	🟨

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
		families. There are too many people who are so poor, for me this hasn't affected me much. Insurance for all parents, esp poor families; supporting in study at school *"Financial burdens are extreme. The insurance issues process should be faster"* *"Need an organisation to support families with money. Or they can help find a good job for parents. Have a special school for the children with chronic diseases"*	🟩			🟨
	Myths are created in absence of information (eg need for special diet / need to stop exercise / fears of side effects of medications such as broken bones / the causes of relapses / ability to marry and have children?)	Families want help to care for their children the best way	🟩		Article 17 – right to information Article 24 – right to education and health literacy Article 24 – right to best treatment	🟩
	Interactions with the health system	Change system - Meetings with Hospital executives - Families only get 3 mins with HCPs in OPD – how can this time be used better? HCPs need more training / awareness of NS Local doctors better trained Opportunity to translate activities to Lupus Community of Vietnam There should be support programs for child with special condition, long-term treatment (medicine, finance support) Need have very good and enthusiastic doctors Provision of information of current state of children in more regular (predictable) way so families are less anxious. Doctor	🟩		Article 8 – right to preserve your identity, including nationality, name and family relations... Where child is illegally deprived of same, governments shall provide appropriate assistance and protection with a view to speedily re-establishing your identity Article 18 – right to access institutions, facilities and services for care	🟨

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
		comes in everyday and says what happened but has no time to explain why / what is the reason; doctors keep saying "be patient" but I don't want general details - I want more details. Charity foundation for poor families. If classified as a "poor" family it can help, but I am not classified as poor in my commune Help patients access tertiary services to have exact diagnosis and good treatment Provide sufficient information for parents, especially about periodic re-examination. Don't make my mistake (loss to follow-up) - it would be so regrettable. Get them to hospital early I don't know what to say. I hope for the help from the government and the hospital. I couldn't do anything to help him, only doctors can help him. Communicate system to support the patients. Need to be educated about the disease Doctor comes in everyday and says what happened, but has no time to explain why / what is the reason; doctors keep saying "be patient" but I don't want general details - I want more details. Providing information and knowledge about NS; going to see Dr for advice *"Consultant Club (for paediatric nephrologists)"*	🟩		Article 23 – right to a full and decent life Article 27 – right to quality of life	🟧
	Interactions with the education system	Supporting in study at school	🟩		Article 28 – right to education Article 24 – right to be informed; right to health literacy Article 29 – right to education to achieve full potential	🟧

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
	Burden of distance from tertiary referral centres and qualified health professionals	Having a hotline (directly consult for the families when they need); Internet (I will access the internet in near future); NS club meeting; Teaching how to cook for children with NS Help poor families from the countryside Improve diagnosis and treatment standards at all levels of the health system; no trust in provincial system (especially lower levels) Improve the local health system;	🟩		Article 24 – right to be informed; right to health literacy Article 18 – right to access institutions, facilities and services for care Article 23 – right to a full and decent life Article 27 – right to quality of life	🟧
	The inter-connectedness of time, money and health					
	Bureaucratic burdens restrict access to health insurance (a protective factor when universally available)	The insurance pay at least 50% the cost of immunosuppression drugs. 100% insurance policy for children. Insurance is the best thing we can expect from the government. If classified as a "poor" family it can help, but I am not classified as poor in my commune Insurance for all parents, esp poor families; supporting in study at school Insurance for all kids; For insurance like in my case - why can't I use my insurance here at (the tertiary hospital)? Only point - can't hope for more.	🟩		Article 26 – right to social security Article 27 – right to quality of life Article 24 – right to healthcare	🟧
	Impact of inequities	The communities should support, there are many poor families who couldn't take care of their child.	🟩		Article 26 – right to social security	🟧
	Male child gender preference		🟩			🟧
	Ethnic minority communities are under-represented		🟩			🟩

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
	Financial burdens (increased costs / reduced income)	Families need to work hard to earn income to afford treatment. Financial support for poor patients The communities should support, there are many poor families who couldn't take care of their child.	🟩		Article 26 – right to social security	🟧
	Entrenched poverty (future earning capacity of children with NS in peril)	For poor families like me, support from charities is very much needed (100% insurance and other support). The question is how to get the money to save the children. Don't fall into debt. Many families here have sold everything they have but still don't get enough money.	🟩		Article 4 – right to all legislative, administrative and other measures to achieve rights Article 26 – right to social security	🟧
	Data on NS in Vietnam is limited		🟩			🟧
Plane 4. Stratification of the embodied personality	Adverse psychological impact – anxiety, fear	Need to encourage, console; support in spirit *"Need to support in spirit. Maybe need psychologists"*	🟩		Article 23 – right to opportunities to achieve fullest possible social integration and individual development	🟩
	Coping mechanisms / resilience	Want greater awareness / advocacy You need to be supported to be able to get over this. Cured or not, it's just fate, we can just try to do our best. Parents must persist; try your best to overcome this difficult time. You should not be too worried because this can be cured, medicine can help, and we should be optimistic. Create video of Club meeting Invite media Invite powerful people Share Club Meeting reports	🟩		Article 23 – right to full and decent life… and active participation in the community	🟩
	Families keen to learn about NS and how to optimally care for their children	Need for education and information to cure their child Provide sufficient information for parents, especially about periodic re-examination.	🟩		Article 12 – right to have views heard Article 17 – right to information and material aimed at promoting health	🟩

Themes	Key challenges	Key recommendations (illustrative quotes)	Justifiable (according to UNCRC)			Resource feasibility?
(Planes 1-4)			Yes	No	Article Number	Yes/ ?/ No
		Communicate system to support the patients. Need to be educated about the disease Give more information about NS Knowledge about NS (for taking care at home)	🟩			🟩
	Families respect and trust health professionals at tertiary referral centres		🟩			🟩
	The impact of myths where information is absent or inaccurate	~~Try your best to give your child a healthy, low sodium and carbohydrate diet. Avoid moving around and have medicine on time.~~	Not changeable (myths)			
	Confidence and resilience of parents and children		🟩			🟩
	Lower parent education levels are associated with poorer health literacy, reduced confidence and poorer health outcomes		🟩			🟨