A Developmental Exploration of Supported Self-Management in Children and Young People with Chronic Conditions

By

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Thesis
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Dedication

To Thomas, Daniel,
Shannon and Emily
whose lives may have been different

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Abbreviations

Acronym	Definition
ADA	American Dietetic Association
AGREE II	Appraisal of Guidelines for Research & Evaluation II
CER-Qual	Confidence in the Evidence from Reviews of Qualitative research
CF	Cystic fibrosis
CCSM	Chronic condition self-management (for adults)
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
iCAHE	International Centre for Allied Health Excellence
ICF	International Classification of Functioning
MeSH	Medical Subject Headings
NHMRC	National Health Medical Research Council (Australia)
PhD	Doctor of Philosophy
PRISMA-P	Preferred Reporting Items for Systematic Review and Meta-analysis Protocols
RCT	Randomised controlled trial
SD	Standard deviation
SRQR	Standards for Reporting Qualitative Research
T1DM	Type 1 diabetes mellitus
QOL	Quality of life

Abstract

Chronic condition self-management is well defined for adult populations as the completion of a range of health-enhancing behaviours that a person with chronic condition/s completes autonomously. As a precursor to autonomous chronic condition self-management, for children and young people, supported self-management involves a shared responsibility for the self-management tasks between children and young people and their caregivers that changes over time. There is clear delineation from family management (i.e. in infancy and early childhood) to supported self-management by the child/young person (i.e. in middle childhood, early adolescence and older adolescence) to ideally autonomous chronic condition self-management (i.e. at the point of transfer to adult healthcare services at approximately 18–20 years of age). However, there is currently little evidence available to guide caregivers, clinicians (of various disciplines) and healthcare policy makers in how to best deliver self-management teaching and support approaches to children and young people.

Across the world, including Australia, more than one in 10 children and young people (0–20 years) live with a chronic medical condition/s. This thesis presents new self-management teaching and support approaches specifically designed to fit with the changing needs of children and young people with a chronic condition as they develop and mature (that reflect changing abilities). More specifically, the research investigated three main areas – (1) the role children and young people have in managing their own chronic conditions at various developmental stages; (2) how children and young people undertake shared responsibility for supported self-management with their caregivers; and (3) the teaching and support approaches that clinicians can use to promote growth in supported self-management skills and healthcare behaviours.

This thesis is predominately exploratory and theoretical, reflecting the limited research on supported self-management for children and young people with chronic conditions done to date. Three focus conditions were used to illustrate supported self-management – i.e. asthma, cystic fibrosis (CF) and type 1 diabetes mellitus (T1DM). Furthermore, so that the research findings can be applied more broadly across paediatric health care settings an interdisciplinary lens was applied.

A pragmatic research philosophy using a mixed-methods approach was chosen and four studies were completed. Specific methods used for the studies included:

- Two **systematic reviews**
    - A systematic review of current guidelines for promoting developmentally appropriate supported self-management in children and young people with asthma, CF and T1DM (Published, Saxby et al. Chronic Illn., 2020) [8]
    - A systematic review of supported self-management education interventions with children young people with asthma, CF and T1DM (Published Saxby et al., Patient Educ. Couns., 2019) [7]
- A **concept analysis** for supported self-management for children and young people with chronic conditions (manuscript in preparation for publication 2020)
- A **Delphi consensus** of developmentally appropriate supported self-management for children and young people (published, Saxby et al., Patient Educ. Couns., 2020) [9]

A rigorous new interdisciplinary method of concept analysis was also developed for the purposes of this thesis (two manuscripts in preparation for publication 2020).

Together, the outputs of this research program conditions (i.e. the three peer reviewed journal articles [7-9], the three journal articles in preparation for publication, and the two versions of a printed book [5, 6]) form an interdisciplinary framework for supported self-Management for children and young people with chronic. Several key differences between supported self-management for children/young people and chronic condition self-management for adults were identified. Supported self-management was found to be a layered and multidimensional process – which supports the complexity and interrelatedness of the attributes, antecedents and consequences of the concept. Moreover, this research found that the presence of the developmental trajectory throughout childhood and adolescence requires a child-centred and individualised, triadic, and an adjustable and responsive approach.

Through the encouragement of children's and young people's lifelong active participation in supported self-management, which begins at the time of diagnosis, the research findings have the potential to influence the quality of life of children and young people. The research findings may also assist in improving interdisciplinary paediatric healthcare practices; in turn, leading to improved transition processes from paediatric to adult healthcare services.

Declaration

Flinders University (Adelaide, South Australia) documentation states that candidates for the Doctor of Philosophy (PhD) are required to present their work as a traditional thesis [1]. I certify that this thesis does not incorporate without acknowledgement 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 in the text.

The work presented in this thesis adheres to relevant ethical codes of research [2, 3]. Under the research title 'Children's Chronic Condition Self-Management Study', the research involving human data reported in this thesis was assessed and approved by:

Flinders University Social and Behavioural Research Ethics Committee – Project identification 7205

Tasmanian Health and Medical Human Research Ethics Committee – Project identification H0017044

Written consent has been received and archived for the research involving all personal data reported in this thesis.

The work described in this thesis was funded by two Australian Government scholarships:

Nursing and Allied Health Scholarship Support Scheme: NAHSSS Postgraduate Scholarship (awarded 2014) ~$24 000

Flinders University Research Scholarship (awarded 2017) ~$54 000

As part of my ongoing employment as the Paediatric Cystic Fibrosis (CF) Coordinator, in-kind contributions (i.e. time, printing services, additional supervisory support) towards completing this PhD were provided by the **Tasmanian Health Service.**

Professional editing was completed by Catherine Greenwood, freelance editor. Editing services were limited to copy editing and proofreading, in line with the requirements of Flinders University [1] and the Institute of Professional Editors guidelines for editing research theses [4].

This thesis contains published work and work prepared for publication, some of which has been co-authored.

Candidate signature: ***(Nicole Saxby) Date: 10/09/2020***

Original output arising from this thesis

Printed books [5, 6]

- N. Saxby, L. Purton, J. Lucus-Banks, G. Bassett, S. Beggs, J. Cooper, A. Diffley, N. Erends, D. Fletcher, K. Ford, C. Hollings, G. Pitts, C. Tichanow, R. Wallace, N. Zaluki, Moving on UP: A Practical Framework to Support Tasmanian Children with Chronic Conditions Transition to Adult Care, 1st ed., Primary Health Tasmania and the Tasmanian Government, Hobart, 2016.
- N. Saxby, G. Bassett, S. Beggs, J. Cooper, A. Diffley, K. Ford, C. Hollings, G. Putts, C. Tichanow, R. Wallace, N. Zaluki, P. MacIntyre, A. MacDonald, G. Mebeza, R. Aalto, K. Waterhouse, Moving on UP: A Practical Framework to Support Tasmanian Children with Chronic Conditions Transition to Adult Care, 2nd ed., Primary Health Tasmania and the Tasmanian Government, Hobart, 2019.https://www.primaryhealthtas.com.au/wp-content/uploads/2019/03/Moving-on-Up-Framework.pdf (accessed 24 July 2019)

Peer-reviewed journal publications [7-9]

- N. Saxby, S. Beggs, M. Battersby, S. Lawn, What are the Components of Effective Chronic Condition Self-Management Educational Interventions for Children and Adolescents? A Systematic Review. Patient Educ. Couns. 102 (2019) 606–622. https://doi.org/10.1016/j.pec.2018.11.001
- N. Saxby, S. Beggs, N. Kariyawasam, M. Battersby, S. Lawn, Do Guidelines Provide Evidence-Based Guidance to Health Professionals on Promoting Developmentally Appropriate Supported Chronic Condition Self-Management? A Systematic Review. Chronic Ill. 16(4) (2020) 239–252. https://doi.org/10.1177/1742395318799844

- N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn, Developmentally Appropriate Supported Self-Management for Children and Young People with Chronic Conditions: A Consensus. Patient Educ. Couns. 103 (3) (2020) 571-581. https://doi.org/10.1016/j.pec.2019.09.029

Peer review manuscripts in preparation for international peer review and publication

- N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn, The Saxby–Page Concept Development Technique: A Rigorous New Method of Concept Analysis Designed for Clinicians Working in Interdisciplinary Settings (2020 in preparation)
- N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn, Exploring Supported Self-management for Children and Young People with Chronic Conditions in an Interdisciplinary Context: A Concept Analysis Protocol (2020 in preparation)
- N. Saxby, K. Ford, S. Beggs, S. Lawn, An Interdisciplinary Framework for Supported Self-Management for Children and Young People with Chronic Conditions (2020 in preparation)

Conference proceedings, workshops and invited presentations [10-12]

Evidence for the following presentations is provided in Appendix A:

- N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn, Self-Management for Children and Young People with Chronic Conditions: An International Consensus, 13th National Conference of Allied Health, Brisbane, Australia, August 2019.
- N. Saxby, R. Littlewood, T. O'Sullivan, C. Collins, V. Kinghorn, Workshop – Empowering Children in Clinical and Research Settings. 36th Dietitians Association of Australia National Conference, Gold Coast, Australia, August 2019.
- C. Spiller, S. Bucksey, N. Saxby, Moving on UP: Paediatric Chronic Condition Self-Management, Grand Rounds Royal Hobart Hospital; Tasmanian Health Service South, Hobart, Australia, November 2018.

Co-authored publications and statements of contribution

This research was overseen by a steering group comprising four PhD supervisors; two from Flinders University and two from the University of Tasmania.

Professor Sharon Lawn	**Primary supervisor**	Flinders University
Professor Malcolm Battersby	Associate supervisor	Flinders University
A/Professor Sean Beggs	Adjunct supervisor	University of Tasmania
Dr Karen Ford from June 2018	Adjunct supervisor	University of Tasmania

Two associate researchers, Dr Nadish Kariyawasm (Central West Hospital and Health Service, Queensland) and Dr Amy Page (Alfred Health, Victoria), also assisted with some aspects of this PhD research. Additional support with the literature searches was provided by a medical librarian, Mary Fraser (Tasmanian Health Service, Tasmania).

The contributions of each individual author to publications arising from this thesis are described here.

Chapter 1

Title: Moving on UP: A Practical Framework to Support Tasmanian Children with Chronic Conditions Transition to Adult Care

Authors: N. Saxby, S. Beggs, K. Ford (and members of the Tasmanian Children's Transition Reference Group)

Book: Primary Health Tasmania and the Tasmanian Government 2016 (1st ed.) and 2019 (2nd ed.) [5, 6]

Contribution: I was the co-chair and primary author of the 2016 'Moving on UP' framework document, with background material being repurposed from the background information chapter (Chapter 4) of this thesis. S. Beggs and K. Ford participated as members of the Tasmanian Children's Transition Reference Group and were responsible for determining the content of the framework, discussions and critical review. In 2017–2018, an external review of the framework was undertaken to ensure that it was still contemporary. S. Beggs, K. Ford and I all critically reviewed the 2019 revised 2nd edition.

S. Lawn and M. Battersby maintained independence from the 'Moving on UP' project.

Chapter 4

Title:	Do Guidelines Provide Evidence-Based Guidance to Health Professionals on Promoting Developmentally Appropriate Supported Chronic Condition Self-Management? A Systematic Review
Authors:	N. Saxby, S. Beggs, N. Kariyawasm, M. Battersby, S. Lawn
Journal:	Chronic Illn., 2020, DOI: 10.1177/1742395318799844 [8]
Contribution:	S. Lawn, M. Battersby, S. Beggs and I conceptualised the study together. I undertook the database searches and screening stages. Data extraction and assessment of guideline quality was completed by me and confirmed by N. Kariyawasm. I drafted the manuscript. All authors assisted with critical review and editing.

Chapter 5

Title:	The Saxby–Page Concept Development Technique: A Rigorous New Method of Concept Analysis Designed for Clinicians Working in Interdisciplinary Settings
Authors:	N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn
Journal:	In preparation for publication
Contribution:	I summarised the strengths and weaknesses of existing concept analysis methods by completing a literature review. I then led the design of the new method for concept analysis – i.e. the Saxby–Page Concept Development Technique. Each proposed methodological step was discussed at length with A. Page who has demonstrated expertise in concept analysis methods. Once A. Page and I had reached agreement about what the steps of the new methodology would be, the new method was presented to the full research group. Critical review of the method and commentary was then provided by S. Lawn, K. Ford, S. Beggs. I then drafted the methodology manuscript. All authors assisted with critical review and editing of the final manuscript.

Chapter 6

Titles:

- N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn, Exploring Supported Self-management for Children and Young People with Chronic Conditions in an Interdisciplinary Context: A Concept Analysis Protocol (2020 in preparation)
- An Interdisciplinary Framework for Supported Self-Management for Children and Young People with Chronic Conditions (2020 in preparation)

Authors: N. Saxby, A. Page, S. Beggs, K. Ford, S. Lawn

Journal: In preparation for publication

Contribution: Based on the method developed in chapter 6, a study protocol was written by me to guide the completion of the concept analysis study. The study protocol was then re-written into the methods section of my thesis.

With the concept analysis study, I was responsible for undertaking the database searches, study screening, data extraction, data theming and quality assessment steps. This study used the Saxby–Page Concept Development Technique. For confirmation purposes, S. Lawn functioned as a second reviewer. S. Beggs and K. Ford then reviewed the themes and conclusions from a clinical perspective. I drafted the manuscript, with all authors providing critical review and assisting with editing.

Chapter 7

Title: What are the Components of Effective Chronic Condition Self-Management Education Interventions for Children and Adolescents?

Authors: N. Saxby, S. Beggs, M. Battersby, S. Lawn

Journal: Patient Educ. Couns., 2019 DOI: 10.1016/j.pec.2018.11.001 [7]

Contribution: S. Lawn, M. Battersby, S. Beggs and I conceptualised the study together. I was responsible for completing the database searches, study screening, data extraction, identification of study design and quality, and drafting of the manuscript. S. Lawn functioned as a second reviewer confirming that data extraction, study design and quality rankings were all appropriate. All authors critically reviewed the manuscript and assisted with revisions and editing.

Chapter 8

Title: Developmentally Appropriate Supported Self-Management for Children and Young People with Chronic Conditions: A Consensus

Authors: N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn

Journal: Patient Educ. Couns., 2019 DOI: 10.1016/j.pec.2019.09.029 [9]

Contribution: I led the design of this study, acted as the chief study investigator, drafted the human ethics committee applications, undertook recruitment, designed the Delphi rounds, performed the qualitative and quantitative analysis and wrote the draft manuscript. S. Lawn and K. Ford assisted me in designing the Delphi rounds. S. Lawn, K. Ford, and S. Beggs provided input into the data analysis. All authors critically reviewed and edited the final manuscript.

I, Professor Sharon Lawn, certify that the student statements regarding their contributions to each of the PhD thesis chapters and related publications are correct

Primary PhD Supervisor: S Lawn ***(Sharon Lawn)*** ***Date: 10/9/2020***

Awards received during PhD candidature

Evidence of the following awards are presented in Appendix B:

- Advanced Accredited Practicing Dietitian Status, Dietitians Association of Australia, 2014
- Cystic Fibrosis - Practice Evidence in Nutrition – Evidence-Based Practice Prize, Dietitians Association of Australia, 2015

Acknowledgements

'Trust yourself. You know more than you think you do.' ***~ B. Spock***[1]

Throughout my six-year candidature I have received a great deal of encouragement, support and assistance from a variety of people.

Firstly, I would like to offer a special thank you to my primary supervisor, Professor Sharon Lawn.

> Sharon – I can't believe that we have worked together for over 10 years! I remember catching the direct flights on cold wintery mornings from Hobart to Adelaide to attend the face-to-face coursework components of the degree of Graduate Diploma in Self-Management offered by Flinders University. I don't know if I have already told you but completing this degree was the first time that I felt a passion light up inside of me while at university. Never had I been so invested in learning – I had fallen in love with the topic of self-management for chronic conditions. With the addition of every subject to my knowledge base, I could see how healthcare practices could be improved to be more consumer and systems focused. I don't know how many times I cursed you for all the 500-word assignments that you prescribed as part of this course, but eventually I learnt the value of eloquent and concise writing. It is to you that I owe my ability to write well.
>
> When I decided to do a PhD looking at supported self-management for children and young people, you were my first choice of supervisors. And I couldn't have found a better supervisor if I tried. Unfortunately, in 2013 there were no longer any direct flights between Hobart and Adelaide – so I had many long and expensive trips (via numerous Qantas airport lounges) travelling to see you and Malcolm. But each trip was worth it. You believed in me at all stages of the research process and, more importantly, you taught me to believe in myself as a researcher. From the bottom of my heart, thank you! I am proud to be finally finishing up my research apprenticeship under your guidance. One day I hope that I get the opportunity to pay it forward.

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[1] At the start of each chapter I have carefully chosen a quote that reflects my personal PhD journey.

To my other supervisors, Professor Malcolm Battersby, A/Professor Sean Beggs and Dr Karen Ford, my sincere thanks for your skilful guidance during my candidature. Completing a PhD as a mostly part-time external student located more than 1400 km away from Flinders University, while I was either in Hobart, Tasmania (February 2013–September 2016 & July 2018–October 2019) or in Longreach, Queensland (October 2016–June 2018), was at times hard. So, it was great to have two adjunct supervisors (Sean and Karen) located in my home town of Hobart. Below, I have written individual comments for each of you.

> Malcolm – thanks for your previous contribution to the adult chronic condition self-management literature; it proved to be inspirational.
>
> Sean – our exploration into the abyss of supported self-management started in the clinical setting way back in 2010. The teamwork between us as work colleagues and as a PhD supervisor/student has been first-rate since that time. Now that you are the Director of Women and Children's Services at the Royal Hobart Hospital and I have a better understanding of the topic of supported self-management, nothing can stop us from succeeding in getting children and young people involved in their own health care.
>
> Karen – you are a beautiful soul with an incredible mind. I don't think qualitative research will ever be my default stance; but, 'gee whiz', isn't it powerful.

Thank you to my closest friends who kept me sane throughout my candidature – Dr Adam Micallef (both husband and great friend), Ms Catherine Painter, Dr Amy Page, and Dr Nadish Kariyawasm. The days I spent pursing my PhD were some of my darkest and some of my brightest. It wasn't the intellectual challenges or the workload that brought me down; it was my fluctuating mental health. Regardless of my headspace, these key people were always by my side supporting me. Furthermore, sharing the journey with friends who were also completing their professional doctorates/PhDs (Adam, Amy and Nadish) made the process much more enjoyable, and a lot less isolating. I'm going to miss all the PhD discussions in person/on the phone and the late study nights that came complete with pizza, cups of Sri Lankan tea and wine.

Talking about food, I should also acknowledge the humble jelly slice.

> Jelly slice – you gave me nourishment and sustenance during the last stage of my PhD journey when I was at work in the CF office at the Royal Hobart Hospital until 11 pm most days. (You also helped me gain an unwanted 20 kg.)

The last couple of months of my PhD journey saw me hospitalised for management of post-traumatic stress disorder. For this reason, recognition also needs to be given to my medical team, which included Ms Kate Savage and Dr Yvonne Turnier-Shea and the wonderful nursing staff. Without their dedication and exceptional level of care, this thesis would not have been completed.

> Kate and Yvonne – you achieved the impossible by making me relax and focus on just a couple of things, i.e. getting better, colouring in (or not - wink, wink), and finishing this PhD.

The final thank you goes to my family. Especially my mother for her love and sacrifices allowed me to pursue an education that she, herself never had the opportunity to do. Mum (Lyn), Dad (Neville), Robert and Christopher – you are all amazing people and thanks for setting me up for my future life! And to my puppy dogs (Nougat and Chilli) – mum hasn't forgotten all the walks and visits to the dog park she promised.

Wow, completing this PhD sure has been the journey of a lifetime!

Additional Acknowledgements – September 2020

Examining a PhD thesis takes a lot of time and effort. It was evident that my examiners undertook the task for the love of science! Their examination reports were constructive and uplifting; as a result, the final thesis presented here is significantly improved.

1. Introduction and general background information

'Children and young people are not just little adults' is often said by paediatric clinicians. Is the same true when it comes to supported self-management?' ~ ***N. Saxby***

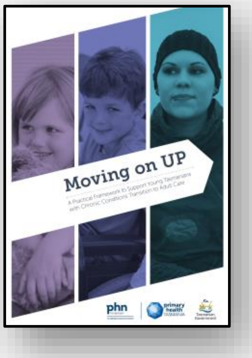
Chapter 1 provides the reader with an understanding of the origins of my PhD research programme. The topic of supported self-management is then introduced and placed within the context of relevant literature and related concepts. The chapter concludes with a succinct problem statement and a discussion about gaps in the literature.

Highlighted in this chapter:

- How origins of this research are embedded in work completed by the Tasmanian Paediatric Cystic Fibrosis Service, and in the 'Moving on UP' program
- Paediatric chronic conditions and supported self-management
- Why the focus conditions (i.e. asthma, T1DM and CF) are important chronic conditions to study
- The impacts the focus conditions have on children/young people, their caregivers, the healthcare system and the wider community
- The necessity of child-centred care in paediatric healthcare settings
- Why adult models of chronic condition self-management do not directly transfer to children and young people
- Why the decision was made to study supported self-management from a developmental perspective
- Identified gaps in the literature and problem statement
- The guiding research question, working hypothesis and objectives

Significant content from chapter 1 was repurposed for the following publications[2]:

Appendix C includes content related to this chapter



- N. Saxby, L. Purton, J. Lucus-Banks, G. Bassett, S. Beggs, J. Cooper, A. Diffley, N Erends, D. Fletcher, K. Ford, C. Hollings, G. Pitts, C. Tichanow, R. Wallace, N. Zaluki, Moving on UP: A practical framework to support Tasmanian children with chronic conditions transition to adult care, 1st ed., Primary Health Tasmania and the Tasmanian Government, Hobart, 2016. [6]

- N. Saxby, G. Bassett, S. Beggs, J. Cooper, A. Diffley, K. Ford, C. Hollings, G. Pitts, C. Tichanow, R. Wallace, N. Aluki, P. MacIntyre, A. MacDonald, G. Mebeza, R. Aalto, K. Waterhouse, Moving on UP: A practical framework to support Tasmanian children with chronic conditions transition to adult care, 2nd ed., Primary Health Tasmanian and the Tasmanian Government, Hobart, 2019. https://www.primaryhealthtas.com.au/wp-content/uploads/2019/03/Moving-on-Up-Framework.pdf [5]

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[2] Limited content from this chapter has been repurposed for publications associated with the 'Moving on UP' program; specifically, parts which have been repurposed include Sections 4.1, 4.2, 4.3, 4.6 and 4.7.

1.1. Research origins

This research focuses on *supported-self-management*[3] in children and young people with chronic conditions. Through the outputs of my PhD research program I hoped to develop self-management teaching and support processes that are tailored to the needs of children and young people at various developmental stages. Inspiration and passion for this research comes from my work as coordinator and dietitian for the Tasmanian Paediatric Cystic Fibrosis Service based in Hobart, Tasmania, Australia (Figure 1). As outlined on my statement of duties, one of the focuses of my work is to provide self-management support: *'research and develop models of best practice, fostering autonomy and independence in patients in developing the capacity to manage their own health as far as possible' [13 p.1].*

FIGURE 1 LOCATION OF HOBART, TASMANIA, AUSTRALIA

Source: Figure from https://pasarelapr.com/map/map-of-tasmania-australia.html, reproduced with permission [14]

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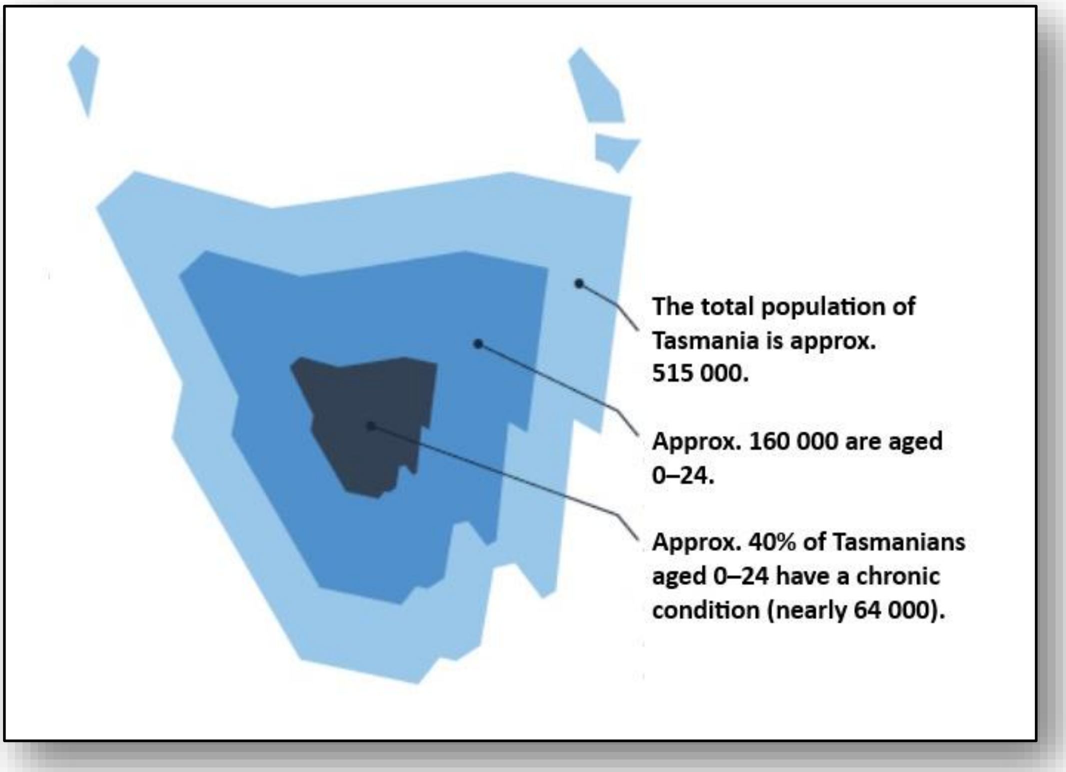
[3] In this thesis, I propose that paediatric self-management is referred to as supported self-management. This terminology acknowledges that conceptually supported self-management involves more than one agent of self-management; it also represents the interdisciplinary expert consensus preferred terminology achieved through the Delphi study presented in Chapter 8.

The Tasmanian Paediatric Cystic Fibrosis Service cares for approximately 60 children and young people living with CF across the whole state of Tasmania. In 2010, clinicians from this service created and implemented a developmentally based program titled ‘Moving on UP – different stages of self-management for children in managing their CF’ [15]. This program was innovative because it was grounded in developmental theories. The program also combined the interdisciplinary clinical and practical knowledge of how children and young people develop and learn supported self-management skills and healthcare behaviours (i.e. knowledge from paediatrician, coordinator/dietitian, paediatric nurse, physiotherapist and social worker). After 18 months of running this program, positive health outcomes were documented for lung functions, nutritional parameters, and quality of life domains. Through my involvement in this program, I identified that the concept of supported self-management was poorly understood and that developmentally based recommendations for self-management teaching and support approaches were scarce.

In 2015, widespread stakeholder engagement from Primary Health Tasmania and the Tasmanian Health Service allowed the ‘Moving on UP – different stages of self-management for children in managing their CF’ program to be expanded to cover all Tasmanian children and young people aged 0–24 years with chronic conditions of any type. It is estimated that up to 64 000 Tasmanians fitted this criteria (Figure 2) [16, 17]. At this point, the name of the program was then shorted to just ‘Moving on UP’. The overarching aim of the ‘Moving on UP’ program is to improve transition processes from paediatric to adult healthcare services within Tasmania, which is why the age range extends into young adulthood.

FIGURE 2 TASMANIAN CHILDREN AND YOUNG PEOPLE (0–24 YEARS) LIVING WITH CHRONIC CONDITIONS



Source: Figure adapted from Saxby et al. [5, 6], with data coming from the Australian Institute of Health and Welfare and the Australian Bureau of Statistics [16, 17]

1.1.1. Context of the candidature

Though related by topic content, the research presented in this PhD thesis is independent from the 'Moving on UP' project. All studies completed as part of this research program were designed and led by me. My primary PhD supervisor (S. Lawn) and associate PhD supervisor (M. Battersby) from Flinders University were not involved in the 'Moving on UP' project, a factor that served to enhance the independence of this research from the project. Conversely, through their employment with the Tasmanian Health Service, my two local adjunct supervisors (S. Beggs and K. Ford) were directly involved in the 'Moving on UP' project.

It is anticipated that the 'Moving on UP' project will provide a vehicle through which to translate the findings of this research. For this reason, it was important that the research resulted in a body of work that could be published in peer-reviewed journals in a timely manner. How the research findings will be translated and implemented into clinical practice is discussed further in the final chapter of this thesis (Chapter 9). Appendix C of this thesis includes the 2019 version of the 'Moving on UP framework' document [5], as well as, a media release and a magazine article.

1.2. Involving children and young people in supported self-management

Across the world, including Australia, more than one in 10 children and young people (0–20 years) live with a chronic medical condition [16, 18]. To maximise health and allow participation in 'everyday' activities (e.g. attend school, play sport, socialise with friends, make sandcastles at the beach), children and young people affected by chronic conditions, and their caregivers[4], need to complete daily treatments and monitoring activities, referred to as *supported self-management* [9].

Observations that children and young people could contribute to their own health care with the support of their caregivers were first discussed in the literature by Creer and Christian in the 1970s [19, 20]. Creer and Christian were informed by the early work of Albert Bandura, a developmental theorist [19, 20]. Within 10 years of these initial observations, primary research into children's/young people's participation in supported self-management, which included developmental considerations had begun [21, 22]. Since then however, most of the research on the topic of self-management in chronic conditions has been completed in adult populations, with many iterations being extrapolated to paediatric settings, as highlighted in the recent 2018 publication by Lozano and Houtrow [23].

Children and young people, especially children under five years of age, cannot self-manage alone [9]. They are on a trajectory of developing skills and healthcare behaviours; and thus, as they develop and mature, they need differing levels of support to be able to complete supported self-management tasks [9]. Self-management support to children and young can be provided by a variety of people including caregivers, community members (e.g. teachers) and clinicians[5].

In 2012, Modi et al. published the first theoretical model for paediatric self-management. The working hypothesis for this research was triggered by one of Modi et al.'s conclusions:

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[4] In this thesis, because all children and young people don't reside with their parents, the term 'caregiver(s)' is used. A caregiver(s) is the person(s) who has overarching responsibility for the day-to-day medical management of a child/young person and their chronic condition in the home environment.

[5] In this thesis, the term clinician(s) is used to describe a broad group of health professionals including doctors, nurses and allied health professionals.

- *‘Developmental transitions … are critical windows of opportunities to investigate family and health care system-based interventions to sustain adaptive self-management’* [24 p. e480]

1.3. General background information and definitions

Pertinent to this thesis is the fact that children’s and young people’s self-management definitions and interventions are generally extrapolated from the adult body of knowledge. Thus, it is useful to explore what self-management means for both adults and children/young people. Gaps and problems arising from relying on using existing adult-based concepts to define and explain the phenomenon of supported self-management in children young people are discussed.

1.3.1. Self-management

While there are definitions available for adult and paediatric chronic conditions self-management [24-27], this thesis acknowledges that there are currently no internationally agreed definitions of supported self-management for children and young people. The current state of the literature is explored here.

1.3.1.1. Adults

The Australian National Chronic Disease Strategy provides a narrow definition relevant to adults but covering the whole of life spectrum of self-management: *‘the active participation by people in their own health care’ [27 p.37]*. This definition was confirmed (i.e. by national agreement), and expanded (i.e. by reviewing the literature) by the Flinders Human Behaviour and Health Research Unit on behalf of the Australian Government Department of Health and Ageing in 2009: self-management *‘is a process that includes a broad set of attitudes, behaviours and skills. It is directed toward managing the impact of the disease or condition on all aspects of living by the patient with a chronic condition. It includes, but is not limited to, self-care and it may also encompass prevention’ [26 p.7]*

1.3.1.2. Children and young people

When it comes to children and young people, there are several apparent issues with the agreed Australian definition. Firstly, the foundation of this definition is the adult literature base, which includes publications by the Centre for Advancement of Health, Lorig, Von Korff, and Gruman [25]. Secondly, the definition is one dimensional, referring to the ‘person’ or ‘patient’ with the chronic condition(s) completing the activities/actions. Referring to the individual fails to recognise that children's and young people's supported self-management involves the shifting of responsibility of self-management activities and decision making between the child/young person and their caregivers. The National Strategic Framework for Chronic Conditions does allude to a person's ability and resources to actively manage their condition varying across the lifespan; however, this has not been incorporated into the definition [28]. Similarly, Modi et al. (2012) propose a definition of children's self-management: *'is the interaction of health behaviors and related processes that patients [children and young people] and their families engage in to care for a chronic condition'* [24 p.e474]. This definition encompasses the child/young person and caregiver dynamics; however, it also fails to acknowledge the transitional shift in responsibility.

To the best of my knowledge, there are no internationally agreed definitions of supported self-management that emphasises child/young person and caregiver/family dynamics and a developmental shift in cognitive ability, independence and increasing responsibility. As part of this research, new consensus-based definitions of supported self-management for each of the five pre-determined developmental stages are presented (Chapter 8).

1.3.2. Self-management support

This thesis uses the Australian agreed definition of *self-management support* from the 2006 National Chronic Disease Strategy: *'Chronic condition self-management support is what health professionals, carers and the health system do to assist the patient to manage their condition'* [27 p.37]. This appropriateness of this definition was reconfirmed in 2009 by the Flinders Human Behaviour and Health Research Unit [26].

1.3.2.1. Frameworks for adults

For adults with chronic conditions, Wagner's Chronic Care Model describes the ideal characteristics and structure of chronic condition self-management support systems, services and interactions [29]. The evidence-base behind this model is internationally recognised (including in Australia) and highly regarded; and it was last reviewed and updated in 2009 [29]. Its purpose is to support care of adults with chronic conditions that is person-centred, effective, safe, timely and equitable [29]. At the clinical practice level, self-management support is identified as one of four key elements influencing the ability of a healthcare team to deliver effective chronic condition care [29].

Self-management support empowers and prepares people with chronic conditions to manage their own health (i.e. effective self-management). This process requires clinicians to be able to:

- highlight the person's central role in their own health care
- assess self-management capacity, understanding and addressing the person's strengths and barriers to self-management
- use proven self-management support strategies, which may include collaboration, personalised care plans, education, targeting, goal setting, planned follow-up and monitoring [29].

The strategies and interventions mentioned above are consistent with the fundamental work of Lorig and colleagues [25], and are all associated with positive outcomes for adults [29].

1.3.2.2. Frameworks for children and young people

The Australian definition of self-management support is appropriate for children and young people. Problems arise, however, when trying to use the Wagner's Chronic Care Model in a paediatric settings [30]. Despite Wagner's Chronic Care Model being considered a crucial component of paediatric care, it is not proven for children and young people [30]. Of particular concern for paediatric clinicians is that Wagner's Chronic Care Model treats the individual in isolation from their surrounding environment [30].

The ability of children and young people to complete supported self-management tasks is influenced at various levels (i.e. individual, family, community and the healthcare system) and also by cognitive, emotional and social processes [24]. A review of the literature found two supported self-mangement models specifically designed to address these specific paediatric challenges: (1) the Pediatric Self-Management Framework [24] and the International Classification of Functioning (ICF), Disability and Health [31, 32]. Both models take a generic (as opposed to a diagnosis specific) view of paediatric chronic conditions.

The 'Pediatric Self-Management Framework' has been applied to the context of various chronic conditions, including type 1 diabetes [33] and asthma [34]. Similarly, the ICF has been applied in various settings: children with chronic conditions [35], adolescents who are transitioning from paediatric to adult health care systems [36, 37], and children with medical complexity [38]. To my knowledge, however, these models have not been used to explore how children and young people develop self-management skills that are appropriate to their developmental stage with the support of others. The lack of availability of developmentally appropriate self-management teaching and support approaches that are specifically designed for children and young people (and their caregivers) is explored extensively throughout this thesis.

1.3.3. Children and young people

This thesis uses the terms ‘children’ and ‘young people’. According to 1989 United Nations Convention on the Rights of the Child, childhood spans the ages of 0–18 years [39]. However, in clinical practice, childhood can range from birth to the point when children/adolescents are transferred to adult care (usually before the age of 20 years) [40]. For the purpose of this thesis, children and young people were further classified into five distinct groupings.

Children

- *Infancy:* birth to 2 years
- *Early childhood:* ages 2–5 years
- *Middle childhood:* ages 6–11 years

Young people

- *Younger adolescence:* ages 12–14 years
- *Older adolescence:* ages 16–20 years.

These developmental stages broadly align with Piaget’s theory of cognitive development, with adolescents being further classified into younger and older adolescent groups [41].

1.3.4. Condition versus disease

The term ‘chronic condition’ is better suited to the needs of children and young people than the term ‘chronic disease’. Despite these terms being used interchangeably in the literature, there are differences between them. ‘Condition’ refers to a state of health, whether well or ill [42]. ‘Condition conferring illness’ can be further classified into diseases, mental and psychological disorders, and physical impairments [42, 43]. In contrast, ‘disease’ denotes a condition that is characterised by functional impairment, structural change and the presence of specific symptoms, which adversely affect the individual [42]. This thesis uses the term ‘condition’ in place of ‘disease’, due to its neutrality. Children and young people with well-managed chronic conditions are often in good health, living relatively symptom and impairment free. Use of the term ‘chronic condition’ is also consistent with key publications by the World Health Organization (WHO) in the area of chronic condition self-management [43].

1.3.5. Paediatric chronic conditions

A common misconception is that chronic conditions affect adults, and not children and young people. There are many types of paediatric chronic conditions. Unlike chronic conditions of adulthood, which are often preventable, paediatric chronic conditions are generally the result of genetics and/or environmental factors [44]. Some individuals are born with them (e.g. CF); other individuals develop them early in life (e.g. asthma and T1DM). The majority of paediatric chronic conditions last a lifetime. Most affected children and young people can live fulfilled lives despite the limitations that may accompany chronic conditions [44]. This requires regular and often complex medical management, involving the caregivers, and eventually the child/young person themselves, completing daily healthcare tasks.

All children and young people with chronic conditions are on a journey from being a child (i.e. a more passive participant in health care) to becoming an adult (i.e. where there is an expectation that they will be or strive to be an autonomous self-manager who can complete daily healthcare tasks autonomously). Successful transfer to adult life and adult medical services marks the end of the journey. At this point, the goal is that young people will have developed greater acceptance, knowledge, health literacy, decision-making capacity, practical and coping skills, and control of their condition [45].

In Australia and internationally, there is no agreed definition of what constitutes a paediatric chronic condition. This review uses the 2007 Chronic Care: Self-Management Guideline Team, Cincinnati Children’s Hospital definition:

> *Paediatric chronic condition ‘a medical condition of more than 3 months duration, and/or; persistent functional limitations; and/or use of healthcare services beyond usual care (beyond resolvable developmental issues – e.g. preschool speech therapy)’* [45 p.1]

1.3.6. The focus conditions (asthma, CF, T1DM)

Many different types of chronic conditions affect children and young people. This thesis focuses on three common paediatric chronic conditions, namely asthma, CF and T1DM. Together, these three chronic conditions, provide a representative example of self-management approaches with different intensities and different treatment plans[6]. These conditions are incurable, although asthma may resolve in adolescence or adulthood [44]. Treatments are aimed at minimising symptoms and preventing complications. Asthma, CF and T1DM were selected due to their differing natures (i.e. aetiologies, symptoms and prognosis) and differing complexities of treatment regimens. Several expert groups have also acknowledged the commonalities between these paediatric chronic conditions, including the need for ongoing monitoring and treatments [23, 25]. Studying three conditions allows the identification of commonalities, and differences, in the supported self-management journey of children and young people.

The Australian Institute of Health and Welfare defines these conditions as:

- *Asthma 'a chronic inflammatory disease of the air passages causing widespread narrowing in them, obstruction of airflow, and episodes of wheezing, chest tightness and shortness of breath'* [44 p.3]
- *CF 'a life-threatening genetic disorder that primarily affects the respiratory system (lungs), the digestive system (pancreas and sometimes liver) and the reproductive system. The muc(o)us glands of people with cystic fibrosis secrete very thick sticky mucus'* [44 p.3]
- *Diabetes mellitus 'a chronic condition in which the body makes too little of the hormone insulin or cannot use it properly. This raises the blood level of the body's major energy source, the sugar glucoses, and causes other widespread disturbances of the body's energy processes'* [44 p.3]
    - *T1DM*, previously known as juvenile-onset diabetes, *'a form of diabetes usually arising in childhood or youth, marked by a complete lack of insulin and needing insulin replacement for survival'* [44]

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[6] In this thesis, when asthma, CF and T1DM are used collectively, they are referred to as the 'focus conditions'.

Table 1 on page 37 shows the common self-management tasks that need to be completed by children and young people with the focus conditions either by themselves or with the support of their caregivers. The domains of self-management presented in this table originate from work previously completed by the Flinders Human Behaviour and Health Research Unit [46]. The acronym KICMRILS represents each of the self-management domains: **K**nowledge, **I**nvolvement, **C**are plan, **M**onitor and **R**espond to symptoms, **I**mpacts, healthy **L**ifestyle, **S**upport services. Regardless of the type chronic condition, it is evident that many of the same self-management tasks need to be completed. Clinicians need to be aware of influencing factors that are modifiable and those that are not [24]. Modifiable factors are those that planned supported self-management interventions can impact on. Non-modifiable factors are not typically targeted in intervention (

Table 2) [24].

Table 1 Supported self-management skills and healthcare behaviours

Skills and healthcare behaviours	Childhood condition		
	Asthma	CF	T1DM
• Develop a Knowledge of condition			
○ Cause	X	X	X
○ Effects	X	X	X
○ Symptoms	X	X	X
○ Treatments	X	X	X
• Be activity Involved with caregivers and clinicians			
○ Open communication with healthcare team	X	X	X
○ Open communication with caregivers about chronic condition	X	X	X
• Follow the Care Plan that is agreed upon			
○ Medications	X	X	X
○ Supplementary vitamins, nutritional supplements, prescribed medical nutrition therapy	N/A	X	X
○ Physiotherapy techniques	N/A	X	N/A
• Monitor and Respond to symptoms			
○ Self-monitoring of symptoms including physical indicators	X	X	X
○ Self-monitoring side-effects of medication	X	X	X
○ Control triggers to symptoms	X	X	X
○ Follow written action/exacerbation/ emergency management plan	X	X	X
○ Problem solving	X	X	X
• Manage the physical, emotional and social Impacts of the condition(s)			
○ Relaxation and stress-reducing techniques	X	X	X
○ Manage impact on education/work and life	X	X	X
○ Maintain social support and social network	X	X	X
○ Maintain relationships with significant others	X	X	X
○ Manage emotions and psychological consequences (e.g. depressed and anxious, mood, uncertainty)	X	X	X
• Life a healthy Lifestyle			
○ Maintain nutrition and diet	X	X	X
○ Exercise	X	X	X
○ Avoid smoking (or give up)	X	X	X
• Ready access to Support Services			
○ Sharing self-management responsibility with caregivers	X	X	X
○ Seeking community services/information	X	X	X

Key: KICMRILS = Knowledge, Involvement, Care plan, Monitor and Respond to symptoms, Impacts, healthy Lifestyle

Source: Table adapted from Flinders Human Behaviour and Health Research Unit (https://www.flindersprogram.com.au) [46]

TABLE 2 EXAMPLES OF MODIFIABLE AND NON-MODIFIABLE INFLUENCES ON SUPPORTED SELF-MANAGEMENT

	Child/young person	Caregiver/family	Community	Health care system
Modifiable	Chronic condition and treatment knowledge Child/young person interalising/exteralising symptoms Coping style Health beliefs and perceptions (e.g. self-efficacy, perceived stigma)	Chronic condition and treatment knowledge Family interalising/exteralising symptoms Family coping style Health beliefs and perceptions Caregiver/family functioning Relationship quality Caregiver/family monitoring and supervision Caregiver/family involvement	Peer support Social stigma School-based accommodations related to health Availability of social networking	Communication style Frequency of clinic visits Clinician training models
Non-modifiable	Age Gender Developmental level Cognitive functioning (e.g. IQ) Socio cultural factors (e.g. race/ethnicity, socioeconomic status, religion)	Family status (e.g. parental marital status) Family structure Cognitive functioning Income Education Socio cultural factors (e.g. race/ethnicity, socioeconomic status, religion)	Neighbourhood Availability of healthcare and wellness resources within communities and schools	Availability of health care resources (e.g. access)

Source: Table adapted from Modi et al. [24].

1.3.7. Epidemiology

Many countries use national surveys and disease-specific data registries to monitor the number of children and young people living with chronic conditions, although these sources vary in quality. The main types of data collected are prevalence and incidence information. Prevalence is the number of cases of a condition in the general population usually expressed as a proportion or percentage, whereas incidence conveys information about the risk of developing a chronic condition [47]. Prevalence and incidence data can be used for many purposes, including healthcare service planning and epidemiological research.

1.3.7.1. Asthma

Asthma is a global condition estimated to affect more than 300 million people [48]. There are significant differences in the prevalence rates of asthma across countries, with 1–18% of the general population of a given country being affected [49]. Prevalence rates of asthma in some developed countries – e.g. Australia, the United Kingdom (UK) and New Zealand (New Zealand) are significantly above average [49-51]. In contrast, many African and Asian countries have lower-than-average prevalence rates of asthma [48]. According to the 2014–2015 Australian Health Survey, the prevalence rate of asthma among children and young people is more than 1000 per 10 000 in the general population [50].

Incidence rates of asthma appear to be on the rise across the world [50, 52, 53]. Increased incidence has been attributed to the effects of environmental and lifestyle factors [48]. While asthma is a chronic condition that affects all age groups, peak incidence usually occurs in early childhood [54].

1.3.7.2. CF

CF is the most common life-limiting and recessive-inherited condition that primarily affects Caucasians [80]. CF affects a small but significant number of people. Since the introduction of newborn screening in the 1990s, prevalence rates for CF condition have generally been easy to define. Cystic fibrosis is estimated to affect around 70 000 people worldwide [55-57]. In 2008, a study by Farrell revealed a mean CF prevalence rate of 0.737 per 10 000 across 27 European countries (with Ireland being an outlier with a prevalence rate of 2.98 per 10 000), which was similar to the United States of America (USA), which had a rate of 0.797 at the time [58]. The most recent data available for Australia (2017) show a prevalence rate of 1.28 per 10 000 [56].

Although prevalence rates for CF across the world are relatively stable, there are shifts in survival rates, with many people with CF now living well into adulthood worldwide [55-57]. Forecasts for 2025 in 16 European countries with good-quality data collection suggest that the number of people with CF will increase by approximately 50% [59]. Most of this increase will be a result of adults living longer, with a small percentage resulting from population growth and thus new diagnoses [59].

1.3.7.3. T1DM

T1DM is a common form of diabetes that affects 20–40 million people worldwide [60]. The prevalence rate of this condition in Australia and other developed countries is less than 100 per 10 000 [60-62].

Although T1DM can occur at any age, it mostly develops in childhood, with peak incidence happening in early adolescence around puberty [44, 61]. Incidence rates are highest in populations of Caucasian origin (e.g. USA, Canada, Australia and NZ) [60-62]. Incidence rates of T1DM appear to be are increasing; however, the cause of this increase is unclear [60, 63, 64]. A recently released study spanning 25 years shows that the incidence of T1DM is increasing by 3.4% a year in Europe [60]. Trend information from the National Diabetes Registry in Australia shows a similar pattern [63, 64].

1.3.8. Impacts

Developing successful management practices for the focus conditions poses formidable challenges for children/young people. Furthermore, chronic conditions also pose many challenges for caregivers, wider family members, clinicians and the healthcare system. Boyse et al. (2012), from the University of Michigan Health System, suggests that caregivers and families are successful at managing children's chronic conditions when they face the additional responsibilities of the chronic conditions as a team [65].

1.3.8.1. Children and young people

Living with one of the focus conditions can be difficult for children and young people. Affected children and young people often worry about their condition; they also tend to find the need to complete daily treatment burdensome [66-68]. In addition to this, clinic visits and hospitalisations (often lengthy ones) are common [50, 57, 69]. Many children and young people report that having chronic conditions is stressful, and that they 'feel different' from their peers [67]. Having chronic conditions may impact on children's and young people's ability to complete everyday activities (e.g. attending school, playing sport, socialising with other children, going to parties) [24]. Children and young people with chronic conditions need to learn how to live with the physical effects of their condition, deal with the treatments, maintain an emotional balance to cope with negative feelings, and maintain confidence and a positive self-image [24].

The way children and young people react to their chronic conditions will partly depend on which of the focus conditions they have, their personality, and their family environment [24, 65]. More relevant to this thesis is that a child's/young person's developmental stage and maturity level are major influencing factors [65]. As they grow up, a child's/young person's ability to understand and manage their condition changes [70]. Developmental transitions (e.g. starting school and becoming an adolescent) have also been identified as critical times in the illness trajectory for children and young people [24]. The growing autonomy of children and young people also impacts on their caregivers and other wider family members; these impacts are discussed further in the following sections.

To maximise health, children and young people with the focus conditions (all ages) need to engage with ongoing monitoring and treatments [24]. Treatments are usually aimed at minimising symptoms [71-73]. Completing these treatments can be time consuming [74]. Depending on which focus condition the young person has, treatments can include medications (oral, inhaled, injected, nebulised), physiotherapy (airway clearance), exercise, diet and lifestyle modifications, and nutritional supplements [71-73]. The average time spent each day on treatments by children aged 10–16 years is 6.4 minutes for asthma, 56.9 minutes for T1DM, and is 74.6 minutes for CF [74]. At the individual level, however, there is wide variability in the time taken to complete daily treatments [74].

Unfortunately, international paediatric research shows a high prevalence of poor self-management and suboptimal adherence to prescribed treatments, particularly among adolescents [66, 75, 76]. Poor self-management and suboptimal adherence has been linked to poorer health and decreased quality of life (e.g. fatigue and absenteeism from school and social activities), and subsequently to increased hospitalisations and visits to clinicians [76]. Hospitalisations can be frightening and lonely for children and young people [65]. Each year, <1% of young people with T1DM are admitted to hospitals, compared to 5% of young people with asthma [AIHW 2018] and 40% of children and young people with CF [57, 69]. For young people admitted to hospital, on average, those with CF spend more days as in-patients (more than 20 days/year) than those with asthma (approximately 2 days/year) [40, 50, 57]. Many of these hospitalisations are avoidable [76].

1.3.8.2. Caregivers/Family

In a family what affects one, affects all.

Children and young people living with the chronic conditions are not the only people affected by it; their caregivers and wider family members also need to learn how to fit the demands of conditions into their everyday lives. Primary caregivers have the dual responsibility of altering schedules and priorities to meet the needs of the children with chronic conditions, and keeping family life 'normal' [65]. Siblings can act as supports, helping each other to deal with challenging life events and with conflict that may arise with high treatment demands [40]. Importantly, each family member will have different experiences, feelings and emotions evoked by chronic conditions and, thus, their responses to condition-related impacts will vary.

Caregivers perceive conditions across a spectrum – from a 'burden to endure' to a 'challenge to be mastered' [77, 78]. These views are formed over time as caregivers interpret their child's treatments and symptoms and their own fears for the child's present and future [77, 78]. Of particular interest to this research topic is that caregiver and family issues are known to change as the children with chronic conditions develop and mature [79, 80].

Infancy is categorised by the forming of attachment bonds and trusting relationships between children and their caregivers. CF is the only one of the focus conditions that is likely to be diagnosed routinely in this age group [57]. Caregivers who have a child with one of the focus conditions must form this relationship at the same time as dealing with the added stress and uncertainty of their child's diagnosis [79, 80]. As their child enters toddlerhood (~18 months to 3 years) and is developing a sense of mastery and autonomy, new family issues associated with the condition start to emerge [81]. These include dealing with the child's fussy eating behaviours, which are more common in children with CF [79] and T1DM [82]. They might also include establishing a new schedule to fit in the demands of treatments and visits to health professionals, setting limits on behaviours, coping with lack of cooperation with treatments from their child, and sharing the burden of care with others [79-81].

Throughout their *early and middle childhood* years, children develop significant cognitive, social, mechanical, and emotional skills [40, 78]. In addition, children consolidate their self-esteem in respect to their peer group, begin to develop confidence in their own abilities (i.e. self-efficacy), and start initiating their own autonomous activities [83]. In contrast to this broad experience of children during their school years, children affected by chronic conditions also develop an awareness of 'being different' to their peers and they often blame themselves for their illness [79, 80].The increasing autonomy of the child presents a new challenge to caregivers; that is, the need to hand over some responsibility ('let go') for the day-to-day management of chronic conditions to their child [80]. Problems in the transfer of responsibility have been found to increase non-adherence in a variety of chronic conditions [79, 80]. Caregivers also worry about the physical and emotional impacts the condition is having on their child/young person. For example, a caregiver of a child with asthma may worry that their child is being excluded from school activities or that their child is hiding their condition to 'fit in' with other children [67].

Adolescence is characterised by significant changes in bodily appearance, increasing independence, and young people developing a sense of their own identity [79, 80]. Adolescence is a particularly challenging time for caregivers because adolescents may take up risky behaviours such as drinking alcohol, smoking or illicit drug use as part this journey towards being independent and autonomous individuals [79, 80].

During the developmental stages of adolescence (i.e. early adolescence and late adolescence), caregivers need to renegotiate responsibilities for the management of chronic conditions with their young person (i.e. both their role and their child's roles), encourage their young person's developing independence, prevent condition-related caregiver/family conflict, and monitor for signs of depression, abnormal eating habits and risky behaviours [79, 80].Caregivers also need to learn coping skills so that they can support their child to become an autonomous self-manager [79, 80].

1.3.8.3. Siblings

A meta-analysis by Vermaes et al. (2012) shows chronic conditions have significant impacts on siblings [84]. More specifically, siblings of children and young people with chronic conditions have more internalising problems (e.g. depression, withdrawal, anxiety and nervousness), more externalising problems (e.g. challenging temperaments, decreased problem-solving abilities and attention difficulties), and fewer positive self-attributes (e.g. self-esteem) [84]. Past experiences have likely taught siblings that 'the condition' takes up most of their caregivers' time and emotional resources [84-86]. In response, siblings may suppress their own emotions, feelings and wants, inducing feelings of helplessness and incompetence. Siblings may feel guilty about following their own dreams, worry about their own health issues, and/or resent the time given to the affected child [84-86]. Older siblings and siblings of children and young people with life-threatening conditions (e.g. CF) and/or conditions with high treatment burdens (e.g. CF, T1DM and asthma) are at increased risk of psychological problems [84, 86]. Comparatively, however, sibling impacts are less than those experienced by the children and young person with the chronic conditions [84-86].

1.3.8.4. Healthcare system

Australia has a three-tiered healthcare system, with clinicians and healthcare services usually falling into one of the following categories:

- *Primary* – is the first point of contact for medical interventions [87]. It involves non-emergency, community-based initiatives designed to assist people to avoid hospital [87]. Many people associate primary healthcare services with general practitioners (doctors), but other clinicians' often seen in community settings include dentists, pharmacists or other allied health professionals [87].

- *Secondary* – is more complex and referral based [87]. Secondary healthcare can be provided by clinicians with specific medical expertise (e.g. paediatricians, psychiatrists, respiratory based physiotherapists) [87]. Secondary care can be provided in community, clinic, or hospital settings [87].
- *Tertiary* – is highly specialised and generally involves care provided in acute hospital systems [87]. Tertiary healthcare services usually require referral from a primary or secondary clinician. In an emergency, however, unwell people can be admitted directly to a hospital via the emergency department [87].

The focus conditions pose many challenges for healthcare systems. Their complex, progressive and lifelong natures cause children to be frequent and significant users of the health system at primary, secondary and tertiary levels. Service delivery involves treatment that is multi-component, specialised and costly [51, 71-73].

Caring for children and young people affected by the focus conditions is resource intensive and challenging for health organisations and clinicians [51, 71-73]. Additional clinic visits and unplanned hospitalisations place additional strain on physical and staffing resources [71-73]. Paediatric clinicians have the added challenge of identifying, acknowledging and encouraging the child/young person's growing autonomy for self-management, while also engaging caregivers in an appropriate way that also respects their role and concerns for the child/young person [65, 88].

1.3.8.5. Community

Asthma and diabetes (including T1DM) have been identified as priority areas by many governments internationally because they cause high social and financial costs [89]. Ineffective management of chronic conditions, including asthma and diabetes, is costly with significant money being spent on avoidable hospital admissions [51, 90]. Health outcomes of these population groups can be significantly improved with targeted and collaborative actions (including supported self-management interventions) [89].

CF affects too few individuals to have a significant impact at the population level. However, financial costs associated with caring for people with this condition are predicted to drastically increase as their life expectancy improves with new and more effective treatment options (i.e. all children and young people with CF can now expect to survive into adulthood) [91]. For example, sophisticated gene-based technologies such as Ivacaftor cost upwards of $300 000 AUD a year [91]. new treatments have the potential to significantly improve the lives of children with CF, positive health outcomes remain dependent on good daily supported self-management practices in the home environment.

1.4. Child-centred care

In recent years, there has been an incorporation of both family-centred and child-centred approaches for paediatric health care [92, 93]. This is due largely to the changing social status of children and young people [94]. The year 2019 marks the 30th anniversary of the United Nations Convention on the Rights of the Child, which acknowledges children and young people as important members of society [39]. Of particular relevance to this thesis is Article 12, which states:

> *'Assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.'* [39]

A *child-centred* approach repositions the child/young person as the focus of healthcare interventions, similar to patient-centred care for adults []. It is acknowledged that children and young people are not comparable to adults and that they are their own social actors (i.e. that they have their own individual wants and desires) [93]. Children and young people have an ethical right to express their own views and to be heard as equals [39, 95]. This, in turn, leads them to feel more valued, respected, happier and less anxious [96-98]. As outlined in the 'Charter of Healthcare Rights of Children and Young People in Healthcare Services in Australia' (2017) every child and young person has an ethical right:

- *'To consideration of their best interests as the primary concern of all involved in his or her care.*
- *To express their views, and to be heard and taken seriously.*
- *To the highest attainable standards of healthcare*
- *To respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts.*

- *To be nurtured by their parents and family, and to have family relationships supported by the service in which the child or young person is receiving healthcare.*
- *To information, in a form that is understandable to them.*
- *To participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.*
- *To be kept safe from all forms of harm.*
- *To have their privacy respected.*
- *To participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.*
- *To continuity of healthcare, including well-planned care that takes them beyond the paediatric context.'* [95]

Paediatric clinicians are ideally placed to deliver developmentally appropriate self-management teaching and support approaches because of their locations in primary, secondary, and tertiary healthcare settings. They also have frequent and lengthy consultations with children and young people with chronic conditions, their caregivers and their wider family members. Actively involving children and young people in discussions and decisions around supported self-management will likely lead to better health outcomes.

1.5. Childhood development

Child development involves physical (i.e. motor skills, physical growth and sexual maturation), cognitive (i.e. perception, memory, judgement and reasoning skills), motor, language and communication, social and emotional (i.e. processes that optimise personal growth and socialization) changes that occur between birth and older adolescence [41]. In the course of development, a child/young person progresses from dependency to ever increasing autonomy.

According to an Australian textbook for trainee paediatricians, normal development can be defined as the third to 97th percentile of the general population learning a particular skill by a set time point [41]. When compared to the general population, most children and young people affected by the focus conditions experience normal development [41]. However, specific circumstances have been identified as causing cognitive impairment in these sub-population groups. For children with T1DM, early diagnosis (i.e. before the age of 5 years) appears to be associated with more severe cognitive impairment, specifically slowing of mental speed and diminished mental flexibility (i.e. applying acquired knowledge in new situations) [99-102]. Whether hyperglycaemia and recurrent hypoglycaemia hampers cognitive development in children with T1DM remains controversial [101]. For children and young people with CF, significantly lower cognitive scores have been correlated with prolonged malnutrition, unfavourable family factors (e.g. single parents and low socio-economic status) and low vitamin E levels on diagnosis. A brief review of the scientific literature did not find any studies investigating the impacts of cognitive or developmental problems on the self-management capacity of children and young people, although from first principles decreased cognitive ability should result in decreased capacity. This phenomenon has been demonstrated in adults with diabetes where impaired cognitive functioning was directly associated with greater healthcare dependency and poorer ability to self-manage their condition [101].

1.5.1. Developmental theories

The developmental literature is vast, conflicting and constantly evolving. Many developmental theories exist. These can be grouped broadly into the categories of *maturation*, *psychoanalytical*, *cognitive* (including information processing), *psychosocial*, *behaviourist*, *moral*, *ethological*, *ecological* and *attachment* [40, 103]. Each theory contains a set of interrelated, coherent ideas that help explain events and make future predications [40, 103].

Table 3 provides a summary of the most influential developmental theories of the 20th and 21st centuries.

TABLE 3 INFLUENTIAL DEVELOPMENTAL THEORIES OF THE 20TH AND 21ST CENTURIES

Theory/approach	Theorist	General description
Maturation	Francis Galton (1822–1911) Arnold Gesell (1880–1961)	Maturation patterns occur in orderly stages and sequences. The rate of maturation is affected by children's individual genetic timetables.
Psychoanalytical	Sigmund Freud (1856–1939) Melanie Klein (1882–1960) D.W. Winnicott (1896–1971)	Development and behaviours are primarily unconscious. Early experiences and emotions are considered to be heavy influences on development.
Cognitive	Jean Piaget (1896–1980) Lev Vygotsky (1896–1934) Jerome Bruner (1915–2016)	Young people are considered active learners who progress through orderly stages/sequences. Over time, qualitative changes can be noticed in the way children think. Emphasis is on the conscious thoughts of young people and the decline in development with age. Notable differences between these theorists:

		• There are no stages in Vygotsky's and Bruner's theories (according to Bruner's 'models of representation', earlier ways of thinking can still be used later in life). • Opposing views: – Piaget believes that development precedes learning versus Vygotsky and Bruner believe learning occurs before development. – Piaget believes that the young person is independent and that development is guided by self-centred focused activities versus Vygotsky and Bruner believe that the young person is a social being and development is led by social interactions. – Vygotsky and Bruner believe language precedes development versus Piaget believes language is a mere result of cognitive development.
Psychosocial	Erik Erikson (1902–1994)	Social interactions and conflicts with family, friends and culture that take place at across eight stages are considered major influencing factors.
Behaviourists (social learning theories)	John Watson (1878–1958) B. F. Skinner (1904–1990) Albert Bandura (1925–present)	The learning of young people is continuous (i.e. no stages), gradual and orderly. Development encompasses a specific sequence. These theories all emphasise environmental influences on how young people learn. **Notable differences between these theorists:** • Bandura is the only one of these theorists to emphasise cognitive influences versus Skinner strongly de-emphasises cognitive factors
Moral	Jean Piaget (1896–1980) Lawrence Kohlberg (1927–1987) Carol Gilligan (1936–present)	Young people develop attitudes and pro-social behaviours (including fairness, helping, respect and honesty) towards other people in society based on cultural and social norms, laws and rules. Moral development is considered to be continuous. **Notable differences between these theorists:** • Kohlberg expands Piaget's work into adolescence and adulthood. • Gilligan challenges Kohlberg's theory by considering gender and caring factors.
Ethological	Konrad Lorenz (1903–1989)	Young people have time periods when they are more sensitive to environmental influences and imprinting. There is a strong genetic view and acknowledgement of discontinuity in development, although no stages are proposed.
Ecological	Urii Bronfenbrenner (1917–2005)	Young people have multiple influences on their development from genetic and environmental perspectives. Also considers socio-historical influences.
Information processing (cognitive)	Noam Chomsky (1928–present)	Each young person is born with an innate ability to learn, and specialised information-processing abilities. These abilities enable them to figure out the structure of their development.
Attachment	John Bowbly (1907–1990) Jerome Kagan (1929–present) Peter Fonagy (1952–present)	Behaviour, and thus development, is a process of proximity seeking to an identified attachment figure in situations of perceived distress or alarm. In infant years, children attach to adult figures, usually parents. As they grow up, children and young people begin to use other people (such as peers) as attachments. Emphasises social interaction and object relations.

Source: Table adapted from Miller [103], dates of birth and death checked on Wikipedia, 27 April 2019 [104]

1.5.2. Core principles of development

While no one theory or science can explain the dynamic nature of children's young people's learning and development, there appear to be four underlying core principles relevant to the supported self-management discussion:

- *Principle 1* Development is affected by both nature and nurture.
- *Principle 2* Developmental patterns are generally orderly and predictable.
- *Principle 3* Development is not a consistently even process.
- *Principle 4* Children and young people develop at different rates.

Principle 1 acknowledges the nature versus nurture debate. Do the intrinsic properties of the child/young person (i.e. genetics) or the extrinsic properties of experience and environment have greater effects on learning and long-term outcomes? It is now generally accepted that the contribution of both is significant, although the weight of each is still up for contest. Sameroff (2010) provide a rough timeline of the nature–nurture debate, which he describes as cyclic (Table 4) [105].

TABLE 4 ROUGH TIMELINE OF THE NATURE–NURTURE DEBATE

Historical era	Side of debate	Empirical advance
1880s – 1940s	Nature	Inherited differences, instincts
1920s – 1950s	Nurture	Reinforcement theory, psychoanalytic theory
1960s – 1970s	Nature	Ethology, behavioural genetics, cognitive revolution
1980s – 1990s	Nurture	Poverty, social ecology, cultural deconstruction
2000s – onwards	Nature	Molecular biology, neuroscience

Source: Table adapted from Sameroff [105]

Principle 2 is based on the fact that children and young people follow a predictable course in relation to physical, cognitive, linguistic, social and emotional development [105]. According to theorists, development occurs through the achievement of developmental milestones (developmental stages); that is, the appearance of new and more sophisticated behaviours and skills [41]. Each developmental stage builds on the previous one, allowing for more advanced skill acquisition. The first skills a young person learns are usually routine, concrete and mechanical [68]. More complex cognitive skills (e.g.

organising, sorting, recalling and connecting abstract information) are acquired as they progress through the milestones [41]. This, in turn, gives young people insight into their own behaviours, namely the purpose and consequences of their behaviours and how their behaviours can be manipulated [41].

By approximately 16 years of age, the cognitive ability of young people is equivalent to that of adults [70]. Nevertheless, the way they perceive risks and thrills is vastly different, particularly for males into their early 20s [106]. An older adolescent may underestimate risks and partake in unsafe behaviours because they see the risk/reward as ‘totally worth it’ [106]. Their impulsiveness is heightened in emotional situations [106].

Principle 3 implies that development is not linear or constant. Children and young people achieve milestones at varying rates, with intervals of rapid progress (e.g. during infancy), versus intervals of slower development (e.g. during adolescence) [106]. In addition, plateaus of development are often followed by bursts of learning and skill attainment [41].

Principle 4 focuses on each child and young person as an individual learner. Some developmental theorists provide average ages (and standard deviations) for milestone achievement [41]. However, age estimates can only be used as an approximation for when clinicians might begin seeing development [41]. Children and young people can, and do, achieve developmental milestones before and after anticipated timeframes [41]. This is not necessarily indicative of advanced or impaired development; clinicians need to consider the broader context of development (e.g. family history) [41].

1.6. Why study supported self-management from a developmental perspective?

The paediatric age span ranges across a spectrum from birth through to older adolescence and encompasses all facets of development. At any given point in time an individual child's/young person's capacity to participate in supported self-management will be evolving [23]. To the best of my knowledge, no conceptual studies have been done on the topic of supported self-management for children and young people from a developmental perspective.

A developmental perspective looks at how children and young people behave and think from birth through to adulthood [107]. As children and young people grow up, they become more confident in managing their own affairs, relating to other people, and being a part of decisions impacting on them [70]. Cognitive development is also a precursor for health literacy [41]. For children and young people with the focus conditions, their journey also encompasses learning of supported self-management skills and healthcare behaviours, and establishing lifelong views towards health care [41].

A child's/young person's level of development will determine:

- their understanding and reaction to their chronic condition
- the healthcare tasks they can complete autonomously, and those that they need to share responsibility for with the caregivers
- what forms of education and self-management support are most likely to be most effective [70].

For paediatric clinicians, a developmental approach to supported self-management is both intuitive and practical. Cognitive development is a fundamental aspect of health literacy. Advocacy for use of a developmental approach is evident within the narrative review by Mickley et al. (2013) [108]. Mickley et al. state that self-management support interventions based on developmental theories and those that encourage self-efficacy are essential to promoting children's and young people's skills and healthcare behaviours in managing their condition and can contribute positively to their normal development [108]. The need to consider developmental transitions in supported self-management for children and young people is also highly emphasised by Modi et al [24].

1.7. Statement of the problem and gaps in the literature

The overarching premise of this thesis is that adult models of self-management do not directly transfer to children and young people with chronic conditions. Significant gaps around supported self-management for children and young people with chronic conditions remain, especially when applying a developmental lens. Further, the research findings which are available are often limited to single chronic conditions, settings and specific developmental brackets, and that they have not yet been translated into clinical practice.

1.7.1. The differences between supported self-management and adult chronic condition self-management are not well understood

Self-management support is an established part of high quality care for adults with chronic conditions [109-111]. Although there is evidence that providing supported self-management in paediatrics can result in improved health outcomes [112], current models are not as well developed for children and young people with chronic conditions [24, 31, 32], and as a result, supported self-management is not formally integrated into paediatric healthcare practices [113]. Adult-based chronic condition self-management models fail to account for some key differences between children/young people and adults [114, 115]. More specifically, they fail to account for dependency, the developmental trajectory and the need for a triadic approach (i.e. children, caregivers and clinicians working together) [114, 115].

1.7.2. Existing supported self-management interventions/models for children and young people are mostly limited to single chronic conditions (non-generic approach)

Researchers, clinicians and health systems have been slow to take a broad and generic approach to supported self-management in paediatric settings [23]. A good quality systematic review by Sattoe et al (2015) on self-management interventions for young people with chronic conditions showed that most interventional studies had been completed in groups with a single chronic condition. More specifically, most frequently studies were condition children and young people with asthma, followed by T1DM and then a handful or other chronic conditions (including cancer, chronic fatigue syndrome, pain, cystic fibrosis, eczema, renal disease, epilepsy) [116].

For adults, a number of generic (i.e. for use across more than one chronic condition) self-management interventions have been created, evaluated and implemented into clinical practice [25, 110]. Creating generic self-management has been relatively straightforward for adults because they are generally affected by only a handful of chronic conditions (e.g. obesity, diabetes, hypertension, arthritis and cancer). In contrast, children and young people are affected by many different diagnoses, each with low prevalence. Paediatric health care is usually managed by paediatricians with input from an interdisciplinary team and subspecialists as needed for complex conditions such as cystic fibrosis. As highlighted recently by Lozano and Houtrow in their narrative review, one consequence of the epidemiological situation in paediatrics is that *'the health system tends to create silos for different paediatric chronic conditions compared with the generic perspective for adult chronic conditions'* [23 p.S233]. Paediatric chronic conditions share many common self-management elements despite the differences in diagnoses and treatment regimens [24].

1.7.3. The concept of supported self-management for children and young people is unclear, especially from an interdisciplinary perspective

No conceptual studies on supported self-management for children and young people from an interdisciplinary perspective could be found prior to completing this PhD research program.

There are several reasons why the concept of supported self-management needs to be better understood including: 1) the fact that adult and paediatric self-management is fundamentally different (i.e. because of the varying need of support from caregivers in paediatrics) [23, 24], and 2) care to children with chronic conditions is general provided by an interdisciplinary team who need to have a 'common language' and shared understanding of the concept [8, 117, 118]. Interdisciplinary efforts can create new knowledge, find solutions to complex problems, and generate leaders who are able to work collaboratively across discipline boundaries [119-122].

There are also several other reasons why the concept of supported self-management may be poorly understood. While the self-management research literature originated in the paediatric space in the 1970s and 1980s [19, 20, 25]; over time, research on this topic has shifted away from children and young people to increasingly focus on adult populations [23]. Furthermore, the evidence around this topic often includes studies that follow a variety of qualitative and quantitative research paradigms. Such evidence can be difficult to summarise. Other issues within the literature base include interchanging terminology (e.g. some researchers such as me write about supported self-management, while others write about paediatric self-management, self-care, compliance, responsibility and disease management). Furthermore, the evidence around the topic of supported self-management often includes studies that follow a variety of qualitative and quantitative research paradigms. Such evidence can be difficult to summarise.

1.7.4. There is limited evidence available to guide developmentally appropriate self-management teaching and support approaches

Guidelines regularly promote that clinicians should be providing self-management teaching and support approaches to children and young people in a developmentally appropriate way; however, the evidence base underpinning guideline recommendations is suboptimal [8]. Most research that has looked at children's and young people's supported self-management has usually done so within a confined age range depending on the expertise of the researchers/clinicians conducting the study. Early research (1980s) conducted on this topic by researchers such as G. Parcel, C. Lewis, D. Evans mostly focused on the middle childhood age bracket [123-125]. Later research (>2000s) led by Bruzzese, Enrst, and Mammen tends to focus on Adolescents with chronic conditions [85, 126-134]. There is an obvious gap in research completed supported self-management in the infancy and early childhood age brackets – with only minimal studies appearing to have been undertaken the 1990s by L. Holzheimer, S.R. Wilson and their associated colleagues [135, 136].

There is also an absence of research that investigates supported self-management skills and healthcare behaviours across the childhood continuum from infancy, through childhood and into adolescence. Furthermore, the impacts of developmental trajectories are irregularly applied to findings of supported self-management studies in children and young people [23, 25].

1.7.5. Developmentally appropriate self-management support recommendations are scarce

One of the problems that this thesis addresses is that there is little evidence and tools available to assist paediatric clinicians in delivering developmentally appropriate self-management teaching and support approaches. There are currently limited tools available to assist clinicians to deliver developmentally appropriate self-management teaching and support approaches. Existing tools appear to be limited to action plans targeted at specific age brackets, and a theoretical self-management developmentally skills guide for children/young people with specific chronic conditions [70, 73, 137].

1.7.6. Clinicians lack the tools and expertise to facilitate developmentally appropriate self-management teaching and support approaches

Identifying and understanding which supported self-management skills and tasks are developmentally appropriate is one of the more challenging aspects of paediatric health care. Furthermore, it can be difficult for clinicians to facilitate a shift in responsibility for supported self-management activities and decision making between the child/young person and their caregivers, over time. These specialist paediatric skills are not currently taught in university curricula and Purpose and scope

1.8. Purpose and scope

1.8.1. Guiding research question

What are the attributes of supported self-management at various developmental stages?

1.8.2. Hypothesis

In this exploratory PhD, the broad research hypothesis investigated was:

> *'Children and young people are not just little adults when it comes to supported self-management because of differing needs at each developmental stage.'*

1.8.3. Aims

The overall aims of this PhD were to:

- Promote consistency in clinicians' and researchers' understanding of supported self-management and in how it is applied in clinical practice and in research (in turn providing a basis for quality assurance).
- Help facilitate the provision of developmentally appropriate self-management teaching and support approaches to children and young people with chronic conditions by informing best practice in paediatric health care.
- Increase the ability of clinicians to identify problems and gaps with supported self-management early, based on developmentally appropriate self-management teaching and support approaches.

1.8.4. Objectives

The objectives of this research were to:

At an individual level

- Support children and young people with chronic conditions (and their caregivers) to achieve developmentally appropriate supported self-management skills and healthcare behaviours, and transition smoothly from paediatric to adult care.

At the level of clinicians and researchers

- Provide guidance to clinicians and researchers to understand the fundamental differences between paediatric supported self-management and the more familiar adult chronic condition self-management models and interventions.
- Support the processes for transition from paediatric to adult care.
- Assist clinicians and researchers to become advocates within their own healthcare organisations for developmentally appropriate self-management teaching and support approaches.

At a healthcare organisational level (policy)

- Provide a broad framework (i.e. can be used across different chronic conditions) that enables paediatric healthcare organisations to deliver developmentally appropriate self-management teaching and support approaches.

2. Thesis structure

A substantial contribution to the growing area of empirical research on supported self-management by children and young people with chronic conditions from a developmental perspective is made by this thesis. Three focus conditions were used to illustrate supported self-management – i.e. asthma, CF, and T1DM. The research underpinning this thesis is predominately exploratory, theoretical and conceptual in nature, and reflects the limited research in this field up to this point in time. Every attempt has been made to offer a balance between the methods chosen and the practical interpretation of the findings.

This chapter, Chapter 2, provides an overview of the thesis structure. This thesis is organised into nine chapters as shown in Figure 3. Four studies were completed: Two systematic reviews, a concept analysis and a Delphi consensus technique.

FIGURE 3 PICTORIAL STRUCTURE OF THESIS

Chapter 1
- Introduction and general background information

Chapter 2
- Thesis structure

Chapter 3
- Methodology and methods

Chapter 4
- A systematic review of the current guidelines for promoting developmentally appropriate supported self-management in children and young people with asthma, CF and T1DM

Chapter 5
- Development of a rigorous interdisciplinary method of concept analysis

Chapter 6
- A concept analysis of supported self-management for children and young people with chronic conditions

Chapter 7
- A systematic review of supported self-management education interventions for children and young people with asthma, CF and T1DM

Chapter 8
- A Delphi consensus of developmentally appropriate supported self-management for children and young people with chronic conditions

Chapter 9
- Discussion and conclusion

The next chapter, Chapter 3, describes the research methodology and methods. This research draws upon pragmatic philosophy and uses a mixed-methods approach encompassing both quantitative and qualitative data. This chapter also examines the origins of the research, and how my personal research perspective shaped and influenced the research process.

Chapter 4 presents, and expands on, a published review of current clinical guidelines promoting developmentally appropriate self-management teaching and support approaches (Saxby et al. Chronic Illn., 2020) [8].

Chapter 5 presents a rigorous new interdisciplinary method for concept analysis named the Saxby–Page Concept Development Technique, in preparation for publication. Concept analysis methods are important for theory development and as an aid for more consistent clinical practice and research applications. Existing methods of concept analysis have been challenged for a variety of reasons. Reported limitations include concept analyses being limited to the discipline of nursing, being undertaken without a conceptual problem being identified, questions of rigour, restrictions in scope, failure to approach conceptual work systematically, lack of documentation, and unclear methods. The new concept analysis methodology presented in this thesis introduces a defined and rigorous process that aims to address these limitations.

Chapter 6 analyses and develops the concept of supported self-management for children and young people with chronic conditions. A growing body of literature on the topic of supported self-management was identified through the concept analysis; however, inconsistent use of terminology in the literature suggests variability in its application. This concept development study (in preparation for publication) paves the way to a better understanding of the role children and young people have in managing their own chronic conditions. It therefore expands interdisciplinary clinical knowledge, providing a solid basis for future research. The Saxby–Page Concept Development Technique was used for this study. Detailed methods are articulated.

Chapter 7 presents another literature review that identifies the components of effective self-management educational interventions and teaching approaches for children and young people, relevant to their developmental status. This study has been published (Saxby et al., Patient Educ. Couns., 2019) [7].

Chapter 8 explores the opinions of interdisciplinary clinical academics with expertise in supported self-management (Saxby et al., Patient Educ. Couns., 2020) [9]. A Delphi consensus process was used to define developmentally appropriate self-management teaching and support approaches, as well as the supported self-management endpoints for five predetermined developmental stages. Finalised statements informed development of the Partners in Health: Consensus List for Children and Young People. To my knowledge, this is the first standardised tool to guide developmentally appropriate self-management teaching and support approaches.

Chapter 9 summarises the contribution of this thesis to scientific and clinical practice knowledge. A broad discussion of the research limitations is presented, as well as a plan to implement the research findings into paediatric clinical practice. Suggestions for further research complete this final chapter.

3. Methodology and Methods

'Unless someone like you cares a whole awful lot, nothing is going to get better. It's not.' ~ Dr Seuss

Chapter 3 describes the use of a pragmatic research philosophy and mixed-methods research design. Also, discussed is my research perspective and how this shaped and influenced the research process. Please note that the methods for the individual studies are described in detail within the chapters (Chapters 4–8).

Highlighted in this chapter:

- Why a pragmatic philosophy and a mixed-methods approach was the best choice to gain insight into supported self-management and developmentally appropriate self-management teaching and support approaches
- What pragmatism means to me as a clinician and as a researcher
- How applying pragmatism can assist in translating research to practice
- Justification for the research methods used

3.1. Research philosophy

It is worth acknowledging here that, as a researcher, my professional and personal views and value system will have influenced my world view and thus, impacted upon my research [138]. Prior to commencing my PhD research program, I critically examined my value system in relation to children's and young people's supported self-management. Questions I asked myself were:

- Why am I doing this research?
- What shaped the research question I chose to study?
- Why did I choose the approaches I did to study the research question?
- How does who I am and my values impact on the research process?

From this process I created a set of personal values, formed a research stance, and identified a methodological approach.

3.1.1. Axiology

Axiology refers to study of judgements, attitudes and values [139]. Being clear about their own value system helps researchers to keep their research ethically appropriate, and also uncovers areas of potential bias. Several personal values were identified as having the potential to impact upon the research process. These values were *collaboration*, *individualism*, *holistic approach*, *equality* and *being equal*, *accountability*, and *creativity*. The underlying reasons why I hold these values are described here.

Collaboration

- I believe that health care should be collaborative. Children and young people should be part of the paediatric healthcare team with the caregivers providing additional support on an as required basis (i.e. a triadic partnership) [140, 141]. This belief was formed through observation that collaboration leads to exceptional health care – a view supported by the literature [141]. Each partner within the triadic healthcare team brings with them different functional and lived expertise [141]. By working together, triadic healthcare teams can be more efficient, effective, innovative and better at managing risks and adversities [141]. This is achieved by considering everyone's views, creating opportunities for discussion, and identifying potential compromises as early as possible to achieve the best possible health outcomes for the children and young people living with the chronic conditions.

Individualism

- According to my world view, at its core, paediatric health care is about caring for children and young people as individuals. This view can be at odds with contemporary management of many chronic conditions, which are largely based on principles of commonalities (e.g. all people with CF or T1DM should be automatically screened for co-morbidities). Individualised health care is about providing a personalised approach and recognising that the individual needs of children and young people are important factors in their development and overall wellbeing. Recognising individuals within healthcare systems means understanding and acknowledging their experiences, expectations, goals and hopes. For children and young people attending paediatric healthcare services, to be treated as an individual is an essential component of their healthcare experience because it allows them to retain a positive sense of self (i.e. dignity and self-esteem) in what can be a stressful period spanning many years [40]. Furthermore, it is worth noting here that children and young people are known to develop at varying rates and thus they will have different physical, creative, language, emotional, social and cognitive needs from each other [40]. An individualised approach also fits in well with the concept of child-centred care, described later in this thesis (Section 1.4).

Holistic approach

- A holistic approach to health care considers the whole person and how they interact with their environment. I like to adopt a holistic approach to my clinical practice to address individual needs. As described by Modi et al. (2012), there are many factors that influence the ability of children and young people to self-manage their chronic conditions including, but not limited to, age and developmental stage [24].

Equality and being equal

- Equality in paediatric health care means that the views of children and young people are equal to those of adults (i.e. caregivers and clinicians) [142, 143]. Equity is giving everyone what they need to be successful [141]. I believe that children and young people should have an active voice and be included in decision-making processes that are appropriate to their developmental level [143]. Through my own clinical observations, when children's and young people's voices are not acknowledged as being equal to those of adults, they tend to feel disempowered. This power imbalance can later lead to adverse health outcomes.

Accountability

- In keeping with my values, responsibility for health outcomes needs to be distributed between children/young people, their caregivers/, clinicians and the senior management of the healthcare system. Accountability is a noun that describes the accepting of responsibility [144]. A child and young person has accountability for their actions and behaviours in relation to supported self-management; caregivers have accountability for overseeing the completion of daily supported self-management tasks; clinicians have accountability for teaching supported self-management skills and health behaviours that are developmentally appropriate, and for ensuring that these can be safely carried out; and the senior management of the health service has accountability for decisions and policies that affect the people in their care [24]. Accountability also encompasses critical reflection [145].

Creativity

- Creativity was the last value I identified having the potential to impact on the research. Creativity encompasses the use of imagination and original ideas to create something new [146]. Throughout my lifetime I have been placed in many situations that required a creative problem-solving approach. I believe in thinking ‘outside the box’ and considering if knowledge from other areas might be able to be applied across contexts (e.g. can education principles be used in a healthcare context?).

3.1.2. Ontological and epistemological positioning

Ontology is the theory about the nature of being [147, 148]. Determining ontological perspective is important because it informs the whole approach to the research and defines how the collected data relate to the world [147, 148].

Epistemology is the theory or science of the methods and grounds of knowledge [147, 148]. It is the core area of philosophical study that includes the sources and limits, rationality and justification of knowledge [149]. Epistemology informs the methodology about the nature of knowledge or where knowledge is to be sought [149].

Traditionally, researchers have been encouraged to adopt one ontological and one epistemological position to the exclusion of others. This has resulted in polarisation of the relativism (qualitative) and realism (quantitative) research paradigms. As argued by Tashakkori and Teddlie, it may be more appropriate for a researcher to think of the research paradigm as a continuum [150].

3.2. A pragmatic approach

This PhD research programme draws on a pragmatic philosophy and uses a mixed-methods approach. Put simply, pragmatism is a research approach that allows for integration and evaluation of ideas and beliefs in terms of their practical functioning [151]. As a research methodology, pragmatism dates back to the works of Peirce and Dewey in the 19th and early 20th century [151]. More recently, however, pragmatism has evolved to include more subtle variations in methods and focus.

From an epistemological positioning, pragmatism is premised on the idea that research should be embraced as a continuum and the focus should be on concrete, real-world issues [150, 152]. I found that a pragmatic approach which focuses on the inquiry process and practicality, more useful than other research philosophies that place emphasis on abstraction or philosophical driven theory. An important feature of pragmatism is that it rejects the distinction between realism and relativism [150, 152]. For pragmatists, there is such a thing as reality, but it is ever changing and shaped by context [147, 148, 150]. A pragmatic approach links theory and practice and may also assist in translating research into clinical practice [147, 148, 153]. By adopting a pragmatic approach, this research was not restricted by any ontological and epistemological constraints [150].

Methodologically, the implication is that pragmatic researchers are well equipped to deal with complex, highly nuanced and dynamic processes where depending on the input variables, varied outcomes are possible and probable [154]. In other words, pragmatism provides a workable approach that goes beyond mere problem solving [154].

3.2.1. Why use pragmatism in research on supported self-management?

As a paediatric clinician myself, I selected pragmatism for its potential to unlock the complex nature of how a child's/young person's developmental stage affected their ability to participate, over time, in supported self-management in their everyday lives. Overarching everything was my desire for my PhD research to translate directly into clinical practice. The research would be considered successful if it changes the way that paediatric clinicians deliver self-management teaching and support approaches to children and young people to be more developmentally appropriate.

Pragmatism argues that the most important determinant of the research philosophy is the research question itself [150, 152] – which in this case was:

> *'What are the attributes of supported self-management at various developmental stages?'*

A pragmatic approach allowed for the study of this research question in multiple ways and provided results that could bring about positive consequences for paediatric health care that are in line with my own value system as described earlier.

For many years, this clinical question has been on my mind. Nothing in my years of graduate and postgraduate training as a health professional had enabled me to answer this question. And my interdisciplinary colleagues seemed to be in the same position. There was no curriculum that we could follow as an interdisciplinary team to teach children and young people we cared for to become effective self-managers. An interdisciplinary approach involves team members from different disciplines working collaboratively towards a common set of goals and purpose. For the management of CF, the core interdisciplinary team usually comprises a paediatrician with respiratory expertise, a paediatric nurse, a physiotherapist, a dietitian and a social worker [71].

I envied teachers who had a set of standards available to improve the learning of the children they taught. Teachers know what students should be taught and what they should achieve for various developmental stages, as they progress through school. The agenda of this research was to try and prove that the developmental stage of children and young people does in fact impact upon their ability to self-manage effectively. And to turn this knowledge into a set of resources for clinicians, a curriculum as such, that sets out descriptions of developmentally appropriate self-management teaching and support approaches. A secondary aim was to create a list of supported self-management endpoints for various developmental stages.

3.2.2. How a pragmatic approach can help with translating research into practice

It has been documented that pragmatism can assist in translating self-management research into clinical practice [155]. During my PhD candidature, I found that applying pragmatism in my research was facilitated by focusing on three core principles which I identified as being specifically relevant to the topic of supported self-management [151]. These core principles were: *linking experience with action; useful knowledge; and, inquiry as a decision making process*. The expected outcome was that the research findings would more easily be able to be applied in practice. The core principles are described below.

Linking experience with action

- This core principle emphasises that knowledge *links together experience and action* [151]. Specifically focusing on knowledge that is practically useful to relevant stakeholders (i.e. in this case paediatric clinicians of various disciplines) at the beginning on a research programme is vital for facilitating the use of any research outputs [151].

Useful knowledge

- The core principle of *useful knowledge* encouraged me as a researcher to engage with multiple paediatric clinicians at the same time. I was able to gather information on from their collective experiences while also directing the inquiry towards practical solutions that helped to solve problems encountered (this is particularly evident in the Delphi consensus study presented in Chapter 8) [151]. Paediatric clinicians often have high workloads and are responsible for the care of children with many chronic conditions thus the practical resource the research provides will be very valuable in supporting their practice.

Inquiry as a decision-making process

- This core principle highlights the everyday pragmatism employed by paediatric clinicians to problem solve and to reach solutions to assist children/young people in participating in supported self-management activities that are appropriate to their developmental level.

3.3. A mixed-methods design

Pragmatism is frequently linked with mixed-methods research [154]. A key justification for undertaking mixed-methods research within this PhD programme is that paediatric healthcare, including supporting children of different developmental stages to self-manage, is complex [148]. Children and young people are dependent on their caregivers to different extents, have different developmental trajectories and there is a need for a triadic approach. Other considerations include the intricacies of supported self-management education interventions, the need to understand how children and young people experience their chronic condition and supported self-management journey, how paediatric health care organisations can integrate supported self-management approaches, and how the context and/or environmental influences may affect outcomes [148].

Mixed-methods research has become increasingly popular over the last two decades in the healthcare sector; and it is widely accepted as a valid methodological approach [147, 152, 156]. While many definitions exist, mixed-methods research generally involves the collection and integration of qualitative and quantitative research approaches either within a single study or across a series of studies. Mixing can occur at the methodological level [150] and/or at the level of the methods [156]. This research integrates a mixed-methods approach at both of these levels.

Collecting both qualitative and quantitative data enabled a holistic understanding of supported self-management for children and young people with chronic conditions from a developmental perspective. The aims of the qualitative aspects of this research were to understand 'how' and 'why' developmental stage is an important factor in relation to healthcare skill development. The aim of the quantitative aspects of this research were to determine relationships among independent and dependent variables – i.e. what supported self-management tasks and healthcare behaviours can children and young people perform at each developmental stage with and without support, and what are the teaching and support approaches clinicians should be providing for children and young people at different developmental stages.

A combination of an inductive and deductive research strategy was used to build theory around supported self-management for children and young people with chronic conditions. Three different methods were used: systematic literature reviews, concept analysis, and the Delphi method.

In the first instance, a systematic review was undertaken to determine if current clinical guidelines recommend that paediatric clinicians should provide self-management support in a developmentally appropriate way. A rigorous new interdisciplinary method of concept analysis was then developed for this thesis and broader general application (i.e. the Saxby–Page Concept Development Technique). This new method was later used to define the concept of supported self-management for children and young people. The research then shifted to focus on how paediatric clinicians could translate the concept of supported self-management into practice. Another systematic review was completed at this point. This second review aimed to articulate the components of effective educational interventions and teaching approaches that help children and young people learn about managing their chronic conditions, relevant to their developmental status.

For primary data collection, a Delphi study explored the opinions of clinical academics with expertise in supported self-management, from a developmental perspective. The Delphi study resulted in the development of a new consensus tool to guide developmentally appropriate teaching and support appropriate for children and young people with chronic conditions (i.e. the Partners in Health: Self-Management Consensus List for Children and Young People).

3.4. Synopsis

This chapter described how a pragmatic research philosophy and a mixed-methods approach was used to investigate supported self-management for children and young people with chronic conditions. Core values held by me, the primary researcher, are also presented to ensure an ethical approach to my research and to uncover any areas of potential bias. Values identified as having the potential to impact upon the research process were *collaboration*, *individualism*, *holistic approach*, *equality* and *being equal*, *accountability*, and *creativity*.

The benefit of applying a pragmatic research philosophy is that it allows the topic to be investigated in many ways, which helps to bridge the gap between research and clinical practice. Collection and analysis of both qualitative and quantitative data (through completing systematic reviews, a concept analysis and the Delphi consensus technique) allows for the understanding of the 'how' and 'why' developmental stage is important in supported self-management, and 'what' teaching and support approaches should be provided for each developmental stage.

The next chapter (Chapter 4) reviews current guidelines promoting supported self-management.

4. A systematic review of the current guidelines for promoting developmentally appropriate chronic condition self-management in children and young people

‘It’s easier to build strong children than repair broken adults’ ***~F. Douglas***

Chapter 4 reviews recommendations on supported self-management in current clinical guidelines.

Highlighted in this chapter:

- How guidelines are developed – their potential, the challenges and limitations
- The importance of appraising guideline quality
- Justification of why it was necessary to do a systematic review of current guidelines
- Whether or not current guidelines provide guidance to clinicians on how to promote supported self-management
- A discussion of ways clinicians can promote developmentally appropriate self-management support in practice

Chapter 4 relates directly to the following publication:

Supplementary data and other information related to this chapter can be found in Appendix D

N. Saxby, S. Beggs, N. Kariyawasam, M. Battersby, S. Lawn, Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate supported chronic condition self-management? A systematic review. Chronic Ill. (2018) https://doi.org/10.1177/1742395318799844 [Epub, ahead of print]

Review

Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review

Nicole Saxby[1,2], Sean Beggs[2], Nadish Kariyawasam[3], Malcolm Battersby[1] and Sharon Lawn[1]

SAGE

Abstract

4.1. Background

Self-management support is an important guideline component in the care of children and young people with chronic conditions. In Australia, the National Health and Medical Research Council (NHMRC) recommends the use of current guidelines to improve the quality of care through the application of consistent evidence-based practice [3, 52, 157]. This is consistent with practices across the world [52].

Developing guidelines is an onerous task [158-160]. I know this from personal experience as I had the honour of leading the 2017 'Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand', a project that involved 60 individuals and took five years to complete [161]. Through my involvement in this nutrition guideline project I developed a desire to understand the evidence behind guideline recommendations. Consequently, as a starting point in my PhD, I wanted to understand which guidelines promoted developmentally appropriate self-management support and if the underlying evidence base was concordant with recommendations.

4.1.1. Guideline development

To develop a quality guideline, several stages need to be completed by the guideline development group [158]. The first stage is defining the topic and setting the scope for the guideline [158]. During stage one the draft practice questions that the guideline will answer are set. The second stage is the guideline development process itself; during this stage practice questions are confirmed, literature is reviewed and assessed for hierarchy and quality, and recommendations are formed [158]. Stage three is usually a consultation stage where the guidelines are reviewed and commented on by peers and consumers [158]. A revision of the guidelines is usually completed based on the feedback of the consultation process [158]. The final stage is submitting the guideline for approval and endorsement through relevant professional organisations [158]. The process described above appears to be very similar across the world [160].

Clinicians have been trained to follow contemporary guidelines, the trustworthiness of these documents can be highly variable [162, 163]. Areas that can be problematic include: *managing conflicts of interest*; *ensuring representativeness and credibility* (i.e. should be developed by a multi/inter-disciplinary group with significant consumer input); *maintaining methodological rigour* (i.e. ideally be based on the best available scientific evidence); and *confirming that recommendations* *are applicable to the setting they were created for* (i.e. need for clear, feasible recommendations for clinicians). For clinicians, another area of concern with guideline development is a lack of transparency in how recommendations are derived [164, 165].

4.1.2. Appraising guideline quality

For the reasons mentioned above, critical appraisal of guidelines is necessary. Appraisal tools help the end users to assess the quality so that they can then make informed decisions about whether or not the guideline recommendations should be followed. Over the years, several systematic reviews have looked into guideline appraisal tools [164, 165]. These reviews have identified that there are more than 50 guideline assessment tools available, including the gold-standard Appraisal of Guidelines for Research & Evaluation II (AGREE II) tool [166], (which is a modification of the Cluzeau 1999 tool [167]), the Hayward 1995 tool [163], and the Wilson 1995 tool [168]. Quality domains assessed by guideline appraisal tools usually include *evaluation of evidence*, *presentation of the guideline content*, *transferability*, *independence*, *scope*, and *information retrieval* [164]. Less frequently assessed are the quality dimensions of *consideration to different perspectives* and *implementation and evaluation plans* [164]. Most guideline appraisal tools were originally developed for research and/or quality control purposes [164, 165].

4.2. Study design and aims

4.2.1. Aim

The aim of this study was to deliver a summary of current international clinical guidelines promoting developmentally appropriate self-management support for individuals with the focus conditions.

4.2.2. Design

The method chosen for this study was a systematic review of guidelines; including mapping of the underlying evidence base and critical appraisal of guideline quality. Systematic reviews offer the most reliable source of synthesised evidence and are often used to guide clinical practice [158].

4.2.3. Guiding research question

‘Do guidelines provide evidence-based guidance to clinicians on promoting developmentally appropriate chronic condition self-management support in children?’

4.3. Methods

4.3.1. Data sources

A comprehensive literature search was conducted. Seven international guideline databases were searched: National Guideline Clearinghouse (USA), Canadian Medical Association Infobase (Canada), National Health Service Evidence and The National Institute for Health and Care Excellence (NICE) (UK), Scottish Intercollegiate Guidelines Network (SIGN) (Scotland, UK), New Zealand Guidelines Group (NZ), and the NHMRC (Australia). The literature search was In line with a recent publication by Bramer et al. (2017) [169] who describes how to complete optimal database literature searches, multiple databases need to be searched under the direction of a medical librarian with significant experience.

4.3.1.1. Additional mechanisms put in place to ensure that no guidelines were missed through using the database search strategy

To ensure that no guidelines of international significance to supported self-management were missed, 15 clinicians from across the world (Australasia n=6, Europe n=3 and North America including Canada n=6) each with more than 5 years' experience in the care of children and young people with one of the focus conditions, were consulted. These clinicians were identified through known personal networks. Contact with clinicians was made via their relevant professional organisation[7].

Furthermore, the websites of 32 professional organisations were searched for current guidelines (e.g. the American Academy of Allergy Asthma and Immunology, the International Society for Pediatric and Adolescent Diabetes, the American Cystic Fibrosis Foundation, and the European Cystic Fibrosis Society). The full list of websites searched are noted in Appendix 1D.

4.3.2. Eligibility criteria

4.3.2.1. Inclusion criteria

Guidelines were included if they were current as of the 22 September 2017 and if they were created by professional organisations (to assist a single discipline or an interdisciplinary team in managing one

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[7] The purpose of a professional organisation (also sometimes referred to a professional body or professional society) is to further a healthcare discipline for the interests of its members. Professional organisations may also promote the interests of their specific discipline in relation to public health.

of the focus conditions (i.e. asthma, CF, and T1DM). Currency was set to include guidelines that published or reviewed within the last 10 years (i.e. 2007 to 2017) [160]. Professional organisation was defined as a collective group with a purpose of promoting and protecting the professional interests of the health profession it represents and/or the health care needs of specific patients and communities.

To meet inclusion criteria, guidelines also needed to have a section dedicated to 'self-management' and within that section contain the words 'development*', 'age', 'age-appropriate' or 'throughout life*'.

4.3.2.2. Exclusion criteria

Guidelines were excluded if they focused on other childhood chronic conditions or were hospital-based guidelines.

4.3.3. Data extraction

A two-stage screening process was completed to confirm that guidelines met inclusion criteria. In stage one, I screened guidelines for relevance through title and abstracts (i.e. they covered children and may include chronic condition self-management), and duplicates were removed. In stage two, I excluded guidelines that did not promote developmentally appropriate self-management support and guidelines that were rescinded. Reasons that guidelines were excluded were recorded on an Excel database.

For guidelines meeting inclusion criteria, the following data were extracted by myself and confirmed by a second person (N. Kariyawasam): general guideline characteristics, methodological development process, clinicians/patient groups targeted, settings and circumstances in which to use developmentally appropriate self-management support approaches, and relevant practice recommendations inclusive of evidence hierarchy ranking.

Recommendations were then classified into six research-defined groups reflecting the components of effective chronic condition self-management:

- *Collaboration* – i.e. the promotion of an active a healthcare triad; children/young people, caregivers and clinicians working together

- *Education* – i.e. the provision of information, and the teaching of skills and techniques to children and young people in an age and developmentally appropriate supported way to improve self-management capacity
- *Clinicians' self-management support skills* – i.e. clinicians who are adequately trained and who will support children's ability to learn self-management skills and healthcare behaviours at differing ages and developmental stages
- *Personalised action plans* – i.e. the provision of written instructions to help children and their caregivers manage the chronic conditions and respond proactively to changes in signs and symptoms
- *Problem solving and decision making* – i.e. the developmentally appropriate teaching of strategies for problem resolution, and the ability to select an appropriate education strategy
- *Assessment and monitoring of self-management needs* – i.e. measuring the self-management capacity of children and young people (as well as their caregivers) over time [24].

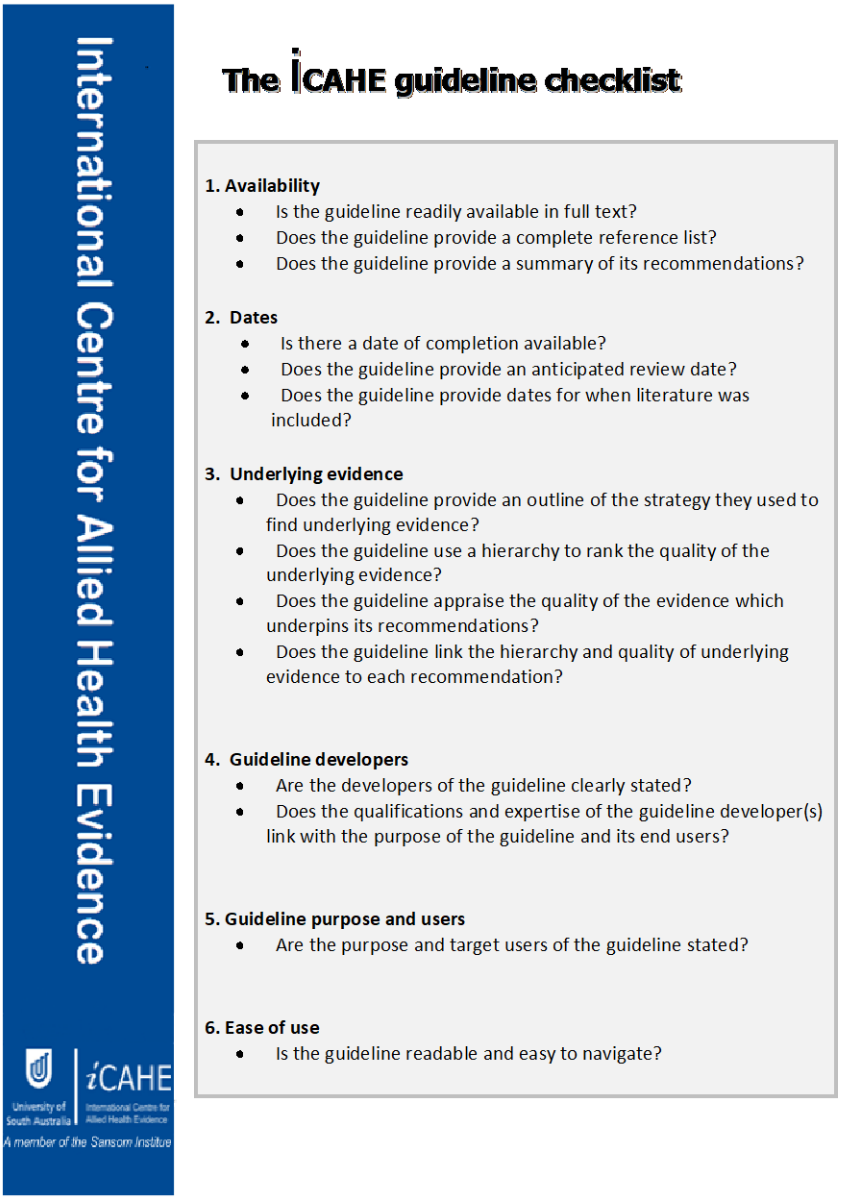
The above groupings were based broadly on paediatric self-management components outlined in Modi et al. 2012 [24]. It is worth noting that there may be some overlap between groupings (e.g. collaboration would be required for effective education and also for problem solving and decision making).

4.3.4. Guideline appraisal

Guideline quality was then appraised using the International Centre for Allied Health Excellence (iCAHE) 'Guideline Quality Checklist' (Figure 4, next page). To ensure appropriate rigour, my quality assessments were confirmed by a second independent reviewer (N. Kariyawasam). Quality rankings were expressed as average % total iCAHE scores with standard deviations to represent agreement between the two appraisees (total agreement SD=0, moderate agreement SD<15, poor agreement SD>15).

The iCAHE 'Guideline Quality Checklist' was chosen because it was time-efficient to administer (takes less than 15 minutes to complete per guideline) and is internationally recognised [170]. The iCAHE checklist is validated for construct validity, inter-tester reliability and clinical utility against the gold standard AGREE-II instrument [170]. Quality domains measured by the iCAHE tool are: availability (i.e. available in full text, complete reference list, summary of recommendations provided); dates (i.e. date of completion and planned review stated); underlying evidence (i.e. strategy to assess evidence and quality stated); guideline developers (i.e. developers qualified to develop the guideline); guideline purpose and users (i.e. purpose and uses clearly articulated); and ease of use (i.e. readable and easy to navigate) [170].

FIGURE 4 THE ICAHE GUIDELINE CHECKLIST



The iCAHE guideline checklist

1. Availability
- Is the guideline readily available in full text?
- Does the guideline provide a complete reference list?
- Does the guideline provide a summary of its recommendations?

2. Dates
- Is there a date of completion available?
- Does the guideline provide an anticipated review date?
- Does the guideline provide dates for when literature was included?

3. Underlying evidence
- Does the guideline provide an outline of the strategy they used to find underlying evidence?
- Does the guideline use a hierarchy to rank the quality of the underlying evidence?
- Does the guideline appraise the quality of the evidence which underpins its recommendations?
- Does the guideline link the hierarchy and quality of underlying evidence to each recommendation?

4. Guideline developers
- Are the developers of the guideline clearly stated?
- Does the qualifications and expertise of the guideline developer(s) link with the purpose of the guideline and its end users?

5. Guideline purpose and users
- Are the purpose and target users of the guideline stated?

6. Ease of use
- Is the guideline readable and easy to navigate?

Source: International Centre for Allied Health Excellence [170]

4.3.5. Data synthesis

Descriptive analysis was undertaken to present each guideline's general characteristics, including the grading system used to assess evidence quality and strength of recommendations. Full-text journal articles listed as evidence for recommendations were then assessed for concordance with developmentally appropriate self-management support considerations.

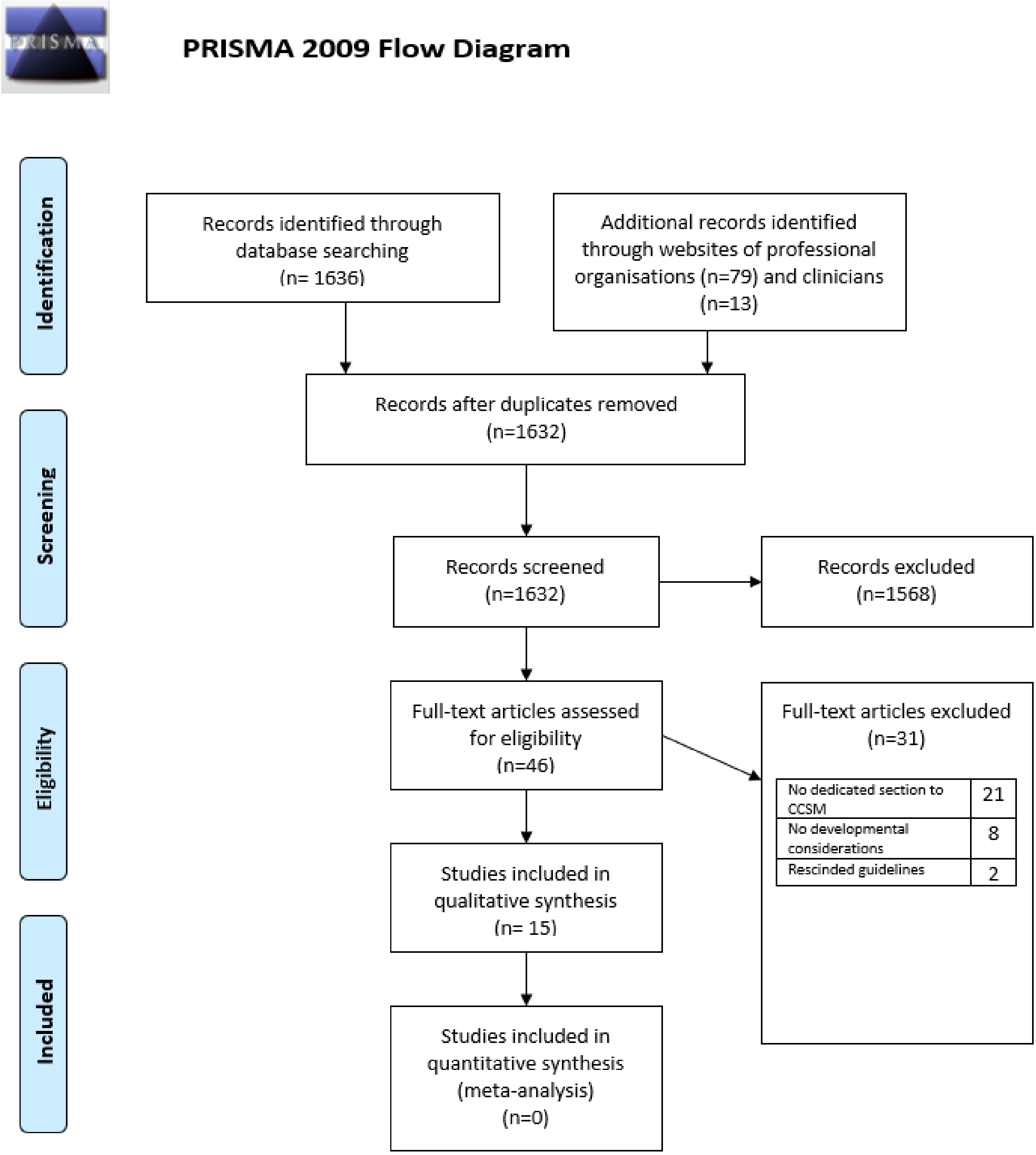
4.4. Results

Seven guideline databases yielded 1636 results. Additional guidelines were identified through reviewing professional organisation websites (n=79) and by asking clinicians (n=13). After removing duplicates and screening (stage 1), 46 guidelines met the inclusion criteria and full texts were obtained. Further screening (stage 2) resulting in the inclusion of 15 guidelines (Figure 5, next page).

4.4.1. General guideline characteristics

In relation to country of origin, guidelines originated from the USA (n=5), Canada (n=4), UK (n=3), Australia (n=2) and Belgium (n=1). They included guidelines for T1DM (n=8), asthma (n=6) and CF (n=1) Table 5 on page 79 provides a general description of summary characteristics of included guidelines.

FIGURE 5 FLOWCHART OF GUIDELINES INCLUDED IN THE REVIEW



4.4.2. Guidelines by quality

The best quality guidelines overall were the Australian ‘National Asthma Handbook’ [73], the ‘British Guideline on the Management of Asthma’ [137], the Australian ‘National Evidence-Based Guidelines for Type 1 Diabetes in Children, Adolescents and Adults’ [72], and the Scottish ‘Management of Diabetes: A National Clinical Guideline’ [137]. These four guidelines ranked first in each of the iCAHE domains. See Table 5 on the next page for all rankings.

Two guidelines did not grade the strength of the evidence and/or recommendations [171, 172]. The other 13 guidelines used 12 different systems to do so: NHMRC n=2 [158], Global Initiative for Asthma n=1 [48], Scottish Intercollegiate Guidelines Network n=1 [173], Oxford n=1 [174], Department of Veteran Affairs and Department of Defense [175], Registered Nurses Association of Ontario n=1[70], Canadian Diabetes Association n=1 [176], American Diabetes Association n=1 [177], National Collaborating Centre for Women's and Children's Health [178], Cystic Fibrosis Foundation n=1 [179], and the American Association of Clinical Endocrinologists n=1 [180]. Grading of the strength of recommendations, depending on scale used, was heterogeneous. Levels given to similar recommendations ranged from the highest level of evidence available down to consensus opinion

TABLE 5 GENERAL DESCRIPTION OF INCLUDED GUIDELINES

	Asthma						Diabetes - T1DM								CF
Guideline	National Asthma Council Australia [2016][73]	Scottish Intercollegiate Guideline Network and British Thoracic Society [2013][137]	Medical Services Commission of British Columbia [2015][171]	Global Initiative for Asthma Science Committee [2015] [48]	Department of Veteran Affairs and Department of Defense [2009] [181]	Registered Nurses' Association of Ontario [2008] [70]	Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [Booth 2013][176]	Craig et al. [2011] [72]	Lange et al. [2014] [182]	Beck et al. [2017] [172]	American Diabetes Association [2014][183]	Healthcare Improvement Scotland and Scottish Intercollegiate Guidelines Network [2014] [184]	Handelsman et al. [2015] [180]	National Collaborating Centre for Women's and Children's Health [2015][178]	Saiman et al. [2014] [179]
Interdisciplinary working group	X	X	-	X	X	-	X	X	-	X	X	X	-	X	X
Status															
New	-	-	X	-	-	-	-	-	-	-	-	-		-	-
Update from the previous	X	X	-	X	X	X	X	X	X	X	X	X	X	X	X
N yr since prior CPG	1	2	-	1	10	4	5	6	3	2	1	3	4	10	10
Level of development															
International	-	-	-	X	-			-	X			-	-	-	-
National	X	X	X	-	X	X	X	X	-	X	X	X	X	X	X
Organisation															
Professional	-	-	X	-	-	X	-	-	-	-	-	-	X	-	-
Government	-	-	-	-	X	-	-	-	-	-	-	X	-	X	-
Other	X	X	-	X	-	-	X	X	X	X	X	-	-	-	X
Methodology															
Systematic (evidence based)	X	-	X	-	X	-	X	X	-	-	X	X	-	X	X
Consensus	-	-	-	-	-	X	-	-	-	-	-	-	-	-	-
Not clearly stated	-	-	-	-	-	-	-	-	X	X	-	-	X	-	-

Usability															
N pages	131	214	17	132	127	131	11	288	8	68	9	170	87	517	68
N recommendations	68	30	12	49	155	27	32	29	6	10	34	40	67	264	77
N references	479	960	38	506	179	87	139	603	74	185	88	762	671	921	500
Internet availability	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Funding stated	X	X	X	X	X	X	X	X	X	X	X	X	-	X	-
iCAHE average total % score (SD)	100 (0)	100 (0)	43 (9.9)	75 (5.1)	89.3 (5.1)	83.9 (2.5)	89.3 (5.1)	100 (0)	78.6 (0)	50 (0)	67.85 (5.0)	100 (0)	71.4 (0)	96.15 (5.4)	78.6(0)
Overall quality	1	1	10	6	3	4	3	1	5	9	8	1	7	2	5

4.4.3. Guideline recommendations

Together, the 15 guidelines provide 29 specific developmentally based recommendations for self-management support approaches. One guideline mentioned these considerations in the narrative text only [48]. Some guidelines included multiple recommendations in the same grouping (e.g. two or three different recommendations for self-management education). Practice recommendations centred on developmentally appropriate:

- *Collaboration* (n=15 recommendations) [48, 70, 73, 137, 172, 178-183, 185].
    - All guidelines stated that chronic self-management support was the responsibility of the entire interdisciplinary team, with triadic collaboration between children, their caregivers and clinicians being routinely encouraged.
- *Education* (n=17 recommendations) [48, 70, 72, 73] [137, 172, 178-183, 185].
- *Clinicians' self-management support skills* (n=4 recommendations) [72, 73, 181, 182].
- *Personalised action plans* (n=3 recommendations) [73, 137, 171]
- *Assessment and monitoring of self-management needs* (n=3 recommendations) (i.e. self-management capacity assessment of the child/young person n=1, and of the child/young person–caregiver/family dyad n=2) [70, 72, 181].
- *Problem solving and decision making (*n=2 recommendations) [70, 184]

Developmental transitions were highlighted as important time points in some guidelines (n=4/14), n=2 preschool [70, 185] and n=3 adolescence [72, 137, 185].

Further analysis showed that developmentally appropriate self-management support recommendations lack a clear evidence base. Fifty-seven studies were provided as evidence for the 28 developmentally based self-management support recommendations and in-text comments. Only 14 (24.6%) of these studies, written in English, were found to be direct evidence for developmental considerations. Evidence was stronger for education (n=6 concordant studies) [135, 186-190]. and less so for all other areas for which each had less than two supporting studies (i.e. collaboration, clinicians' self-management support skills, action plans, and problem solving and decision making). In all guidelines, developmental considerations were only one part of multi-component recommendations.

4.4.4. Support tools available for clinicians

Two guidelines provided clinicians with practical tools to increase children's and young people's participation in their health care [70, 171]. The Registered Nurses' Association of Ontario asthma guideline included two tools: (1) a summary of developmental theories and issues concerning health and illness; and (2) a practical guide of what are developmentally appropriate asthma self-management behaviours, based on Piagetian concepts of cognitive development and Erikson's theory of psychosocial development [70]. A developmental psychologist was involved in the creation of the Royal Nurses' Association of Ontario tools [70]. The Medical Services Commission of British Columbia asthma guideline provided asthma action plans in two age groupings – less than 6 years old, and 6–18 years old [171].

Conversely, none of the three guidelines that recommended clinicians assessed self-management and developmental capacity of the child/young person and/or child/young person–caregiver dyad provided any measures to do so [70, 72, 181].

4.5. Discussion

The most prominent finding of this review was that guidelines promoting developmentally appropriate self-management support approaches lack a clearly articulated evidence base. Only 14 (24.6%) of the 57 studies listed as evidence were concordant with the recommendations made, with the strongest evidence provided by guideline authors being for self-management education provision.

Overall, 15 guidelines of various quality recommended that self-management support be provided in a developmentally appropriate way. This finding was applicable and generalisable across a variety of conditions (i.e. the focus conditions). The 29 clinical care recommendations within these guidelines centred on developmentally appropriate collaboration, self-management education provision, clinicians' self-management support skills, personalised action plans, problem solving and decision making, and assessment of children's and/or caregivers' knowledge about the condition and its treatment. Nonetheless, all 29 of these guideline recommendations were too vague to be of any practical relevance to clinicians.

4.5.1. Collaboration

The 15 included guidelines promoted the use of triadic partnerships without providing any supportive evidence. Children over the age of five years should be presumed competent to be involved in their own health care, in partnership with their caregivers and clinicians [191]. Unfortunately, according to a good-quality systematic review completed in 2007, children tend to have little meaningful healthcare involvement [191]. Children are least likely to be active participants in the treatment planning and discussion parts of consultations when supported self-management is often raised [191].

For clinicians, three-way consultations are more complex than didactic consultations due to the need to contextualise health information in a way that both children/young people and adults can understand, and the need to listen to children and adults equally and to consider any differences of opinions before planning ongoing health care [192, 193]. Ways that clinicians can involve children and young people more in consultations include ensuring that all adults in the room are supportive of their participation, and engaging children and young people within the first half of a consultation [191].

4.5.2. Education

All but one of the included guidelines (n=14/15) promoted the delivery of developmentally appropriate self-management education to transfer knowledge, skills and health care behaviours necessary for children and young people to look after their own healthcare needs. In these guidelines, six studies were quoted as evidence for providing developmentally appropriately self-management education [135, 186-190]. However, a further literature search as part of this PhD research revealed that there are several additional randomised controlled trials completed in children and young people with the focus conditions (with statistically significant results) that were not referenced by the guideline authors (Chapter 7).

Common themes for delivering developmentally appropriate education to children and young people are as follows.

- Age-appropriate stages of developmental psychology must be followed, with children and young being directly involved in supported self-management from infancy through to adulthood.
- Educational programs should be tailored specifically for infants, school-aged children, younger adolescents, older adolescents and caregivers.
- Supported self-management should be facilitated in conjunction with self-efficacy.
- Structured written curriculum is beneficial, with modular components building on self-management skills and healthcare behaviours that have been previously learnt by children and young people.
- Curriculum topics should include knowledge of condition, impact of condition, symptom monitoring, responding to symptoms, actively participating in their own clinical care, being able to use a written action plan, lifestyle, and accessing support services.
- Problem solving and decision making should be emphasised.
- Using play, role playing and arts-based activities may facilitate the learning of infants and children in the younger and middle years of childhood.

These themes are consistent with proven adult self-management education programs [25].

4.5.3. Clinicians supported self-management support skills

The need for clinicians to have developmentally appropriate skills and tools to support children and young people to participate in supported self-management was articulated in four guidelines. Nonetheless, what these clinical skills would look like was not clearly articulated. Published in 2009, Flinders University's self-management capabilities resource outlines the skills that the healthcare workforce needs to deliver effective self-management support across the lifespan [26]. Paediatric clinicians keen to improve their self-management support skills may consider completing professional development in areas such as communication, assessment of self-management capacity (understanding strengths and barriers), collaborative care planning, use of peer supports, psychosocial assessment and support, understanding of models of health behaviour change, motivational interviewing, and how to work better in an interdisciplinary environment [137].

Tools, such as the developmentally based self-management skill guide seen in The Royal Nurses' Association of Ontario guideline [70], may help with translation to practice.

4.5.4. Action plans

Three guidelines recommended that children and their caregivers be provided with written instructions to manage the chronic conditions in everyday life [73, 137, 171]. Written instructions for self-management in the home environment are commonly referred to as 'action plans', and their purpose is to help guide prevention, management of symptoms and when to seek medical help. Only one out of three guidelines promoting action plans provided versions targeted at children and young people of different ages – i.e. an asthma action plan for children aged <6 years, and a separate action plan for children aged 6–18 years [171]. As mentioned in the Australian Asthma Handbook [73], the reason behind a lack of developmentally appropriate action plans for children and young people may be related to there being no established guidance regarding the ideal format and the critical instructions that need to be included. However, research has shown that individuals with low health literacy can comprehend pictorial action plans [194].

4.5.5. Problem solving and decision making

Two guidelines recognised the importance of children and young people being taught developmentally appropriate strategies for problem resolution. Structured problem solving for children and young people with chronic conditions appears to be significant gap in the current literature base. Further research in what is developmentally appropriate problem solving and decision making is required before useful guideline recommendations can be made.

4.5.6. Assessment and monitoring of supported self-management needs

While three guidelines recommended that clinicians measure the self-management capacity of children and young people over time, none of these guidelines cross-referenced any appropriate tools to do so. To date, no systematic reviews have been completed that look at the validity of tools to assess children's and young people's self-management capacity and thus this remains a gap in the knowledge base. Clinicians would benefit from having research to go to that clearly articulates appropriate self-management capacity tools for children and young people.

4.5.7. Translating guideline recommendations into practice

The mere presence of high-quality evidence in clinical guidelines does not necessarily result in translation to practice [195, 196]. As was highlighted in this review, despite most guidelines having been developed systematically, their recommendations for developmentally appropriate self-management support approaches are vague and do not provide clinicians with practical advice.

An example of a recommendation that is difficult to implement is to *'Assess patient and/or family for educational needs as well as for preferences and/or barriers to learning'* [181]. This recommendation requires clinicians to consider literacy, physical, developmental, emotional or psychological challenges as well as specific cultural and/or spiritual beliefs. Despite a level-A evidence ranking being assigned to this recommendation (i.e. there is strong evidence for this recommendation and clinicians should be applying this intervention to all eligible patients), none of the references included in this review support the assessment of a child's developmental stage. Clinicians may have difficulty interpreting the unclear evidence base of recommendations such as this.

A coincidental finding, resulting from different methodologies used by the guideline development groups, was that multiple systems for grading evidence and recommendations were included in the guidelines. For clinicians, this creates unnecessary confusion. One guideline development group reported having previously trialled (twice) the international GRADE system in 2009; however, they ultimately decided to not adopt this methodology because of the major resource challenges it would present [48].

Evidence-based recommendations need to be presented in a way that is both assessable and relevant, and integrated into strategies that are feasible for clinicians to use in their busy clinical practice.

4.5.8. Strengths and limitations

The strengths of the first systematic review presented in this thesis include: a comprehensive guideline search which was supported by a medical librarian; that I had previously developed skills in developing and assessing guidelines through my work with the ‘Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand’ project [161]; inclusion of only guidelines that were current and from six different countries; and the systematic summary of recommendations that promote developmentally appropriate self-management support approaches. Moreover, each guideline was assessed for quality by two appraises; this approach meets the minimum standards for a systematic review [158].

This review has limitations. Firstly, only guidelines written in English were included. Secondly, the exclusion of guidelines published as grey literature may have introduced biases. I excluded grey literature as a systematic and rigorous process to local guideline development processes could not routinely be ascertained. The risk of not including grey literature was mitigated through a search of professional association websites and by asking clinicians which guidelines they used to guide supported self-management support teaching and support approaches. Thirdly, four older guidelines (i.e. still current but more than 5 years old) were included despite recommendations for guidelines to be updated every 3–5 years [158].

4.6. Synopsis

Chapter 4 systematically reviewed and critiqued current paediatric clinical guidelines. Developmentally appropriate self-management support was deemed to be important in 15 international guidelines for the management of asthma, CF and T1DM, particularly in the areas of collaboration, education provision, clinical skills, personalised action plans, problem solving and decision making, and assessment of self-management capabilities. The most prominent finding of this study, however, was that guidelines promoting developmentally appropriate self-management support approaches lack a clearly articulated evidence base. Furthermore, the guideline recommendations provided were too vague to be of any practical relevance to clinicians. Less than 30% of the studies listed as evidence were concordant with the guideline recommendations made, with the strongest evidence being provided by guideline authors for developmentally appropriate self-management education and teaching approaches. It is evident that more work needs to be done to translate developmentally appropriate self-management support approaches for children and young people into practice. This was the last chapter within this thesis to highlight why supported self-management for children and young people with chronic conditions is an important research area.

The next two chapters (Chapters 5 and 6) seek to explore and understand the concept of supported self-management for children and young people with chronic conditions.

4.6.1. Summary of contributions to the literature

- To the best of my knowledge, this is the first study to look at the evidence unpinning current clinical guidelines recommendations for supported self-management.
- Guidelines promoting developmentally appropriate self-management support approaches lack a clearly articulated evidence base.

4.7. Guideline chapter acknowledgements

I would like to thank Ms M. Frasier (Librarian, Tasmanian Health Service) for her assistance in the completion of the literature searches presented in this chapter.

5. The development of a rigorous interdisciplinary method of concept analysis

'Facts are the materials of science, but all Facts involve Ideas. … we must, for the purposes of science, take care that Ideas are clear and rigorously applied.' ***~W. Whewell***

This chapter presents a new method of concept analysis developed for this thesis and broader general interdisciplinary use, later used to define the concept of supported self-management as it applies to children and young people with chronic conditions (Chapter 5). This new method has been named the Saxby–Page Concept Development Technique to indicate the core contribution of A. Page, as well as, myself.

Highlighted in this chapter:

- Justification for a rigorous new interdisciplinary method of concept analysis
- Strengths and limitations of existing concept analysis methods
- The development of the new method
- Detailed description of the steps
- Strengths and limitations of the method
- Next steps for the method

Chapter 6 directly relates to the following publication, in preparation:

N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn, The Saxby-Page Concept Development Technique: A Rigorous New Method of Concept Analysis Designed for Clinicians Working in Interdisciplinary Settings.

There are no appendices related to this chapter.

5.1. Background and justification

Concept analysis is an essential part of theory development in nursing; however, concept analysis methods are seldomly used (if at all) by other health disciplines [197]. There is an opportunity to extend the application of concept analysis beyond nursing. Extending the use of concept analysis to other disciplines aligns well with contemporary healthcare practices that encourage an interdisciplinary approach to care (i.e. clinicians of various disciplines along with the patient and their family working together collaborative, with a common purpose [197].

5.1.1. Why a rigorous new approach to concept analysis is needed

The breaking down for concept analysis is to identify attributes, which are the patterns and aspects of a phenomenon that are clustered together to form ideas [197]. This is done through examination of theoretical patterns in the literature [197]. Analysing a concept is essential for three reasons: (1) for theory development; (2) as an aid for better, more consistent clinical practice; and (3) so that, when future research is developed, there is a shared understanding that will allow comparison and pooling of data [197].

There are several different methods available to analyse concepts, including Wilsonian-derived, evolutionary and pragmatic utility methods (Table 6, next page) [198]. These methods follow a logical process that usually includes a concept being selected, a literature review, and a way of validating the adequacy of the conceptualisations being made (e.g. use of case studies).

Concept analysis methods are deemed important by many (especially in the nursing sciences) and are highly citied, existing methods have been challenged for a variety of reasons including poor identification of conceptual problems, questions of rigour, restrictions in scope, failure to approach conceptual work systematically, lack of documentation, and unclear methods [197-203]. Some authorship groups have even gone on to recommend that concept analysis methodology be expanded to cover concept development; that is, concept analysis findings are then used to move the body of knowledge forward in a way that is translatable into clinical practice [197, 198].

Continuing to isolate concept analysis methods to the nursing discipline in the 21st century may not be ideal. Over the last two decades there has been (and continues to be) a shift from discipline specific health care theories and practices to interdisciplinary approaches [118, 120, 121, 204]. Working across disciplines, however can result in the lack of a ‘common language’ and shared understanding of a concept [118]. When it comes to interdisciplinary health care teams, having a shared comprehension is central to effective communication and decision-making process [117, 118].

An interdisciplinary approach to concept analysis is not a new idea. In 2006, to describe ethical sensitivity, Weaver and Morse applied the practical utility method across the context of various health and non health disciplines (i.e. nursing, medicine, dentistry, psychology, clinical ethics, education, theology, law, accounting/business, journalism, philosophy, and political and social sciences) [205]. An interdisciplinary approach appears to have been chosen by Weaver and Morse as a way of enhancing holistic comprehension and practical relevance. The analysis itself, however, was undertaken by two nurses [205]. This is not surprising because concept analysis methods are regularly taught in graduate nursing curriculums [206]. Clinicians (beyond nurses) could also benefit from skill development and relevant tools to undertake concept analysis. It is also not common that clinicians complete concept analysis.

TABLE 6 COMPARISON OF EXISTING CONCEPT ANALYSIS METHODS

	Wilsonian-derived methods			Evolutionary method	Pragmatic utility approach
Step	Walker & Avant	Chinn & Jacobs/Kramer	Schwartz-Barcott & Kim	Rodgers	Morse *
1	Choose concept	Select concept	Theoretical phase: select concept, determine meaning and measurement of concept, choose working definition, search the literature	Select concept	Clarify purpose of the concept analysis
2	Determine rationale for analysis	Establish purpose for creating conceptual meaning	Fieldwork phase: collect and analyse data	Determine realm for data collection	Select literature to ensure validity Organise literature
3	Identify defining attributes	Examine data sources	Analytic phase: compile findings	Collect data re attributes and contextual basis of the concept	Identify critical questions Comprehend topic Ask questions of key literature
4	Develop a model case	Develop criteria for validating the soundness of the tentative conceptualisation		Analyse the data	Synthesise and compile results
5	Construct additional cases (which may include fictitious cases) of what counts/doesn't count as an example of the concept			Identify a real-life model case	
6	Identify antecedents and results			Identify hypotheses and area(s) for further development	
7	Determine empirical referents				

** Instead of using steps, the Morse Pragmatic Utility approach is based on a set of guiding principles.*

Source: Table adapted from Weaver and Mitcham 2008 with permission [198]

5.2. Study design and aims

The Saxby–Page Concept Development Technique has been developed to support clinicians of various disciplines in completing concept analysis. Clearly documented steps provide an explicit, reproducible methodology.

The method combines aspects of existing concept analysis methods with three widely used processes that are familiar to clinicians:

- the PRISMA-P 2015 systematic review reporting template [208, 209]
- thematic analysis at a meta-synthesis level [210]
- the 2018 Grading of Recommendations Assessment, Development and Evaluation (GRADE)—Confidence in the Evidence from Reviews of Qualitative Research (CER-Qual) confidence measure [211].

Building on the work of Rodgers [212, 213] and Morse [214], the method integrates, in a rigorous and systematic way, the meta-synthesis of qualitative themes from various study design types. This type of meta-synthesis avoids the partial conceptualisation likely to be revealed by relying on synthesis of one type of research in isolation. Incorporating a confidence measure then allows for any identified themes/sub-themes to be transparently assessed for quality and provides a way of confirming the adequacy of the conceptualisations being made. Furthermore, by including a separate methodological step for identifying practice implications, our method also expands concept analysis to include concept development.

The method presented in this thesis chapter is not intended to compete with other existing methods of concept analysis. It is offered as an alternative. Researchers may choose to use this method if they are trying to define a concept across disciplines.

5.3. Philosophical underpinnings

Concepts can be viewed from different ontological perspectives and epistemological perspectives [117]. While the ontological underpinnings of existing concept analysis methods are not readily identified in the international literature [117], they appear to have shifted from realism to relativism over time (i.e. Walker and Avant method = realism, Rodger's Evolutionary method = relativism). Epistemological foundations are more consistent with most methods being based on a constructionist paradigm [117].

A pragmatic approach was chosen for the 'Saxby-Page Concept Development Technique' (Section 3.2). The appropriateness of using a pragmatic research philosophy in concept analysis has been demonstrated by Morse et al. [214]. The method begins with identifications of issues from the 'real-world' practice arena, progresses through a cycle/series of logical steps in evidence synthesis, and then returns to application in 'real-world' practice. By applying an interdisciplinary lens, the method also extends the applicability of concept analysis to be broadly clinically useful.

5.4. Method development

5.4.1. The impetus behind the method

The Saxby-Page Concept Development Technique was originally developed to explain the concept of supported self-management by children and young people with the focus conditions. Current guidelines recommend interdisciplinary management for these focus conditions (Chapter 4) [8]. Team members involved in the care of chronic conditions for children and young people with these focus conditions include paediatricians, nurses, dietitians, physiotherapists, social workers and other medical specialities) [8]. With the method of concept analysis, the aim was to integrate the insights of all involved disciplines through the construction of a more comprehensive perspective of supported self-management. It was quickly identified, however, that the method had a wider application with the potential to support clinicians working in interdisciplinary settings and contribute to evidence-based theory development and practical real-world applications.

5.4.2. How the Saxby-Page concept development technique was developed

Development of the Saxby–Page Concept Development Technique began in mid-2018 and while led by me, it was overseen by a research steering group consisting of A. Page and my

PhD supervisory team (except for M. Battersby who was on leave at the time). Each group member had minimum of 10 years clinical experience and five years research experience. Whilst a generalist clinical and research skill set was required to be on the steering group, each team member also brought with them specific expertise:

- qualitative research and synthesis (K. Ford, S. Lawn)
- systematic reviews (N. Saxby, A. Page, S. Beggs, S. Lawn)
- evidence-based guideline development (N. Saxby, A. Page, S. Beggs)
- healthcare decision making (N. Saxby, A. Page, K. Ford, S. Beggs, S. Lawn)
- concept analysis (A. Page).

Existing concept analysis methods were identified through a search of the PubMed database using the keyword ‘concept analysis’, unlimited date range. Once identified, the first task completed was to create a summary of the strengths and weaknesses of each existing concept analysis method through the completion of a literature review (Table 7, next page). The content of Table 7 was derived from reviewing the analysis, commentary, and critiques of specific concept analysis methods by nurse researchers published in peer review literature over the last four decades. An additional column, outlining the perceived strengths and weaknesses of the new method from my perspective is also included.

I then led the design of the new method for concept development. Each proposed step was discussed at length with A. Page, who has demonstrated expertise in concept analysis methods [215]. Once A. Page and I had reached consensus about what we thought steps of the new methodology should be, the new technique was presented to the full steering group. Consensus about the steps of Saxby–Page Concept Development Technique was reached through discussion.

TABLE 7 IDENTIFIED STRENGTHS AND WEAKNESSES OF SELECTED CONCEPT ANALYSIS METHODS

	Wilsonian-derived methods			Evolutionary method	Pragmatic utility method	Saxby-Page method
	Walker & Avant [216-220]	Chinn & Jacobs/Kramer [221-227]	Schwartz-Barcott & Kim [228]	Rodgers [212, 213, 229]	Morse [214]	
Strengths	- Well known approach - Stepwise linear process - Systematic - Handbooks (various editions) are available to researchers choosing to use this method - Provides criteria to evaluate the characteristics of concepts (limited) - Promotes the use of a variety of case studies (model, borderline, illegitimate and related cases)	- Stepwise process that is less linear than Walker & Avant - Systematic - Stresses the importance of also clarifying the context as well as the concept - Method has been substantially modified over time to incorporate scientific knowledge with aesthetic, ethical and personal patterns of knowing	- Combines an analytic approach with field work - Extensive literature review - Uses real (nursing) situations - Cases identified after data areanalysed - Incorporates some techniques of qualitative analysis - Clearly articulates how the steps are integrated with one another	- Well-known and interdisciplinary approach - Many concept analysis studies using this method have been published by Rodger's herself - Systematic - Clear articulation of philosophical underpinnings - Handbooks (various editions) are available to researchers choosing to use this method - Examines the change in use of concepts over time - Uses a select sample from the available literature (both a strength and weakness)	- Based on a set of guiding principles that are integrative, cohesive and comprehensive - Systematic - Sets inclusion criteria for literature search - Examines underlying assumptions (both implicit and explicit) - Uses analytical questions to explore concepts - Encourages researches to evaluate a concept's level of maturity - Involves a critical appraisal process - Provides some evaluation criteria (i.e. extensiveness of data base, depth of analysis, logic of argument, validity, level of	- Combines three commonly used systematic review and meta-synthesis processes - Step-wise linear approach - Transparent process - Clear articulation of philosophical underpinnings - Encompasses a parsimonious process relating to the applied clinical setting - Systematic - Extensive literature review - Clearly documented steps provide an explicit, reproducible methodology - Study protocol available - Encourages detailed note keeping and for literature to be reviewed

				- Allows for use of various data collection methods - Provides criteria to evaluate the characteristics of concepts (limited) - Attempts to provide clear boundaries to distinguish a concept from its context - Uses thematic analysis - Qualitative approach to data analysis - Case studies identified after data are analysed to avoid reaching premature conclusions	abstractness, and knowledge contribution) - Promotes a comprehensive analysis of results and findings - Interdisciplinary - Includes some expansion into concept development	by a minimum of two reviewers - Includes a confidence assessment measure to evaluate the characteristics and themes/sub-themes of a concept - Interdisciplinary - Includes some expansion to concept development - Provides analytical tools for evaluation of confidence (i.e. CER-Qual) - Promotes use of summary statements for the findings
Weaknesses	- Mainly limited to nursing sciences - Lack of clarity about when a it is appropriate to use method - Potential for large volumes of literature - Incomplete and vague descriptions of the application of the method	- Mainly limited to nursing sciences - Lack of clarity about when a it is appropriate to use method - Incomplete and vague descriptions of the application of the method - Separation of data collection from analysis	- Limited applications of method found in the literature - Lack of clarity about when it is appropriate to use method - Incomplete and vague descriptions of the application of the method - Limiting analysis to prechosen subjects and	- Sampling techniques used are based on statistical representativeness and may not fully depict the concept - Incomplete and vague descriptions of the application of the method - Uses a single case study may limit data richness	- Incomplete and vague descriptions of the application of the method and lack of a handbook - Potential for large volumes of literature that may overwhelm researchers - Method relatively new and appears to be constantly evolving	- Brand new method - Application of method limited at this stage to one conceptual area - Method requires prior familiarization with the CER-Qual approach - Potential for large volumes of literature to overwhelm researchers - Time consuming - Generates large volumes of documentation

	- How to identify attributes is not clear and subjective - Heavy reliance on identifying the uses of a concept through definitions - Separation of data collection from analysis - Limited depth in analysis - Case-studies constructed by the researcher/s - Use of too many case studies may restrict, rather than clarify a concept - Failure to discuss how the steps are integrated with one another - Limited depth of analysis - Does not promote the use of summary statements, syntheses, or list of outcomes of major findings - Does not expand into concept development - Limited utility	- Failure to discuss how the steps are integrated with one another - Requires researchers to develop their own specific criteria to validate the adequacy of resulting conceptualisations - Limited depth in analysis - Does not promote the use of summary statements, syntheses, or list of outcomes of major findings - Does not expand into concept development - Limited utility	one nursing situation is restrictive - Does not promote the use of summary statements, syntheses, or list of outcomes of major findings - Does not expand into concept development - Limited utility	- Lack of cohesion between steps and failure to discuss how the steps are integrated with each other - Does not promote the use of summary statements, syntheses, or list of outcomes of major findings - Does not expand into concept development - Limited utility	- Potential for confused boundaries between concept and context - Quality of concept analysis completed using this method is directly related to the nature of the analytical questions asked - Does not provide analytical tools for evaluation	- Potential for individual disciplinary irrelevance - Contextually limited

5.5. An overview of the steps

The nine systematic steps of the Saxby–Page Concept Development Technique are described here in detail. The steps align with the Standards for Reporting Qualitative Research (SRQR) [230]. A flowchart of the steps is also presented (Figure 6).

Figure 6 Concept development flowchart

5.5.1. Step 1: Identify the conceptual problem

The first methodological step conveys the issues and context that give rise to the study. In 2018, Rogers et al. noted that many concept analysis studies were completed without a problem being identified [197]. However, while acknowledged as being complex, there appears to be no consensus definition as to what concepts are [117, 202]. To address these concerns, we suggest that use of the Saxby–Page Concept Development Technique is appropriate if less than 50% of included studies use the same terminology *and* if less than 25% of the included studies apply a shared definition or state a definition. These thresholds are suggestions only that were chosen pragmatically and may need to be adjusted based on the concept being explained. Using terminology and definitions as a way of determining if a concept is poorly defined relates back to the concept analysis method of Walker and Avant [216].

5.5.2. Step 2: Establish a research steering group

An interdisciplinary research steering group consisting of experts who are responsible for overseeing the research process needs to be established early on. This group provides transparency around decision-making, offers advice and troubleshoots problems where necessary.

When selecting an interdisciplinary steering group, it is important to identify the knowledge needs of the concept analysis you wish to complete, including appropriate disciplinary representatives who are known topic experts (e.g. if your steering group wants to study people with type 1 diabetes, think about what health disciplines are involved in providing care to this population group. It is likely that you will have identified disciplines such as medicine, nursing, dietetics, podiatry, and exercise physiologists). We also recommend that the research steering group has experience in systematic reviews of research, as well as expertise in concept analysis and applied qualitative research. It is useful to have multiple viewpoints so that different disciplines and different paradigms can be incorporated to understand the research that is included within a concept analysis study.

5.5.3. Step 3: Define the research question and set eligibility criteria

Write a research question in response to the identified conceptual problem. Interdisciplinary research questions can be particularly challenging as they are highly complex and require insight across multiple disciplines. For this reason, it is important that a research question emerges from a team effort (i.e. the steering group agrees to the question being asked) and that the question is phrased in a way that does not favour any specific disciplines [122, 231]. A research question also needs to be clinical important, precise in scope, directly relevant to the population you are studying and phrased in a way as to facilitate the search for an answer [122, 232, 233].

PICO is a useful mnemonic that can help frame up clinical questions [234]. Slightly different versions of this concept are used to search for quantitative and qualitative studies [234]. The Saxby-Page concept development method uses the modified PICo in its qualitative form, with a S added at the end to form PICoS (Table 8). The modified PICoS search has been demonstrated to have greater sensitivity and is more time efficient than the other commonly used mnemonics used frame up qualitative research questions including SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) [235].

Table 8 PICoS for Qualitative Studies

P	I	Co	S
Population or Problem	Phenomena of Interest	Context	Study type
What are the characteristics of the Population or the patient? What is the Problem, condition or disease that you are interested in?	Concept development studies tend to be generalist in nature. Interest relates to a defined event, activity, experience or process	Context is the setting or distinct characteristics	The Study types you want included (consider methodology and data collection)

Source: Adapted from Murdoch University [232, 234]

An example of a research question that is appropriate for concept analysis is:

> *'In adults with type 1 diabetes who are inpatients in Australia what are the essential survival skills that clinicians in an interdisciplinary team (i.e. disciplines of medicine including endocrinology, nursing, dietetics, podiatry, exercise physiology) should cover when providing health education?'*

The elements of the guiding research question are then to be used by the research steering group to determine the specific inclusion (and exclusion) criteria [236].

5.5.4. Step 4: Develop a systematic search strategy

The validity of a systematic review is directly related to the comprehensiveness of its literature search, as is the rigour of a concept development study. Step 4 involves the selection of electronic databases and appropriate search terms. It is recommended that all relevant databases be searched as advised by an experienced medical librarian or an academic librarian [237, 238]. Responsibility for the choice of databases to be searched will be with the librarian (such as the commonly known MEDLINE and EMBASE databases) and will depend upon the concept selected. It. Having a librarian involved maximizes recall and deals effectively with a number of potentially subjective factors. The research steering group may help contribute to this process by identifying keywords and highly specialist literature that may not be available in the main databases [238].

5.5.4.1. Set eligibility criteria

One of the most important tasks in using the new method of concept analysis is locating relevant and pertinent literature about the same concept. Things to consider when designing your search strategy: using the PICoS as a guide to set eligibility criteria (Section 5.5.3), study types, time period used for reference, disciplines to include in the literature synthesis, and language and geographical considerations.

Study types

It is our opinion that only empirical studies[8] should be included within a concept development study that uses the Saxby-Page method; however, these can include studies of quantitative, qualitative and mixed methods design. Qualitative and quantitative research studies are suitable for answering clinical queries and offer the best balance. Furthermore, inclusion of only empirical studies his limits the potential for repetition, ensuring that only the original go to sources of information are included in the analysis.

It is recommended that methodological filters for study design are not applied to the search strategy as these are known to reduce the sensitivity of the searches.

Time period

Another important consideration when developing the search strategy is the date range chosen for included literature. Building on the work of Rodgers and Knafl (2000), we suggest including a wide span of dates to allow for the identification of shifts in usages of the concept over time [213].

Disciplines to include in literature synthesis

When using the method, it is recommended that only the literature of disciplines directly involved in providing healthcare to the targeted population is included.

Language and geographical/cultural considerations

Ideally, a systematic search completed would include all available literature [239]. In principle, to avoid language subjectivity, this involves including studies written in all languages [239]. However, because the meaning of a concept can be sensitive to language and culture it is recommended that searches are limited to studies published in one language to reduce the impact of cultural differences. It is also worth considering if there are any geographical

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[8] For the purposes of this thesis, an empirical study is defined as a study that involves the collection and analysis based on primary data based on direct observation or experience of the research team [114]

considerations that need to be included in your search strategy (e.g. if you are researching adults with type 1 diabetes in Australia you would need to consult Australian literature or literature from countries with similar healthcare systems).

5.5.5. Step 5: Screen and select appropriate research studies

Search strategies often result in a large number of potentially relevant studies [232]. A three phase systematic screening strategy is to be used to confirm all studies included in the concept analysis meet eligibility criteria. It is important that the reasons for excluding studies are recorded. In phase 1, two independent reviewers will screen the database search results for relevance through title and abstracts. Of particular interest to the reviewers will be how the phenomena of interest is described. Duplicates are to be removed at this point. Phase 2 involves the two independent reviewers completing a full text screen for eligibility. Through discussion, two independent reviewers are required to reach consensus on the final list of studies to be included based on their eligibility for inclusion. Phase 3 involves the two independent reviewers hand searching the reference lists of all the included studies for any additional empirical studies to be included.

5.5.6. Step 6: Extract and manage data

5.5.6.1. Data extraction

As with all research, the extraction and management of data are important considerations in concept analysis work [147, 148]. In keeping with existing concept analysis methods [213, 216], the following outcome measures should be extracted from each included study: terminology used, attributes, antecedents, and consequences. All sections of an included paper are to be considered for data extraction including abstract, introduction/background, methods, results, discussion and conclusion sections.

Terminology use

- *Definitions provided*
    - Definitions used to define the named concept of interest, surrogate terms, and related concepts should be gathered.

- *Surrogate terms*
    - Surrogate terms are synonyms [213].
    - To a certain extent, surrogate terms must be identified before beginning the formal concept development study. This is necessary because terms that are used interchangeably need to be used to identify an appropriate population for sampling.
    - Additional surrogate terms can be extracted during the data collection and management step [213].
- *Related concepts*
    - Related concepts are those that can be confused with the concept of interest because they bear some relationship with the concept of interest but do not seem to share the same set of attributes [213].

Attributes

- Attributes, similar to signs and symptoms, are words and phrases that are commonly used to describe characteristics of a concept. Attributes can help to differentiate one concept from another related concept and clarify its meaning [216].
- Attributes can be classified further as being either essential (i.e. central to the concept of interest) or desirable (i.e. nice to have, but not critical to the concept of interest).

Antecedents

- Antecedents are the events or attributes that must arise prior to a concept's occurrence [216]. Antecedents also encompass enablers and barriers.

Consequences

- Consequences are things that can happen as a result of the occurrence of a concept [216]. New research avenues are stimulated through the identification of consequences [216].

5.5.6.2. Data management

Each included study is assigned an identification number. The choice of identification system used is up to the research group conducting the study. Using an identification system provides an easy means of noting a source when collecting the data, and it will also help to differentiate between the various perspectives. This system also provides a simple way of cross-referencing the individual included studies.

A summary page/electronic spreadsheet is used collect and collate the extracted data. All notes/decisions/memos transcribed by the reviewers will be collected. Collection of this level of data is in line with qualitative research methodology that stipulates that all methodological decisions made are clearly transparent [148, 240]. Furthermore, keeping these records will provide the basis for an audit, further enhancing the scientific rigour of any analysis completed using our new method.

5.5.7. Step 7: Complete thematic analysis and qualitative meta-synthesis

Meta-synthesis, the analysis of the findings, is a necessary step to coherently connect disparate aspects across multiple studies across literature published by various disciplines [147, 148]. Meta-synthesis allows the research steering group to develop an overarching interpretation of the concept. Unlike qualitative systematic review methods, qualitative meta-synthesis is still in a developmental phase with several methods described [241-243].

An important differentiation of the method from the PRISMA-P systematic review template [208, 209] is that the completion of the meta-synthesis step happens before the 'assess the body of evidence for confidence and quality' step. An understanding of what the concept entails is required before the research steering group appraise whether studies adequately address the concept.

The method uses thematic analysis to explore common themes and sub-themes from the extracted data. Thematic analysis is primarily an aggregative method of synthesis. That is, the interpretation of data is largely completed during the synthesis process to build meaning.).

While there are many approaches to thematic analysis, the method follows five phases: familiarisation, coding, generating themes, and reviewing and finalising themes. To maintain quality, each stage of the analysis requires two reviewers.

A sematic approach to thematic analysis is to be used with the analysis occurring at the level of the existing interpretations of the data (i.e., how the researchers interpreted their own data) and a semantic approach is to be used. Themes can be both deductively (i.e., arising from the research hypothesis) and inductively driven (i.e., allowing ideas to develop organically) [147, 148, 244].

5.5.7.1. Familiarisation

To start the thematic analysis process, each reviewer needs to become familiar with the literature from an overarching perspective. This is to be done by reading through each included paper and taking initial notes about any potential themes and sub-themes that may be present [147, 148, 244].

5.5.7.2. Coding

Next up, the data needs to be coded individually by each reviewer. This is to be done manually by highlighting sections of text in each included study – usually phrases and sentences. The shorthand codes you use to describe the content can be adapted as to suit your personal preference as a researcher [147, 148, 244].

A short example of sample text for the topic supported self-management is provided below (

Table 9). In this example, I have highlighted various phrases in different colours responding to different codes.

TABLE 9 SAMPLE TEXT ABOUT SUPPORTED SELF-MANAGEMENT WITH CODING APPLIED

Extracted text from the abstract of Saxby et al 2020 [9]	Codes
Sixteen clinical academics participated: 12 completed round one; 14 completed round two; and 12 completed round three. Of 101 statements, 90 reached consensus, with statements separated into five developmentally appropriate groups. Statements covered broad self-management and self-management support domains including knowledge, involvement, monitoring/responding to symptoms, transition, impact, lifestyle, and support. Division of responsibility and autonomy were distinct themes.	Support network Co-management Responsibility Autonomy

** Data presented is an example only and is not representative*

5.5.7.3. Generating themes

A table with the following headings needs to be created: reference, type of article, defining attributes, antecedents, consequences, surrogate terms and related concepts. One of the reviewers is then to put in their potential coded themes into the relevant parts of the table. Once the first review has completed this, the second review then adds/removes coded themes they believe should or should not be included. It is highly probably that the individual reviewers have used different codes – thus, it is important that the two reviewers come together face to face to identifiy patterns among the codes used to come up with consistent theme names.

TABLE 10 TURNING CODES INTO THEMES

Codes	Theme
• Children working with parents to look after their health • Completes self-management tasks independently/completes with support • Sharing of self-management tasks	Co-management
• Ability to complete self-management task • Competency • Can complete task to a high standard at least 50% of the time	Mastery

** Data presented is an example only and is not representative*

5.5.7.4. Reviewing and finalising themes

Generally themes will be broader than codes [147, 148, 244]. It is likely that several codes will be combined to form a theme, see Table 10 for an example. To ensure that themes are reflective of the literature it is important that the research steering group goes through all the extracted ata and codes to make sure than support the theme, and if there are contradictions or any overlapping of themes. Themes and sub-themes will be finalised through discussion.

5.5.8. Step 8: Assess the body of evidence for confidence and quality

The completion of a confidence assessment of the identified themes enables researchers and clinicians to identify those themes are supported by a solid body of evidence, and those that are not. In 2018, a new approach called the CER-Qual was made available by the GRADE (Grading of Recommendations Assessment, Development and Evaluation) steering group for this exact purpose [211]. The CER-Qual assesses the evidence in qualitative synthesis by addressing four components:

- methodological limitations of the individual studies
- relevance to the review question
- coherence
- adequacy of the data [211].

This CER-Qual assessment can be used to identify the extent to which each identified theme is a reasonable representation of the phenomenon of interest. Furthermore, incorporating this confidence measure also allows identified themes to be assessed for quality, and confirms the adequacy of the conceptualisations being made. Importantly, CER-Qual assessments do not give scores because these may give a false sense of precision regarding the assessments. CER-Qual assessments enable transparency around the decisions of confidence made by the research steering group. Detailed information about the CER-Qual assessment can be found in the series of papers by Lewin et al. [211]. For the purpose of this thesis, a summary is provided here.

Once the themes from the qualitative meta-synthesis have been finalised, the research steering group is to begin drafting short statements or 'CER-Qual Summaries of the findings' that provide a clear but succinct description of each of the themes (and any sub-themes) identified. In healthcare settings, it is important to make sure that the summary findings are written in a way that is useful to key stakeholders and end users – this helps with translation to practice.

A minimum of two reviewers should assess the four CER-Qual components for a level of concern for each identified theme and sub-theme:

- No or very minor concerns
- Minor concerns that may reduce confidence in the findings
- Moderate concerns that will probably reduce confidence in the findings
- Serious concerns that are very likely to reduce confidence [245].

Any concerns identified also need to be described in text.

Once the CER-Qual evidence profile has been written up for each identified theme and sub-theme, an overarching level of confidence should then be assigned:

- High – i.e. it is highly likely that theme/sub-theme is a reasonable representation of the phenomenon of interest
- Moderate – i.e. it is likely that the theme/sub-theme is a reasonable representation of the phenomenon
- Low – i.e. it is possible that the theme/sub-theme is a reasonable representation of the phenomenon of interest
- Very low – i.e. it is not clear whether the review finding is a reasonable representation of the phenomenon of interest [211, 245].

This rating is to be discussed between the entire research steering group until consensus is reached.

Following the assigning of an overarching CER-Qual assessment rating for each theme and sub-theme, a 'CER-Qual evidence profile' should be developed. The evidence profile includes five elements: (1) a summary of each identified theme and its classification category; (2) references to the studies contributing to the body of evidence for each theme; (3) an explanation of the assessment made for each CER-Qual component for each identified theme; (4) an overall CER-Qual assessment for each identified theme; (5) and an explanation of the overall CER-Qual assessment, including clarification of the contexts in which the included studies were conducted. See Table 11 on page 112 for an example of a completed CER-Qual evidence profile.

The identified themes are then entered into a diagrammatic representation of the concept. Colour coding is used to represent the overarching CER-Qual assessment scores given for each outcome theme and sub-theme, based on the traffic light system commonly used in the fields of nutrition, medicine and nursing. Green represents themes with the strongest evidence base and red/dark red represents themes with the least available evidence. See Section 6.4.2 on page 128. for the completed diagrammatic representation for exemplar concept of supported self-management.

TABLE 11 AN EXAMPLE OF A CER-QUAL EVIDENCE PROFILE

Theme/sub-theme name and category	CER-Qual summaries of the findings' statements	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	CER-Qual assessment of confidence in the evidence	Explanation of CER-Qual assessment
Responsibility, ESSENTIAL ATTRIBUTE	Transfer of responsibility is a shifting and shared process between caregivers and the child/young person as the child/young person becomes older	List studies contributing to evidence base here	Minor methodological limitations [n=24 studies with no or minor methodological limitations, n=4 studies with moderate methodological limitations (no reflexivity, no audit trail, unclear recruitment)]	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance [n=20 studies with direct relevance, n=8 studies with unclear relevance. Studies from three high-income countries (UK, USA, Australia)]	High confidence	No or minor concerns regarding methodological limitations, coherence, adequacy and relevance

** Data presented is an example only and is not representative*

5.5.9. Step 9: Identify practice implications

So far, I have provided detailed information about how to choose a concept, select appropriate literature, complete the analysis, and interpret the data. These are all important parts of the Saxby–Page Concept Development Technique. However, what is then done with the findings (i.e. the implications for practice) is equally important [246]. The addition of step 9 ‘identify practice implications’ expands on existing methods of concept analysis to include concept development. It is worth highlighting here that Rodger’s evolutionary approach and Morse’s pragmatic utility method already include some expansion into concept development [213, 214].

Practice implications are the conclusions made by the research steering group after the concept development study has been completed [246]. Identifying the implications of the findings from the concept development study is important for practice, policy, research and subsequent theory work. The inclusion of the CER-Qual confidence assessment measure ensures that there is substantive evidence to support the conclusions being made and is a safeguard against overgeneralisations [208]. Where possible, practice implications should give explicit recommendations for action and provide instructions as to how to implement these actions [246]. The person/persons responsible for completing the actions should also be clearly identified [246].

While the new method has controls in place to help ensure that appropriate conclusions are drawn from the data, it is worth noting that qualitative research is never completely unbiased, and thus any identified biases (e.g. personal, imposed by study parameters) should be noted in the final manuscript [239, 240].

5.6. Discussion

The overarching benefit of the new concept analysis method is that it promotes a shared and holistic understanding of a concept across disciplines, which substantially increases potential for clinical guidance and usability. In other words, our method of concept analysis takes the knowledge currently embedded within specific disciplines to broader interdisciplinary application. Other strengths related to how the method was developed, design characteristics, and uses are articulated below.

5.6.1. Strengths related to how the method was developed

A diverse group of clinical academics were brought together to develop a rigorous new method of concept analysis. Team members had experience in qualitative research, systematic reviews, evidence-based guideline development, health care decision making, concept analysis methods and in the topic being studied (i.e. supported self-management for children and young people with chronic conditions). Systematic review experience facilitated the rigorous, replicable and well documented approach to the 'Saxby-Page Concept Development Technique'. Demonstrated experience in concept analysis facilitated the understanding of complexities and nuances associated with existing methods. Health care decision making experience led to the inclusion of a specific step on practice implications. Qualitative research knowledge was vital as it ensured the appropriate selection of philosophical underpinnings (e.g. use of a pragmatic approach) and terminology choices.

Experience and expertise in guideline development led to the inclusion of the CER-Qual confidence assessment tool. Through experience, the researchers were familiar with tools used to classify the direction and strength of guideline recommendations (e.g. the Australian National Health and Medical Research grading of recommendations scale [158], and the GRADE assessment classification of recommendations [247, 248]. It was important that a similar approach was used within the 'Saxby-Page peer review Concept Development Technique' to classify the level of confidence to allocate the findings of qualitative themes/sub-themes. Strengths related to the design of the method.

The new method expands on existing concept analysis methods by applying increased rigour and replicability. This has been done by a variety of strategies. I have incorporated systematic review methodology and have stipulated that a research steering group with both expertise in the topic being studied and in systematic synthesis (including qualitative meta-synthesis) is responsible for overseeing the concept development study. The new method also advocates for detailed note keeping for a minimum of two reviewers for data extraction, analysis and synthesis. This allows audit trails to be completed if necessary. Inclusion of the CER-Qual approach allows for identified themes and sub-themes to be assessed for confidence, providing a way of confirming the adequacy of the resulting conceptualisations. It was also important to us that the theoretical underpinnings and terminology choices we made were appropriate for qualitative research.

5.6.2. Strengths related to uses of the method

Our new method has been designed to be used in interdisciplinary settings and is appropriate for use for concepts that are emerging (i.e. those that clack clarity, have competing definitions, unknown characteristics and boundary) as well as those that are mature (i.e. clear, consensual, clearly described and demonstrated, delineated boundaries).

5.6.3. Limitations

Interdisciplinary approaches are known to challenge traditional discipline boundaries [121]. By placing concepts within an interdisciplinary setting, a potential area of concern arises being – i.e. the loss of relevance for individual disciplines. Furthermore, a shared and generalised understanding of a concept does not allow for considerations re specific population groups, settings and/or complex influences related to context. A level of consideration will need to be employed when using generalised findings obtained using the new method outlined in this article.

It is also important that researchers choosing to use our new method understand that confidence assessments of qualitative evidence synthesis are subjective in nature. Other limitations include the time taken to complete. Application, at this stage is limited to a single conceptual area (i.e., supported self-management for children and young people with chronic conditions) (next Chapter). Prior familiarisation with the CER-Qual approach is also strongly encouraged [211].

5.7. Synopsis

The Saxby–Page Concept Development Technique is a rigorous new methodology combining components from existing concept analysis methodology with systematic review processes, qualitative synthesis approaches, and a confidence assessment measure. Use of *the 'Saxby-Page* Concept Development Technique' will help to expand comprehension, relevance, and nuances of concepts relevant to interdisciplinary health care teams. To enable transparency and reproducibility, what is required for each methodological step has been clearly articulated in this manuscript and accompanying exemplar study protocol. In the next chapter (Chapter 7), I present a completed study using the Saxby–Page Concept Development Technique for the concept of supported self-management.

5.7.1. Summary of contributions to the literature

- Methodological limitations have been reported with existing methods of concept analysis.
- The new method of concept analysis presented in this chapter bridges the translation gap between systematic reviews and clinical practice.
- Incorporating a confidence measure allows identified themes and sub-themes to be assessed for quality, and provides a way of confirming the conceptualisations being made.

6. A concept analysis of supported self-management for children and young people with chronic conditions

'Make it your business to draw out the best in others by being an exemplar yourself.'

~ Epictetus

This chapter is central to the thesis and is a culmination of work over the past decade. It results in the articulation of the very complex and nuanced concept of supported self-management from themes identified through already published literature. To complement the theoretical work presented here, the subjective perspectives of clinical academics were also gathered in parallel using the Delphi consensus technique (Chapter 9).

Highlighted in this chapter:

- Application of a theoretical framework to clarify the concept of supported self-management used in research and clinical practice
- Examination of the theoretical patterns and themes/sub-themes around supported self-management for children and young people as they develop and mature
    - Including identification of attributes, antecedents and consequences
- Confidence (i.e. quality) assessments for each outcome theme/sub-theme identified

Chapter 6 directly relates to the following publications, in preparation:

Supplementary data and other information related to this chapter can be found in Appendix E

- N. Saxby. A. Page, K. Ford, S. Beggs, S. Lawn, Exploring Supported Self-Management for Children and Young People with Chronic Conditions in an Interdisciplinary Context: A Concept Analysis Protocol.
- N. Saxby, K. Ford, S. Beggs, S. Lawn, An Interdisciplinary Framework for Supported Self-Management for Children and Young People with Chronic Conditions.

6.1. Background

Conceptually, supported self-management for children and young people is very different from the more familiar term ‘chronic condition self-management’ for adults, which implies that an individual largely manages their chronic condition(s) themselves. As has been previously discussed in this thesis, children and young people cannot self-manage alone and they need differing levels of support to develop self-management skills and healthcare behaviours appropriate to their developmental stage.

6.1.1. Why study supported-self-management in an interdisciplinary context?

No previous conceptual studies have been completed on the topic of supported self-management in children and young people with chronic conditions from an interdisciplinary perspective to the best of my knowledge. Previous concept analyses completed around the topic of paediatric self-management appear to be limited to single health care disciplines (and/or specific chronic conditions and/or specific developmental stages) [222–224].

According to the 2004 publication from the National Academies, interdisciplinary research is defined as ‘a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice’ [119].

Current clinical guidelines for asthma, CF, and T1DM recommend that paediatric healthcare services be provided by interdisciplinary teams [8]. Team members involved in the care of chronic conditions for children and young people include paediatricians, nurses, dietitians, physiotherapists, social workers and other specialities such as endocrinologists and gastroenterologists [8]. One of the common challenges of completing interdisciplinary research is a lack of a ‘common language’ and a shared understanding of a concept. It can be difficult to work on a clinical (and/or research) problems when members of the research team have been trained to approach it from different directions [117, 118].

Interdisciplinary efforts can create new knowledge, find solutions to complex problems, and generate leaders who are able to work collaboratively across discipline boundaries [119-122].

6.2. Study design and aims

6.2.1. Aims

The aim of this study was to clarify the concept of ‘supported-self-management’ as applied to an interdisciplinary context. More specifically, the aim was to enable the identification of the theoretical patterns underlying children’s and young people’s capacity to self-manage their healthcare needs as they develop and mature.

6.2.2. Study design

This study uses the ‘Saxby–Page Concept Development Technique’ (Chapter 6).

6.3. Methods

This study used the nine steps of the Saxby–Page Concept Development Technique are described in detail here.

6.3.1. Step 1: Identify the conceptual problem

The exemplar concept of supported self-management was selected on the basis of our own clinical and research expertise. The research steering group had noted an inconsistency in the use of terms and definitions to describe supported self-management before deciding to apply our concept development methodology.

The purpose of the concept development study was determined, i.e. to clarify the concept behind the terminology. The degree to which this heterogeneity of terminology and definitions varied was quantified using the following criteria:

> *‘use of the Saxby–Page Concept Development Technique is appropriate if less than 50% of included studies use the same terminology to describe supported self-management and if less than 25% of the included studies apply a shared definition or state a definition’.*

6.3.2. Step 2: Establish a research steering group

A research steering group with expertise in paediatric clinical practice (N. Saxby, K. Ford, S. Beggs), chronic condition self-management (N. Saxby, K. Ford, S. Beggs, S. Lawn), systematic review methods (N. Saxby, S. Beggs, S. Lawn), and concept analysis methods (N. Saxby, A. Page) has already been put together. Each group member came from a different professional discipline relevant to the topic of interest (i.e. paediatric medicine, nursing, dietetics, social work, pharmacy). Furthermore, each group member works as an active clinician and a minimum of 10 years clinical experience.

6.3.3. Step 3: Define the research question and set eligibility criteria

The guiding research question for the exemplar concept, in PICoS format, is:

> *'In children and young people with chronic conditions aged birth to 20 years, how does developmental stage impact upon self-management skills according to the views of clinicians/caregivers and the children themselves?'*

The working hypothesis behind this research question was:

'That children's and young people's understanding and ability to self-manage will increase with developmental maturity.'

6.3.3.1. Inclusion criteria

(P) Population or Problem

Studies that include children and young people aged 0–20 years were be considered. According to 1989 United Nations Rights of the Child, childhood spans the ages of 0-18 years [39]. However, in clinical practice, childhood can range from birth to the point when children/adolescents are transferred to adult care – usually before the age of 20 years [40].

Consistent with the other studies presented in this thesis, ages were extrapolated to represent five predetermined developmental stages based around the developmental theory of Piaget (i.e. infancy—birth to two years, early childhood—ages 2–5 years, middle childhood—ages 6–11 years, younger adolescence—ages 12–14 years, older adolescence—ages 15–20 years).

Three chronic conditions of childhood were selected as the population group for analysis: asthma, CF and T1DM. These conditions cause a significant health burden among children and young people. While these conditions differ in terms of severity and treatment regimens, they all require the completion of daily self-management tasks. Examination of three different chronic conditions with no restriction on settings allows for the distillation of common themes of the current evident that is available, allowing findings to be presented in a generalisable framework.

(I) Phenomena of Interest

The phenomenon of interest for this concept analysis study are the self-management skills and tasks that children and young people can complete independently or with support for the five predetermined developmental stages. Clinicians, caregivers and children's/young person's perspectives will be included, allowing for later triangulation.

(Co) Context

Clinicians, caregivers and children's/young person's perspectives were included. There were no exclusions placed on study settings; therefore, studies completed in the home, community, educational and hospital settings were included.

(S) Study types

All studies of primary research were included regardless of type; therefore, quantitative, qualitative and mixed method studies were included.

Further considerations re study designs are discussed below:

> **Time period (publication dates):** Literature over the last four decades was included. Including a wide span of dates will allow for the identification in shifts of usage of the concept of supported self-management over time.
>
> **Disciplines to include in literature synthesis:** As previously mentioned in the background section, literature on supported condition self-management is often produced by various disciplines. By following the 'Saxby-Page Concept Development Technique', however we are restricted to only including disciplines directly involved in providing healthcare to the targeted populations – thus in our instance this encompasses medicine (including paediatric, gastroenterology and endocrinology specialities), nursing, diabetes education, dietetics, physiotherapy, social work, and psychology.
>
> **Language/geographical/cultural considerations:** Studies from developed countries published in English were considered for inclusion.

6.3.3.1. Exclusion criteria

Studies that included palliative participants and participants with developmental disabilities were excluded.

6.3.4. Step 4: Develop a systematic search strategy

A search strategy was completed under the professional guidance of a medical librarian with experience using medical and academic databases [249]. Three electronic ProQuest databases (Health Research Premium Collection, PsychINFO and Sociology Database) were searched. Initial keywords to be searched will be 'supported self-management' or one of its known surrogates with Boolean operators applied (Box 1). Methodological filters for study design were not applied to the search because these are known to reduce the sensitivity of searches [148]. Searches were limited to studies of human subjects aged between 0 and 20 years, published between 1st January 1980 and 7th October 2019 in English.

BOX 1 SEARCH STRATEGY USED FOR DATABASES

(('asthma', OR 'diabetes mellitus, type 1', OR 'diabetes' OR 'cystic fibrosis' OR 'CF' OR 'respiratory condition' OR 'chronic condition' OR 'long term') AND ('child*/exp', OR 'adoles*/exp', OR 'youth', OR 'infant', OR OR 'young people', OR 'child health care') AND ('self-care', OR 'self-management' OR 'self-management support' OR 'health education' OR 'patient education' OR 'coping/behaviour' OR 'behaviour modification' OR 'coping behaviour' OR 'management', 'self-care', OR 'self-responsibility', OR 'responsibility', OR 'mastery', OR 'decision making', '[disease/illness/chronic condition] management', OR 'compliance' OR 'adherence'.))

6.3.5. Step 5: screen and select appropriate research studies

Titles and abstracts of all retrieved studies were reviewed by me. All irrelevant, non-English and duplicates were removed at this stage. Full text screening was then completed to confirm eligibility by two reviewers (N. Saxby and S, Lawn). As a safeguard, for each included study, the reference lists were then hand searched to identify any additional literature that should be included. Through discussion, both S. Lawn and I agreed to the final list of studies to be included in the concept analysis.

6.3.6. Step 6: Extract and manage data

6.3.6.1. Data extraction

Data extraction was completed independently by two reviewers (N. Saxby and S. Lawn). All sections within a study were subject to data extraction (i.e. abstract, introduction, methods, results, discussion, and conclusion sections).

From each study that met the inclusion criteria, the following was extracted: *terminology use* (definitions provided, surrogate terms), *related concepts*, *attributes* (essential and desirable), *antecedents* (enablers, factors that can be either enablers or barriers, barriers), and *consequences*.

6.3.6.2. Data management

Each reviewer used a separate sheet of paper to record extracted information.

6.3.7. Step 7: Complete thematic analysis and qualitative meta-synthesis

Following the data extraction process for each included study, findings were then grouped together, and the major and sub themes were identified by thematic analysis. A four-phase thematic analysis process applied: *familiarisation*, *coding*, *generating themes*, and *finalising themes*.

6.3.7.1. Familiarisation

Included studies were initially read in their entirety by two reviewers (N. Saxby and S. Lawn) to identify the patterns in the literature. The studies were then re-read multiple times by both reviewers to gain an understanding of the authorship group's use of the concept.

6.3.7.2. Coding

A manual highlighting technique was used then by each reviewer to identify sections of relevant text and coding was applied. Due to the subjective nature of interpreting text the coding systems used by each reviewer were different (later rectified when generating themes).

6.3.7.3. Generating themes

Following the data extraction process for each individual study, findings will be grouped together, and the major and minor themes identified. This was done by creating a summary table (Appendix 1E). The table headings used were *reference ID*, *type of article*, *perspectives*, *developmental stages covered*, *attributes*, *antecedents*, *consequences*, *surrogate terms*, and *related concepts*. The table was initial created by me using my own extracted data and codes, S. Lawn then added/removed added/removed codes and other information to the table as she deemed necessary.

Once the table was filled in by both reviewers, S. Lawn and I then got together in person to discuss the coding and to identify patterns among the codes to come up with consistent theme names.

6.3.7.4. Finalising themes

Themes and sub-themes were finalised through a discussion with the entire research steering group.

6.3.8. Step 8: Assess the body of evidence for confidence and quality

The confidence in qualitative findings for each theme was assessed using the CER-Qual [211] and a rating assigned: high (highly likely that the theme/sub-theme is a reasonable representation of the phenomenon of interest), moderate (likely that the theme/sub-theme is a reasonable representation of the phenomenon), low (it is possible that the theme/sub-theme is a reasonable representation of the phenomenon of interest), very low (it is not clear whether the review finding is a reasonable representation of the phenomenon of interest). Consideration was given to methodological limitations of the included studies, coherence, adequacy of data, and relevance [211, 245]. CER-Qual ratings were discussed with the entire research steering group until consensus was reached.

Confidence ratings are provided against each theme in the results section (Section 6.4.2). Furthermore, the body of evidence for each theme/sub-theme was also summarised into a Summary of Qualitative Findings table (Appendix 2E).

The identified themes for supported self-management were then entered into a diagrammatic representation of the concept with colour coding being used to present the overarching CER-Qual assessment scores given for each theme and sub-theme (Green represents themes with the strongest evidence base and red/dark red represents themes with the least available evidence).

6.3.9. Step 9: Identify practice implications

The research steering group identified practice implications through a robust discussion. This was aided by reviewing each themes/sub-theme in detail with its associated CER-Qual confidence assessment rating.

6.4. Results

The initial search strategy returned 316 records identified through database searching, plus 32 additional records identified through citations and from my own personal library. This number was reduced to 66 records after all irrelevant, inappropriate and duplicate records were removed. Eligibility assessment was then completed, and the full texts read for the remaining 58 included records. The majority of studies were published on the topic of T1DM either studied as a sole condition or with other focus conditions (n=38/58, 66.5%), with years of publication ranging from 1983 [21, 22] through to 2019 [9].Figure 8, on the next page, articulates the search strategy used.

6.4.1. Terminology use

6.4.1.1. Publications over time

The concept of supported self-management from a developmental perspective has been present in the literature since 1983 [21, 22]. While some studies had looked at self-management in children and young people prior to 1983, these studies did not include developmental considerations and thus were excluded. Publication rates have been relatively stable with between zero and three studies being published each year (Figure 7). By decade, the number of studies published were 15.5% (n=9) in the 1980s, 29.3% (n=17) in the 1990s, 17.2% (n=19) in the 2000s, and 22.4% (n=13) in the 2010s.

FIGURE 7 PUBLICATION COUNT PER YEAR FOR SUPPORTED SELF-MANAGEMENT

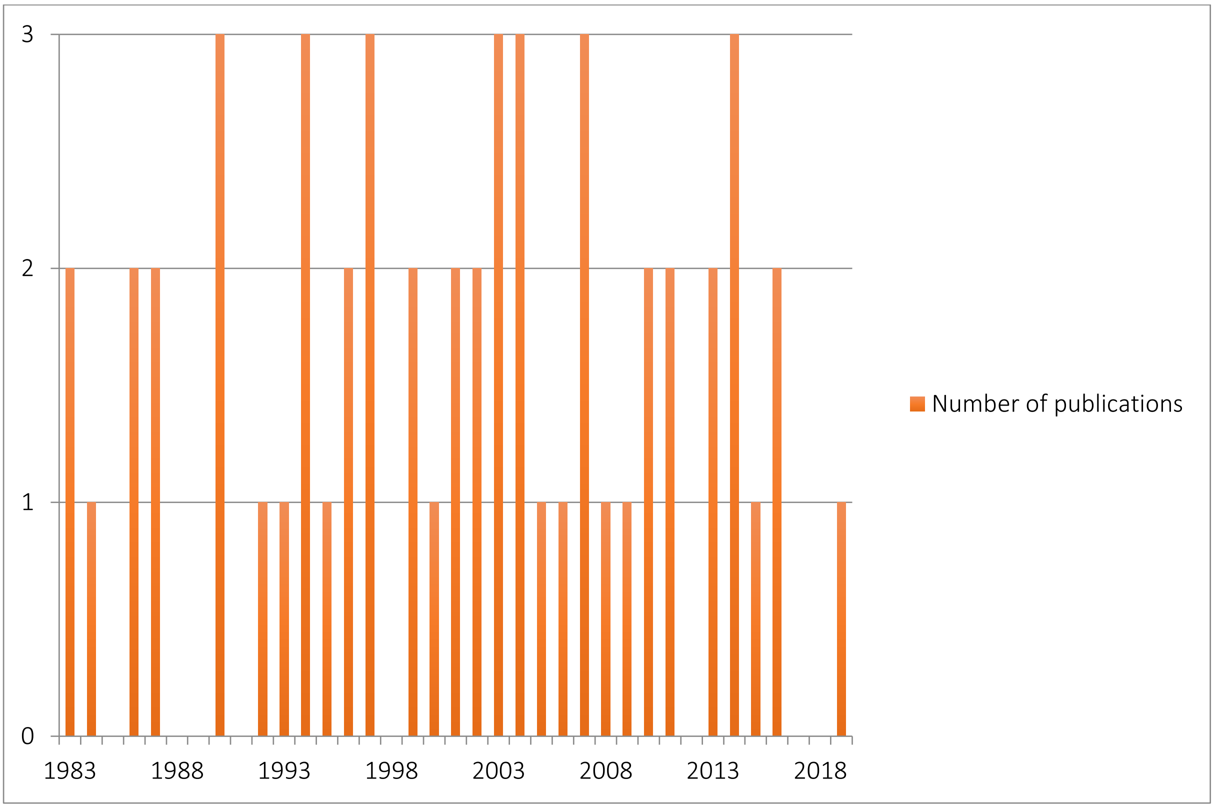
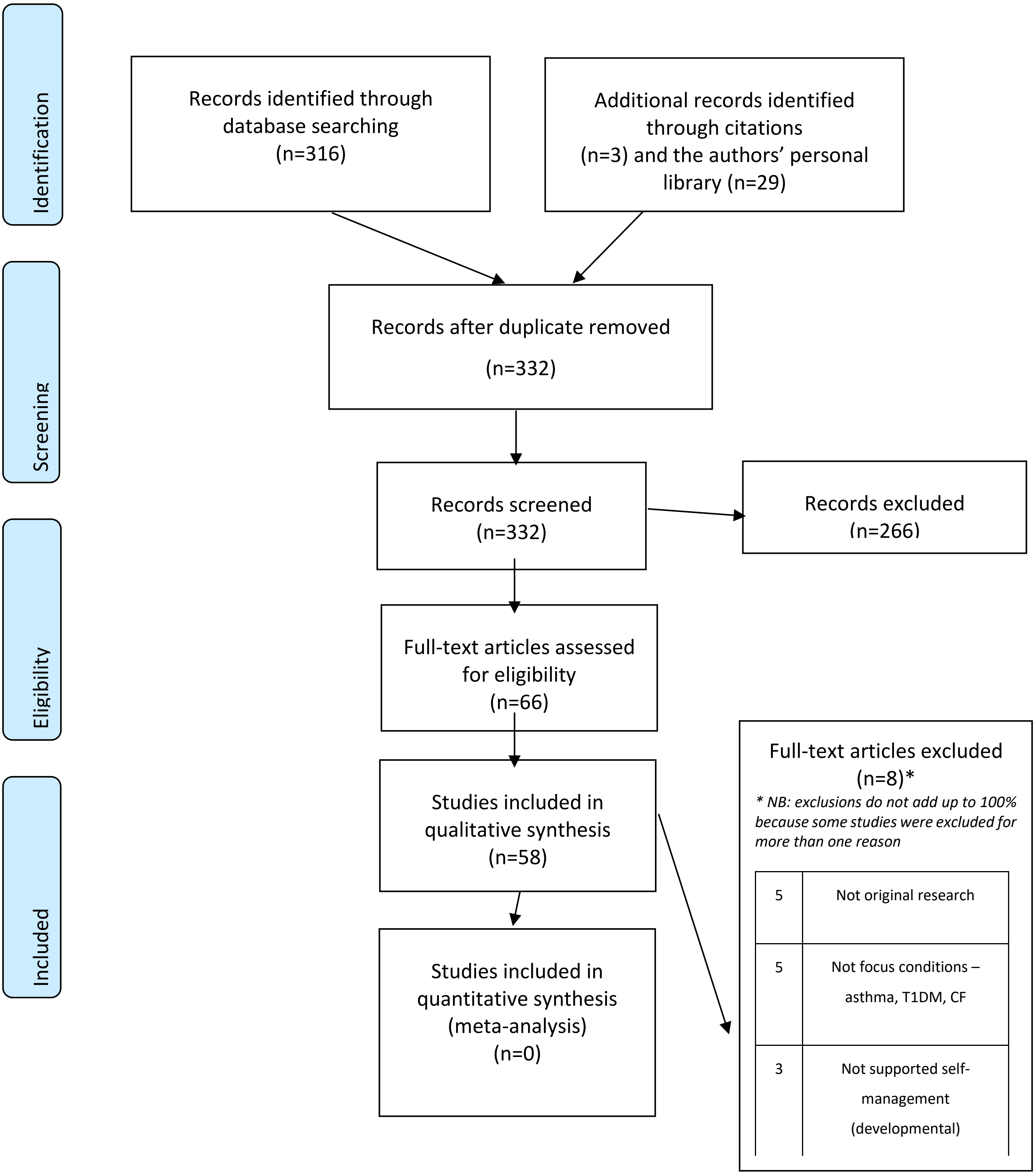


FIGURE 8 SEARCH TREE FOR STUDIES INCLUDED IN THE CONCEPT ANALYSIS ON SUPPORTED SELF-MANAGEMENT

PRISMA 2009 Flow Diagram



6.4.1.2. Definitions and surrogate terms

While the concept of supported self-management has been around in the literature since the early 1980s, until recently, it has not been referred to using this specific terminology. Early work on supported self-management used surrogate terms (synonyms) to describe the concept. The three most used surrogate terms were:

- *Self-care* (n=23) [250-267]
- *Self-management* (n=14) [250, 253, 268-278]
- *Disease/chronic condition/illness management* (n=9) [21, 22, 279-285]

The following terms have also been used to describe the concept of supported-self-management, albeit much less frequently: *disease/chronic condition management behaviours* [262, 286], *self-care independence* [259], *self-care autonomy* [287], *self-medication* [288], *self-responsibility* [289], *disease/chronic condition/illness related capabilities* [262], *life skills for managing disease/chronic condition/illness* [268]*, and self-management behaviours* [273]. Several of the studies included in this study did not use any specific terminology to describe the concept [290-292].

Very few studies cited a definition of the concept they were researching (n=5/58), and none of the definitions provided were shared across studies. This confirms the suitability of using the Saxby-Page Concept Development Technique. The specific term supported self-management was introduced into the paediatric literature in 2019 by Saxby et al. [9]. Via expert consensus, Saxby et al. defined *supported self-management* as:

> *'a process where children and young people develop a broad set of attitudes, behaviours, and skills to help them minimise the impacts of their condition on all aspects of life for themselves and their caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills.'* [10]

By incorporating the developmental trajectory for children and young people and by acknowledging the subsequent shifts in their ability to complete self-management tasks, the definition by Saxby 2020 et al. [9] extends previous definitions of the concept provided in the studies by Saucier 1984 [251], Schmidt 2003 [263], Martin 2010 et al. [271], and Kelo 2011 et al. [266].

6.4.2. The components of supported self-management

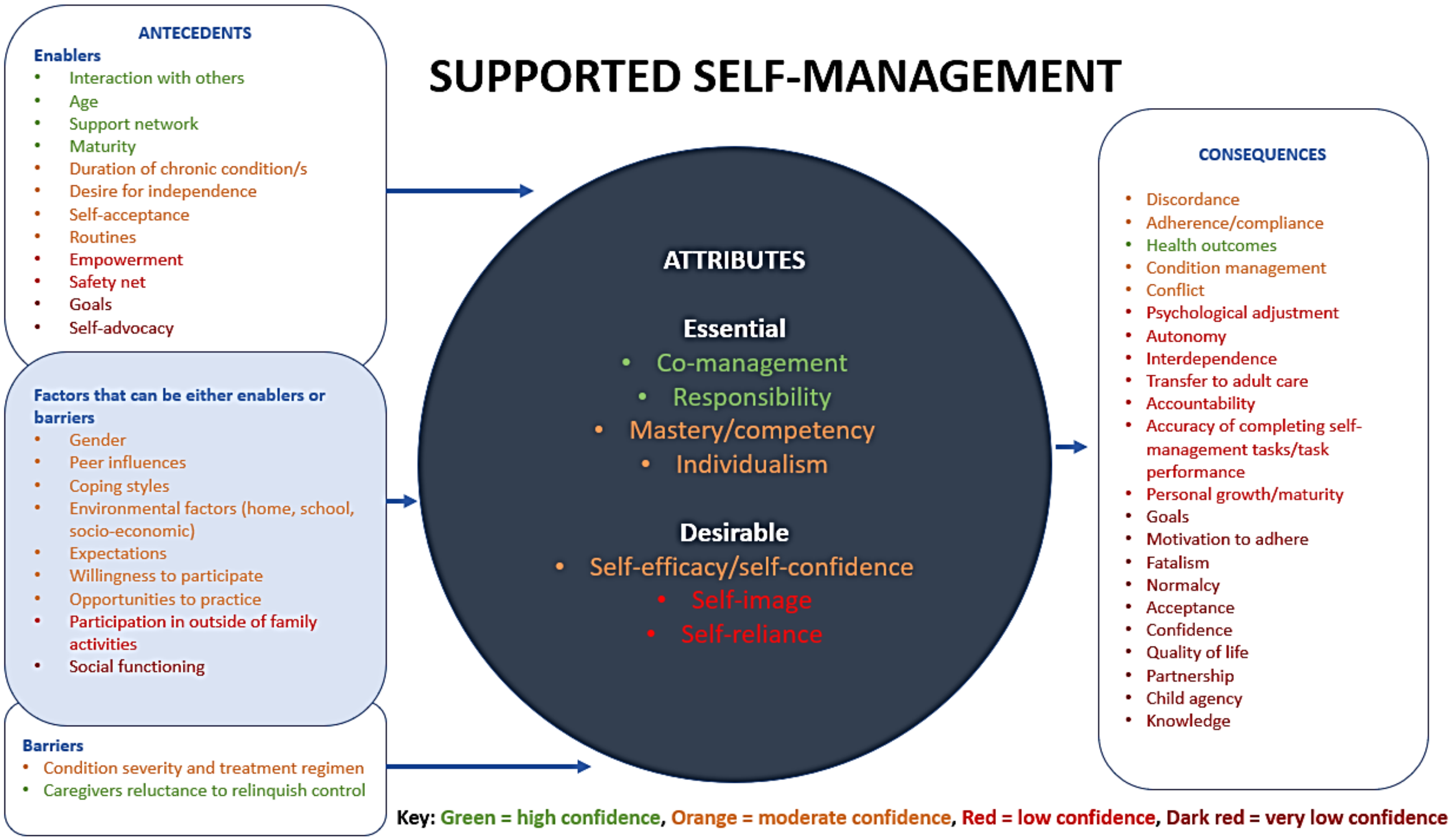
A diagrammatic representation of supported self-management in children and young people with chronic conditions is displayed in Figure 9. The outcome themes depicted within the diagram were informed by the extant literature and preceding analysis. In total, this concept analysis identified seven attributes, 23 antecedents, and 22 consequences of supported self-management. Colour coding has been used to represent the overarching CER-Qual assessment scores given for each outcome theme, based on the traffic light system commonly used in the field of nutrition. Green represents themes with the strongest evidence base and red/dark red represents themes with the least available evidence. For simplicity, the sub-themes (i.e. specific themes within the context of an identified outcome theme) are not presented in the diagram.

A discussion of each outcome theme and related sub-themes is presented below. Two summary spreadsheets were also used to collect and collate the evidence and CER-Qual assessments scores for each theme and sub-theme identified. For brevity of this thesis, these spreadsheets can be found in Appendix 1E (i.e. theming for each individual study) and Appendix 2E (i.e. CER-Qual evidence tables).

6.4.2.1. Attributes

This concept analysis acknowledges seven attributes of supported self-management. Of these, four were deemed essential attributes and the other three desirable attributes. Essential attributes are those characteristics that are always present within a concept. The essential attributes identified for supported self-management were *co-management, responsibility, mastery/competency* and *individualism.* Desirable attributes are those characteristics that are nice to have, but are not critical to the concept of interest. The three desirable attributes of supported self-management were identified related as: *self-efficacy/self-confidence, self-image,* and *self-reliance*.

FIGURE 9 DIAGRAMMATIC REPRESENTATION OF SUPPORTED SELF-MANAGEMENT



6.4.2.1.1. ESSENTIAL ATTRIBUTES

Co-management and *responsibility* are the essential attributes that are most likely to be representative of supported self-management.

- *Co-management* (n=44/58) (CER-Qual ratings: high confidence).
    - *Co-management* was a very common attribute [9, 250, 253-273, 276, 280-285, 288-290, 292-298]. This attribute relates to the child/young person and their caregivers managing chronic conditions jointly. There is clear delineation from family management (i.e. in infancy and early childhood) to supported self-management by the child/young person (i.e. in middle childhood, early adolescence, and older adolescence) to chronic condition self-management (i.e. at the point of transfer to adult healthcare services at approximately 18–20 years of age).
- *Responsibility* (n=44/58) (CER-Qual ratings: high confidence)
    - *Responsibility* was found to be an attribute as equally common as co-management. This attribute relates to the state of being accountable for the completion of self-management tasks [9, 250, 252, 253, 255, 257-275, 278, 281-285, 287-290, 292-295, 297-299]. Transfer of responsibility was found to be a shifting and shared process between the child/young person and their caregivers. Reasons for transferring of responsibility included responding to the child/young person's mastery/competence, promoting competency, increasing age, maturity in the child/young person, and minimising hassles and conflicts. It was also recognised in many studies that the child/young person taking over responsibility was not necessarily a consistent process and that some responsibilities may revert to the caregiver (e.g. especially during periods of adolescence or acute illness) [9, 255-257, 262, 267, 271-274, 280, 289, 294, 300, 301]. Clinicians need to be aware that during the younger and older adolescence developmental stages, transfer of responsibility for supported self-management tasks is not necessarily balanced by the young person assuming the required responsibility [263, 273]. Furthermore, responsibility for preventative management tasks was identified to be a specific area where caregiver supervision and support may be required for a longer period [252, 253, 274, 300, 301].

The next two attributes discussed, *mastery/competency* and *individualism*, were found to be moderately representative of the phenomenon of interest.

- *Mastery/competency* (n=33/58) (CER-Qual rating: moderate confidence)

- In order to take responsibility for self-management, the child/young person needs to have achieved *mastery/competency* (n=33) [9, 22, 250, 252-254, 257, 260, 262-266, 268-270, 274, 275, 278, 281, 282, 287-290, 293, 296, 298, 301, 302]. Mastery/competency relates to the child/young person developing comprehensive skill, ability or behaviour for a particular chronic condition self-management task. This perception differentiates supported self-management from simply being the handover of healthcare tasks from caregiver to the child/young person. Patterns for developing self-management mastery/competency were found to be generally orderly and predictable [9, 22, 253, 254, 262-264, 268, 270, 274, 275, 278, 281, 287, 290, 296, 301]. Tasks involving basic mechanical skills and rote learning were expected to be acquired at an earlier age. Complex tasks for which errors yield relatively certain aversive consequences (e.g. CF and not taking pancreatic enzymes, T1DM and missing insulin dosing) were also expected to be learnt earlier – specific cause and effect. Supported self-management tasks learnt later are those that relate to preventative strategies and skills and healthcare behaviours that involved judgement, decision making and/or the manipulation of the environment and emotions or involved complex problem solving, and self-regulation (e.g. T1DM and operating an insulin pump). There appear to be three specific areas for developing competency/mastery:
    - (1) Prevention (i.e. actions taken by the child/young person to avoid symptoms or prevent occurrences),
    - (2) Intervention (i.e. actions taken by the child/young person after the symptoms appear), and
    - (3) Compensatory behaviours (i.e. the actions the child/young person takes as part of adaption or adjustment to the condition; for example, dealing with peers)

- *Individualism* (n=14/58) (CER-Qual ratings: moderate confidence).
    - *Individualism* focuses on each child/young person as an individual self-management learner [9, 21, 253, 254, 263, 270, 271, 281, 282, 286, 288, 297, 298, 302]. Children and young people will develop supported self-management and healthcare behaviours at different rates [9, 21, 253, 254, 263, 270, 271, 281, 282, 286, 288, 297, 298, 302]. Average ages (and standard deviations) for achievement of self-

management task milestones were provided in some studies. In one study, it was suggested that the greatest variability in self-management capacity is during mid-adolescence [298].

6.4.2.1.2. DESIRABLE ATTRIBUTES

In comparison to the essential attributes described above, less confidence can be placed in the themes identified as desirable attributes (CER-Qual ratings: low or very low confidence). All three of the desirable attributes of supported self-management related to the child/young person's notion of self, namely in the areas of *self-efficacy/self-confidence* (n=10) [251, 256, 261, 265, 272, 274, 282, 284, 287, 294], *self-image* (n=4) [251, 256, 261, 275], and *self-reliance* (n=2) [274, 303]. Of clinical interest is the fact that children and young people with positive views of themselves were more likely to participate in developmentally appropriate supported self-management tasks [251, 256, 261, 265, 272, 274, 282, 284, 287, 294].

6.4.2.2. Antecedents

Antecedents are the events or attributes that arise prior to the occurrence of a concept [185]. In total, 23 antecedents to supported self-management were identified. Antecedents were further classified as being enabling factors (n=12), barrier factors (n=2) or factors that can serve as enablers for some children/young people and barriers for others (n=9).

6.4.2.2.1. ENABLERS

Four enabling antecedents were assessed as being highly representative of supported self-management; these were: *interaction with others*, *age*, *support network*, and *maturity.*

- *Interaction with others* (n=42/58) (CER-Qual ratings: high confidence)
    - Interaction with others was the most common enabling antecedent [9, 250, 252, 253, 255, 257-259, 261, 264-266, 268-275, 278, 280-282, 284-292, 294, 295, 297-299, 301]. This antecedent relates to the shifting responsibility and the amount of support needed from others to undertake self-management activities. The studies contributing to this theme indicate that, over time, there is a shift from family management to supported self-management, to autonomous self-management; however, this pattern is not clearly articulated based on developmental stage or age of the child/young person.
- *Age* (n=33/58) (CER-Qual ratings: high confidence)

    - *Age* was the next most common antecedent [9, 21, 22, 251, 254, 256-259, 262, 264, 266-268, 270, 271, 274, 278, 279, 281, 283, 285, 288, 290, 292, 294-298, 303]. Self-management skills and healthcare behaviours were found to generally increase with age, with children in the early childhood years (i.e. from 18 months to 6 years of age) being able to begin participating in self-management tasks with support [9, 254, 262, 270, 271, 281, 283, 288, 302].
- Maturity (n=15/58) (CER-Qual ratings: high confidence)
    - While related, *maturity* was identified as a separate construct to age [21, 255, 259, 263, 264, 266, 273, 275, 277, 282, 287-289, 294, 302]. Maturity refers to a child's/young person's ability to respond to a given environment in an appropriate way [30]. There are four types of maturity underpinning the development of self-management skills and healthcare behaviours:
        - (1) Physical (i.e. development of motor skills),
        - (2) Cognitive (i.e. progressive building of learning skills related to perception, memory, judgement and reasoning),
        - (3) Language and communication (i.e. all the ways that the child/young person understands and communicates), and
        - (4) Social and emotional (i.e. processes that optimise personal growth and socialisation).
- Support (n=19/58)
    - *Support* for self-management activities can be provided by a variety of different people. Apart from caregivers and wider family, a child's/young person's *support network* can also include teachers, peers, clinicians and members of the wider community [9, 21, 253, 255, 259, 266, 271, 274, 275, 280, 282, 283, 288, 289, 291, 293, 295, 298, 301].

The next four enabling antecedents (i.e. *duration of chronic condition*, *desire for independence*, *self-acceptance* and *routines*) were identified as being moderately representative of supported self-management.

- *Duration of chronic condition* (n=12/58) (CER-Qual ratings: moderate confidence)
    - Lived experience by virtue of extended exposure may be related to increased self-management skills and healthcare behaviours [21, 22, 257, 261, 263, 270, 272, 278, 281, 283, 287, 300].
- *Desire for independence* (n=8/58) (CER-Qual ratings: moderate confidence)

    - *Desire for independence* appears to be important at all developmental stages, with adolescents in particular being motivated by independence in managing their chronic conditions [21, 263, 266, 274, 285, 289, 293, 301]. It is, however, unknown if children's/young people's desire for independence is productive or counter-productive as they age.
- *Self-acceptance* (n=7/58) (CER-Qual ratings: moderate confidence)
    - The degree of *self-acceptance* children/young people have for managing their chronic conditions may impact upon supported self-management capacity, with those with higher self-acceptance being more likely to participate [21, 263, 266, 274, 285, 289, 293, 301].
- *Routines* (n=6/58) (CER-Qual ratings: moderate confidence)
    - There appears to be a need for supported self-management activities to be incorporated into daily life. *Routines* (n=6) may help children/young people and their caregivers complete daily supported self-management tasks [9, 250, 253, 270, 274]. This is particularly relevant to children in the early and middle years of childhood. In younger and older adolescence, influences outside of the family (including peer influences) play a larger role in structuring healthcare behaviour practices.

The remaining antecedents (i.e. *empowerment, safety net*, *goal*s and *self-advocacy)* had a limited and unclear evidence base. As a consequence, these themes were assigned low or very low CER-Qual confidence assessment ratings. *Empowerment* was identified as an enabler in three studies (n=3). Caregivers who empower children and young people to participate in self-management may be more likely to achieve positive outcomes [9, 255, 270]. By a similar mechanism, individuals who *self-advocate* (n=1) could also have a slight advantage [301]. The need for a *safety net* to project against possible adverse outcomes from children/young people taking on self-management skills was also occasionally raised (n=3) [274, 275, 280]. The final identified enabling antecedent was developing and prioritising goals (n=1) [301]. Discussing goal setting may be a way to actively engage children and young people in their care and learning what is important to them. However, the evidence base supporting this antecedent is very limited to one study completed with younger and older adolescents.

6.4.2.2.2. BARRIERS

The barriers for children/young people participating in developmentally appropriate supported self-management were *condition severity and treatment regimen* and *caregiver's reluctance to relinquish control.*

- *Condition severity and treatment regimen* (n=14/58) (CER-Qual rating: moderate confidence)
    - *Condition severity and treatment regimen* was the most prominent barrier identified. Treatment demands imposed by chronic conditions may influence children's/young people's ability to assume supported self-management responsibility; however, there were inconsistencies between study findings [253, 255, 269, 272, 279, 288, 290, 301]. Some studies suggested that the more severe a chronic condition, the more ability the child/young person has to participate in supported self-management (note: seems particularly relevant for asthma) [255, 272, 279]
- *Caregiver's reluctance to relinquish control* (n=9/58) (CER-Qual rating: high confidence).
    - While *caregiver's reluctance to relinquish control* was less frequently mentioned in the existing literature, the findings of the contributing studies were consistent. Caregivers can feel tension between giving their child/young person opportunities to complete supported self-management tasks' and the fear of negative health consequences [21, 253, 264-266, 269, 274, 278, 279, 285, 288, 290].

6.4.2.2.3. FACTORS THAT CAN EITHER BE ENABLERS OR BARRIERS

Several themes (n=9) served as enablers for some children/young people and barriers for others. Of these, seven themes were assessed as being moderately representative of supported self-management: *gender, peer influences, coping styles, environmental factors, expectations, willingness to participate,* and *opportunities to practice*. The evidence base supporting the remaining two potential themes (participation in outside family activities and social functioning) was unclear.

- *Gender* (n=13/58) (CER-Qual rating: moderate confidence)
    - Clinicians need to be aware that *gender* may influence a child's/young person's ability to complete supported self-management tasks [21, 22, 256, 257, 261-263, 267, 275, 285, 289, 294, 300]. Most of the studies contributing to this theme suggest that girls often display more capacity for supported self-management than boys, or that girls achieve mastery/competency at earlier ages [21, 22, 256, 257, 261-263, 267, 275, 294, 300]. Four studies, however, reported findings inconsistent with this sub-theme, reporting that there were either no significant differences between genders [256, 267, 285] or that females' capacity for supported self-management was worse than males [289].
- *Peer influences* (n=8/58) (CER-Qual rating: moderate confidence)
    - Children and young people with chronic conditions can find it embarrassing to be unlike their peers and to fit the demands of their chronic conditions into their daily

    lives. *Peer influences* were found to be relevant to all developmental groupings, but especially relevant to young people in younger and older adolescence [263, 266, 271, 272, 274, 283, 289, 304].
  - *Willingness to participate* (n=4/58) (CER-Qual ratings: moderate confidence)
    - Furthermore, peers can either have positive or negative impacts on children's/young people's *willingness to participate* in supported self-management tasks either with support from their caregivers or autonomously [263, 283, 289, 305].
- *Coping styles* (n=6/58) (CER-Qual ratings: moderate confidence)
  - The *coping styles* of children/young people and that of their caregivers was identified as being important in six studies [21, 257, 261, 266, 272, 274]. Several different coping styles were described, including protective, active problem solving and support seeking, responsive, use of humour, spiritual, withdrawn and avoidance. The types of coping styles seemed to be consistent across children and young people living with chronic conditions and their caregivers (although findings are primarily related to mothers rather than fathers). Like all behaviours, coping styles reflect the intrinsic and extrinsic influences relevant to the individual [21, 257, 261, 266, 272, 274]. Two studies also suggested that the coping styles of caregivers can be affected by severity of illness, with severity of illness being loosely associated with less positive coping styles [255, 272].
- *Environmental factors* (n=5/58) (CER-Qual ratings: moderate confidence)
  - *Environmental factors* influencing supported self-management were wide ranging and embraced home, school, and wider socio-economic influences [9, 255, 262, 268, 272]. It was not possible to isolate the effects of individual environmental factors as their effects were highly intertwined.
- *Expectations* (n=4/58) (CER-Qual ratings: moderate confidence)
  - *Expectations* of significant others may influence the self-management capacity of children and young people. The significance of this theme, however, remains unclear [260, 275, 281, 293]. Several studies suggested that caregivers and clinicians may have low expectations and unwillingly suppress children's and young people's motivation to start taking chronic condition self-management responsibility, which may foster resistance and reduce motivation [260, 281, 293].
- *Opportunities for practice* (n=4/58) (CER-Qual ratings: moderate confidence)

    - *Opportunities for practice* relates to the provision of specific opportunities to practice supported self-management skills, decision making and problem solving [9, 250, 253, 289]. Adults often have overarching influence on the amount of time that is available for a child/young person to practise skills and healthcare behaviours [9, 289]. Provision of limited opportunities to practise can impinge on the ability of a child/young person to participate in supported self-management [9, 289].

There was limited evidence for the remaining two antecedents (CER-Qual ratings: low or very low confidence). *Participation in outside family activities* (n=3) such as camps and hobbies can provide opportunities for children and young people to experience play, pleasure and social interaction with individuals of a similar age who are also living with chronic conditions [251, 262, 297]. Furthermore, children and young people with higher *social functioning* (n=1) abilities may be better adjusted to living with chronic conditions and thus, they may be more able to participate in supported self-management. However, the theme of social functioning only appeared in one study that was completed with children and young people with T1DM in the middle childhood and early adolescence stages [256].

6.4.2.3. Consequences

Consequences are the events that occur after children/young people participate in supported self-management and take a level of responsibility for their chronic conditions. These consequences can be both positive and negative. In total, 22 consequences were identified. Of these, the five most prominent consequences that are either moderately or highly representative of supported self-management are discussed here in detail: *discordance*, *adherence/compliance*, *health outcomes*, *condition management* and *conflict.*

- *Discordance* (n=19/58) (CER-Qual rating: moderate confidence)
    - Of particular interest to clinicians is the consequence of *discordance*, identified in 19 studies. This refers to differences in perceptions (potential of actual) between child/young person, caregivers, and/or health professional reports of chronic condition self-management skills and healthcare behaviours, and/or allocation in responsibility. While most studies included in this theme inferred differences between children/young people and their caregivers' perceptions [252, 254, 257, 260, 273, 280, 283, 290, 292, 294-298, 300, 301], two studies provided a contradictory observation that their views of these two groups were consistent and comparable to each other [21, 264]. Some studies also indicated that the perception of caregivers

    and clinicians could differ [260, 283]. A further complication is that perceptions between different health professional disciplines may also vary [254, 296]. In the 1990 study by Wysocki et al., clinicians (doctors, nurses, dietitians, psychologists, and social workers n=229) working with children with T1DM were surveyed about when they expected children/young people to be able to acquire supported self-management skills that were appropriate to their developmental stage [296]. The findings of this study suggest that doctors generally expect supported self-management skills to be mastered at later ages than nurses or allied healthcare do.

- *Adherence compliance* (n=14/58) (CER-Qual rating: moderate confidence)
    - While children's and young people's participation in supported self-management was recognised as being an essential element in the control of managing their chronic conditions, the consequence of this involvement on *adherence/compliance* to recommended treatments was much less clear [21, 252, 256-258, 266, 279, 284, 292, 298, 299, 301]. Some studies suggested that, although young people in the later developmental stages (i.e. younger and older adolescence) knew more about the management of their chronic conditions and assumed more responsibility, their adherence was lower than that of younger children[21, 256, 258, 279, 298]. Similarly, the study by Walders et al. (2000) found that higher levels of non-adherence were observed when caregivers overestimated the level of adolescents' involvement in supported self-management [252].
- *Health outcomes* (n=10/58) (CER-Qual rating: high confidence) and *condition management* (n=6/58) (CER-Qual rating: moderate confidence)
    - *Health outcomes* can potentially change because of children's and young people's participation (or not) in supported self-management. It was consistently reported across several studies that *health* outcomes [257, 258, 261, 265, 266, 273, 277, 294, 297, 299] and also *condition management* [252, 261, 266, 286, 292, 301] have the potential to worsen with increasing age.
- *Conflict* (n=6/58) (CER-Qual rating: moderate confidence)
    - *Conflict* between children/young people and their caregivers is a potential risk for supported self-management [21, 262, 270, 274, 282, 298]. Five of the studies contributing to this theme suggested that conflicts are more likely to happen when children/young people become more autonomous with managing their chronic conditions [21, 270, 274, 282, 298]. Diet management/modification can be a particular source of caregiver–child/young person conflict (as dietary-related

supported self-management aspects involve the family unit to a greater extent than other supported self-management tasks) [21, 262, 298]. The consequential theme of conflict is likely to be related to the previously discussed theme of discordance.

For more information on the 17 remaining consequences of supported self-management (Figure 9), please see Appendix 2E.

6.4.2.4. Related concepts that may be confused with supported self-management

Through the completion of this concept analysis study, 30 related concepts that can be confused with supported self-management were identified – with the three most common of these being: *adherence/compliance*, *responsibility* and *self-care*. All these terms involve the degree to which the treatment regimen is enacted and, although related, they are separate constructs:

- *Adherence/compliance* (n=17) is the degree to which a person's and/or their family's healthcare behaviour matches the treatment recommendations provided by clinicians [250, 252, 255-258, 261, 279, 287, 295].
- *Responsibility* (n=7) refers to taking accountability for supported self-management tasks and healthcare behaviours. In paediatric care, responsibility for self-management tasks is shared between children/young people and their caregivers [21, 251, 252, 269, 272, 295].
- *Self-care* (n=4) is any task a person (and/or their caregivers) takes towards their physical and emotional wellbeing. Self-care activities are done in isolation from health care services [276, 287-289].

Other related terms were: *concordance* [255, 300], *mastery/competency* [256, 260, 303], autonomy [254, 287, 290], *independence* [270], *self-reliance* [261, 274], *self-regulation/regulation* [277, 297], *self-determination* [293], self-concept [251], *compensatory behaviours* [250], prevention [306], *supervision* [288], *life skills* [307], *non-adherence* [295], *family-based management* [280], *child-directed care* [270], *reasoning* [279], *problem solving* [22, 277, 278], *transfer* [270], *decision making* [270, 298], *decision sharing* [272], *letting go* [270], *division of labour* [298], *obligations* [308], *health enhancing and compensatory behaviours* [265, 286], *resourcefulness* [253] and *supervising* [253]. For succinctness, these related terms have not been discussed here in detail.

6.5. Discussion

From a theoretical perspective, the concept of supported self-management was found to be a layered, multidimensional, all-inclusive, dynamic, complex and nuanced process with many characteristics that must be tailored to meet each child's/young person's unique and constantly changing needs. Over the last three and half decades, however, the concept of supported self-management appears to have been applied in the literature to various degrees of precision, as indicated by the highly varied CER-Qual confidence assessment scores assigned to each outcome theme/sub-theme. Some ambiguities associated with the concept of supported self-management of chronic conditions in children and young people have been addressed through the completion of this study.

Four essential attributes particularly illustrative of the concept were identified, namely: *co-management, responsibility*, *mastery/competency* and *individualism*. *Interactions with others*, *age*, *condition severity and treatment regimen*, and *maturity* were found to be most important antecedents of the concept. A range of consequences (positive and negative) of supported self-management were also identified including *discordance*, *adherence/compliance*, *health outcomes*, *condition management*, and *conflict*.

This concept analysis found that it is important to involve the child/young person in self-management of their condition/s from early childhood and to continue their involvement throughout the entire developmental trajectory. While children and young people are expected to follow a predictive and developmentally related (related to both increasing age and maturity) trajectory of supported self-management skill development and mastery, it was also clear that they will develop these healthcare skills and behaviours at different rates from each other.

Supported self-management skills and healthcare behaviours involving basic mechanical skills and rote learning are expected to be acquired at an earlier age. Complex tasks for which errors yield relatively adverse consequences are also expected to be learnt earlier (specific cause and effect). Skills that are learnt later were found to be those related to preventative strategies and skills that involved judgement, decision making and/or the manipulation of the environment and emotions, or ones that involved complex problem solving, and self-acceptance.

The developmental stages of younger and older adolescence were found to be particularly challenging. Young people in the adolescent years are particularly influenced by their desire for independence and peer acceptance. Adherence and condition management may worsen with increasing age. Where possible, and when infection control guidelines permit, opportunities should be provided for young people to interact with others who have the same or similar chronic conditions. If face-to-face socialising is not possible or is limited, then mobilisation of social network communities is a viable option (e.g. Facebook groups).

Another underpinning theme of the concept of supported self-management was the requirement that children/young people, caregivers and clinicians work together in triadic partnerships. An important way that clinicians can promote triadic partnerships is to inform caregivers of the predictable developmentally related trajectory of self-management skill development and mastery. Furthermore, clinicians should not assume that within a family unit the child/young person and their caregivers communicate about the sharing of self-management responsibilities or about the changes in expectations that each may develop over time.

Importantly, the majority of outcome themes/sub-themes identified (i.e. attributes, antecedents and consequences) within this study align with existing research completed by internationally regarded expert groups [23, 24, 98, 132-134, 266, 309]. Consistency with the existing literature serves to further enhance the evidence base for supported self-management.

6.5.1. Critical analysis of how the Saxby-Page Concept Development Technique performed

This study used the Saxby–Page Concept Development Technique (Chapter 5) which provided the structure to be able to methodologically elucidate abstract themes. This new method combines components from existing concept analysis methodology with systematic review processes, qualitative synthesis approaches, and a confidence assessment measure. Because a new method was used, a critique of how the method performed is provided here. Critiquing how the method performed helps to determine if the research findings are usable [147].

The choice of method fitted well with the purpose of the study which was to clarify the concept of supported self-management behind the terminology within an interdisciplinary context. Because the studies that met the inclusion criteria were highly varied and included research conducted by a variety of health disciplines in a multiple of different settings, the overall findings are more likely represent a holistic comprehension and be of practical relevance. Prior to undertaking the actual concept analysis, a detailed study protocol was written up (paper in preparation for publication). The presence of a protocol provided a solid structure to follow that can be easily replicated. The protocol also ensured that there was a clear PICoS clinical practice question to guide the concept analysis.

Something very different about the method was that clinicians (of various disciplines) were responsible for completing the actual analysis (N. Saxby's clinical background is in dietetics and S. Lawn's clinical background is in social work). It is unusual for clinicians to be directly involved in concept analysis processes. As I believe that theory guided practice, in the form of practice theory generated through methods such as concept analysis, it makes sense to have clinicians directly undertaking concept analysis themselves. Clinicians are the closest to the patients and they are also the people that need to be able to communicate a shared understanding of a concept within their interdisciplinary teams [26, 121]. Research has continually shown that clinicians learn by actively practicing a new skill, with learning enhanced when they are required to teach/share their new knowledge among their colleagues [26, 121, 207].

A particular strength of the method was the inclusion of the highly recognised and regarded CER-Qual confidence assessments [245]. These assessments provided a measure of confidence in how representative a theme/ sub-theme was within an interdisciplinary context. The use of a simple colour coding system further helped to clearly present the strength findings to the readers.

One area where the method did not perform so well was with the search strategy. Many papers were missed using the search strategy described (32 additional studies were only identified through the review of reference lists of included studies and/or from using my own personal library). This is not a particularly surprising as prior to completing the analysis the research steering group had noted an inconsistency in terminology used to describe supported self-management (i.e. use of surrogate terms to describe the same thing). The search strategy was based on surrogate terms already known to the research steering group – i.e. *supported self-management, self-management, self-care, self-responsibility, responsibility, mastery, disease/chronic condition* management, compliance and *adherence*. During the process of completing the study many additional surrogate terms were identified including *disease/chronic condition management behaviours* [262, 286], *self-care independence* [259], *self-care autonomy* [287], *self-medication* [288], *disease/chronic condition/illness related capabilities* [262], life *skills for managing disease/chronic condition/illness* [268], and *self-management behaviours.* If this study was to be repeated in future years these additional surrogate terms would also be included in the search strategy.

Another limitation is that, at this stage, the application of the Saxby–Page concept development technique is limited to just one area (i.e. supported self-managing). Further development and evaluation of the method is required. A plan to further develop the method is presented in Section 9.4.1.

6.5.2. Other strengths and limitations

A factor that serves as both a strength and limitation is that this concept analysis study was that three focus conditions (i.e. asthma, CF and T1DM) were chosen as examples of paediatric chronic conditions. Exploring themes associated with supported self-management across multiple chronic conditions with different complexities will likely have made the research findings more broadly applicable, which substantially increases potential for clinical usability. It cannot be assumed, however, that the concept can be applied consistently across all paediatric groups. Mental health, developmental disability, and culturally linguistically diverse populations could benefit from specific studies in the area of supported self-management. A detailed discussion as to the appropriateness of using the findings of this study (and other studies completed as part of this PhD research program) for conditions other than asthma, CF and T1DM is provided in Section 9.7.

The fact that this study was that analysis was conducted on secondary data that was not specifically designed to reflect a longitudinal and developmental trajectory of how children and young people participate in supported self-management over time is a further limitation. Nevertheless, the use of pooled secondary data can be a powerful research tool in areas such as this, where there is little research available.

6.6. Synopsis

This concept analysis study enabled the identification of theoretical patterns underlying children's and young people's capacity to self-manage their healthcare needs as they develop and mature. Supported self-management was found to be a multidimensional, layered, all-inclusive, dynamic, complex and nuanced process.

It is hoped that the findings of this study will help pave the way to a better theoretical understanding of the role children and young people have in managing their own chronic conditions, thus expanding interdisciplinary clinical knowledge and providing a solid basis for future research.

In the next chapter (Chapter 8), I present a second literature review that identifies the components of effective supported self-management educational interventions and teaching approaches for children and young people, relevant to their developmental status.

6.6.1. Summary of contributions to the literature

- Prior to this study being completed, no conceptual studies appear to have been done on the topic of supported self-management for children and young people over the developmental trajectory from infancy through to older adolescence.
- This study identified the underlying theoretical patterns of supported self-management for children and young people with chronic conditions.

7. A systematic review of supported self-management education interventions for children with asthma, cystic fibrosis and diabetes

'Education begins the moment we see children as innately wise and capable beings. Only then can we play along in their world.' ***~Author unknown***

This chapter explores self-management educational interventions. In the context of supporting children to become autonomous self-managers, it is crucial that the most effective, and developmentally appropriate self-management education interventions and teaching approaches are employed.

Highlighted in this chapter:

- Why self-management education interventions for children and young people should include developmentally appropriate educational content
- How this systematic review builds on my previous work looking at clinical guidelines promoting developmentally appropriate self-management support
- Identification of developmentally appropriate theory, teaching approaches and components

Chapter 7 directly relates to the following publication:

Supplementary data and other information related to this chapter can be found in Appendix F

- N. Saxby, S. Beggs, M. Battersby, S. Lawn, What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A Systematic review, Patient Educ. Couns. 102 (2019) 606–622.

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Review article

What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review

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ABSTRACT

Objective: To articulate the components of educational interventions that help children learn about managing their asthma, cystic fibrosis, or diabetes, relevant to their age/developmental status.
Methods: A systematic review of chronic condition self-management (CCSM) educational interventions that included age/developmentally appropriate components, published before 27 January 2018, including evidence level and quality assessments. Teaching approaches were extracted and translated into practical components.
Results: Twenty education interventions were identified, published across 30 studies. Most studies (n = 20/30) were based on the theories of Piaget and Bandura. Similar teaching approaches were used across conditions, incorporating sequenced curriculum and a variety of active elements. Age/developmentally appropriate interventions resulted in improvements in the CCSM capabilities of children. Outcomes were improved when compared with usual care.
For very young children, educational interventions were directed at parents/families. As children reached school age, interventions increasingly became child-focused, promoting autonomy. Integrated play and reinforcement were common. Adolescent interventions placed greater emphasis on communication, problem-solving, and role division.
Conclusion: Eight key components were identified: structured and sequenced curricula; reinforcement; active participation; collaboration; autonomy; feedback; multiple exposures; and, problem-solving. Different components are relevant to specific life stages.
Practice implications: Clinicians require age/developmentally appropriate practical education tools to provide effective paediatric health care.

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Contents

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7.1. Background

Children's learning of self-management strategies related to the prevention and management of their chronic conditions is associated with many positive outcomes. More specifically, childhood supported self-management educational interventions have resulted in improvements in health outcomes, knowledge, quality of life, attendance at school, participation in social activities and a decrease in health service interactions [310, 311]. Self-management educational interventions aim to empower children to be involved in their health care through the provision of information, teaching of skills and techniques and reinforcing positive behaviours over time [25].

In their 2003 landmark article, Lorig and Holman [25] suggested that the effectiveness of supported self-management educational interventions is maximised when they are designed to assist children and their caregivers in setting goals, solving problems and planning for positive health behaviours. Others have stated that educational interventions should be motivational, equipping the family unit (i.e. the child, their caregivers and siblings) with the knowledge, skills and confidence they need to manage the daily demands imposed by chronic conditions [310]. Despite the inclusion of these components, some interventions have failed to achieve their potential [312]. Clark et al. (2010)

advocate for the use of developmentally appropriate program educational content and tasks; a view that is supported by older systematic reviews and meta-analyses, which show that asthma self-management educational interventions are most effective when they are guided by evidence-based strategies and a cognitively appropriate theoretical framework [311, 313].

To the best of my knowledge, presented in this chapter is the first ever systematic review to look at self-management educational interventions that are tailored to the developmental needs of children with the focus conditions.

7.2. Study design and aims

7.2.1. Aims

The aim of this study was to articulate the components of effective educational interventions that help children learn about managing their asthma, cystic fibrosis (CF) or type 1 diabetes mellitus (T1DM), relevant to their age developmental status.

7.2.2. Study design

7.2.2.1. Supported self-management educational interventions

This is the second systematic review presented in this thesis.

7.2.3. How this systematic review builds on my previous guideline work

Previously in this thesis (Chapter 4) I presented a systematic review at looked at whether Australian and international clinical guidelines encouraged developmentally appropriate self-management education for children with the focus conditions [8]. Almost all guidelines promoted the delivery of developmentally appropriate education to transfer knowledge, skills and health care behaviours necessary for children and young people to look after their own healthcare needs. In these guidelines, only six studies were quoted as evidence for this type of approach [135, 186-190]. It is likely that there are many more studies out there that provide further evidence. This second systematic review study presented here in Chapter 7 seeks to identify all evidence sources to date for a developmentally appropriate approach to self-management education.

7.3. Methods

The protocol for this review follows guideline recommendations as set out in the PRISMA statement for systematic reviews and meta-analyses [206]. Due to a large amount of heterogeneity between self-management educational interventions, a meta-analysis could not be performed.

7.3.1. Data sources and search strategy

Studies were identified through an extensive search of medical databases: EBSCO (Medline, CINAHL, Biomedical Reference Collection, Nursing and Allied Health Collection, Psychological and Behavioural Sciences Collection, PsychInfo, SocINDEX), Elsevier (Embase) and Informit (Health sub-database). Search terms used were based on the National Library of Medical subject headings (i.e. MeSH terms https://meshb.nlm.nih.gov/search) with Boolean operators used as indicated in Box 2. To ensure that no studies of relevance were missed, the search strategy was supplemented with a review of citations listed for all included studies. Only studies published in English were eligible for inclusion.

Box 2 SEARCH STRATEGY FOR ALL DATABASES

((‘asthma’, OR ‘diabetes mellitus, type 1’, OR ‘diabetes’ OR ‘cystic fibrosis’ OR ‘CF’ OR ‘respiratory condition’ OR ‘chronic condition’ OR ‘long term’) AND (‘child*/exp’, OR ‘adoles*/exp’, OR ‘youth’, OR ‘infant’, OR OR ‘young people’, OR ‘child health care’) AND (‘self-care’, OR ‘self-management’ OR ‘self-management support’ OR ‘health education’ OR ‘patient education’ OR ‘coping/behaviour’ OR ‘behaviour modification’ OR ‘coping behaviour’ OR ‘management’, ‘self-care’, OR ‘self-responsibility’, OR ‘responsibility’, OR ‘mastery’, OR ‘decision making’, ‘[disease/illness/chronic condition] management’, OR ‘compliance’ OR ‘adherence’.))

7.3.1.1. Study selection

Studies were included if they were published before 27 January 2018 and if they focused on children and adolescents (aged ≤20 years) with asthma, T1DM or CF as active participants in the supported self-management education strategy. Studies were excluded if they focused on adults or other childhood conditions or if they did not contain developmentally based supported self-management education components. A two-stage screening process was used to confirm studies that met the inclusion criteria – in stage one, studies were screened for relevance through title and abstracts and duplicates were removed. Stage two excluded studies that did not consider developmental aspects of supported self-management’ education. Furthermore, because developing effective skills and healthcare behaviours to manage their own health was the endpoint of this review, to be eligible, studies were required to report outcomes related to children’s: supported self-management skills and healthcare behaviours; knowledge; cooperation and communication; sharing in decision making; monitoring and responding to symptoms; managing the impact of the condition; confidence in managing their condition (self-efficacy); and quality of life.

The types of studies included in this review were not restricted; thus, a variety of different study designs ranging from randomised controlled trials to pre-/post-cohort studies were included. Descriptive studies were also included if they contained detail about the intervention educational strategy used and if subsequent follow-up studies using the same education strategy provided outcome measurement data.

7.3.2. Data extraction

For studies meeting the inclusion criteria, the following data was extracted by myself and confirmed by a second person (S. Lawn): detail about the interventional education strategy, including duration, mode of delivery and other support mechanisms; information about underlying developmental theories or age-based considerations, including teaching approaches; whether there was a manual/sufficient detail to reproduce the educational strategy; the study setting; target age group/s; interventionist/s; training provided to the interventionist/s; and relevant outcome data.

All information extracted was tabulated in a standardised evidence table (presented later in Table 14 on page 155). Data extraction was not blinded to study author/s, year of publication or journal.

7.3.2.1. Developmentally appropriate theory, teaching approaches and components

There are many well-known theories of childhood development, including those proposed by Piaget, Erikson, Kohlberg, Bandura, Vygotsky, Kagen, Ausubel and Gilligan [103]. Each included study (full text) was reviewed for any mention of developmental theory or age appropriate teaching approaches or components that could be attributed to a distinct philosophy. As required, study authors were contacted to provide additional information about the developmental aspects and teaching approaches they included in their supported self-management educational interventions. Teaching approaches used were subsequently classified into seven groups:

- *Directive learning* – i.e. involves the use of a structured evidence-based curriculum to teach skills and knowledge to children
- *Active and experiential learning* – i.e. acknowledges that learners come with many useful and relevant experiences; provides authentic hands-on learning experiences
- *Differential learning* – i.e. activities address a range of learning styles, abilities and readiness; values differences between children
- *Interactive play* – i.e. uses tools such as games, art-based activities, puppets and competitive exercises to motivate children to learn better

- *Integrated learning* – i.e. learning brings together content and skills from more than one subject area
- *Enquiry-based learning* – i.e. learning is directed by questions, problems or challenges that children work to address
- *Cooperative and peer learning* – i.e. promotes learning with and from other children; group and cooperative learning strategies are a priority; provides opportunities for children to show their knowledge and skills) [314]

7.3.2.2. Setting

Settings for supported self-management education delivery were classified into three categories: school, community (incorporating primary and secondary health care) and hospital (incorporating tertiary health care).

7.3.2.3. Facilitators

Facilitators were broadly classified into four groups: clinicians, teachers, lay people and social scientists. Where available, additional details about the facilitators were provided. For example, health professionals may be listed by discipline (e.g. doctors, nurses, credentialed educators, physiotherapists and dietitians).

7.3.3. Assessment of study design and quality

The strength of each study design was ranked by two reviewers (N. Saxby and S. Lawn) according to the Australia NHMRC levels of evidence shown in Table 12, next page [158]. Both reviewers also assessed the quality of studies using a modified version of the Academy of Nutrition and Dietetics (formally known as the American Dietetic Association) quality assessment checklist for primary research as shown in Table 13 below (i.e. positive, neutral or negative quality). Modifications included questions directly related to dietetic practice being expanded to cover a variety of health disciplines (see Appendix 1F for a completed quality assessment example) [315]. When the reviewers did not agree on study design or quality rankings for individual studies, an internal discussion took place until an agreement was reached.

TABLE 12 NHMRC LEVELS OF EVIDENCE FOR INTERVENTION STUDIES

Level of evidence	Intervention Study
Level I	Evidence obtained from a systematic review of all relevant randomised controlled trials
Level II	Evidence obtained from at least one properly designed randomised controlled trial
Level III-1	Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method)
Level III-2	Evidence obtained from comparative studies with concurrent control and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group
Level III-3	Evidence obtained from comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel group
Level IV	Evidence obtained from case studies, either post-test or pre- and post-test.

SOURCE: NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL **[158]**

TABLE 13 ASSESSING PRIMARY RESEARCH QUALITY USING ACADEMY OF NUTRITION AND DIETETICS QUALITY ASSESSMENT CHECKLIST

Quality	Definition of Quality for Primary Research
Positive	If most of the answers to the above validity questions are yes (including criteria 2,3,6, 7 and at least one additional yes), the report should be designated with a plus symbol (+)
Neutral	If the answers to validity criteria questions 2,3,6, and 7 do not indicate that the study is exceptionally strong, the report should be designated with a neutral symbol (Ø)
Negative	If most (six or more) of the answers to the above validity questions are no, the review should be designated with a minus symbol (-)

Source: Academy of Nutrition and Dietetics [315]

7.3.4. Selection of key findings

Eight key educational components are presented in the discussion section: *structured and sequenced curricula*, *reinforcement*, *active participation*, *collaboration, autonomy*, *feedback*, *multiple exposures* and *problem solving*. Component selection was based on the frequency in which the educational components were used in the included studies, as well as, whether the components were evidence-based in educational settings.

7.4. Results

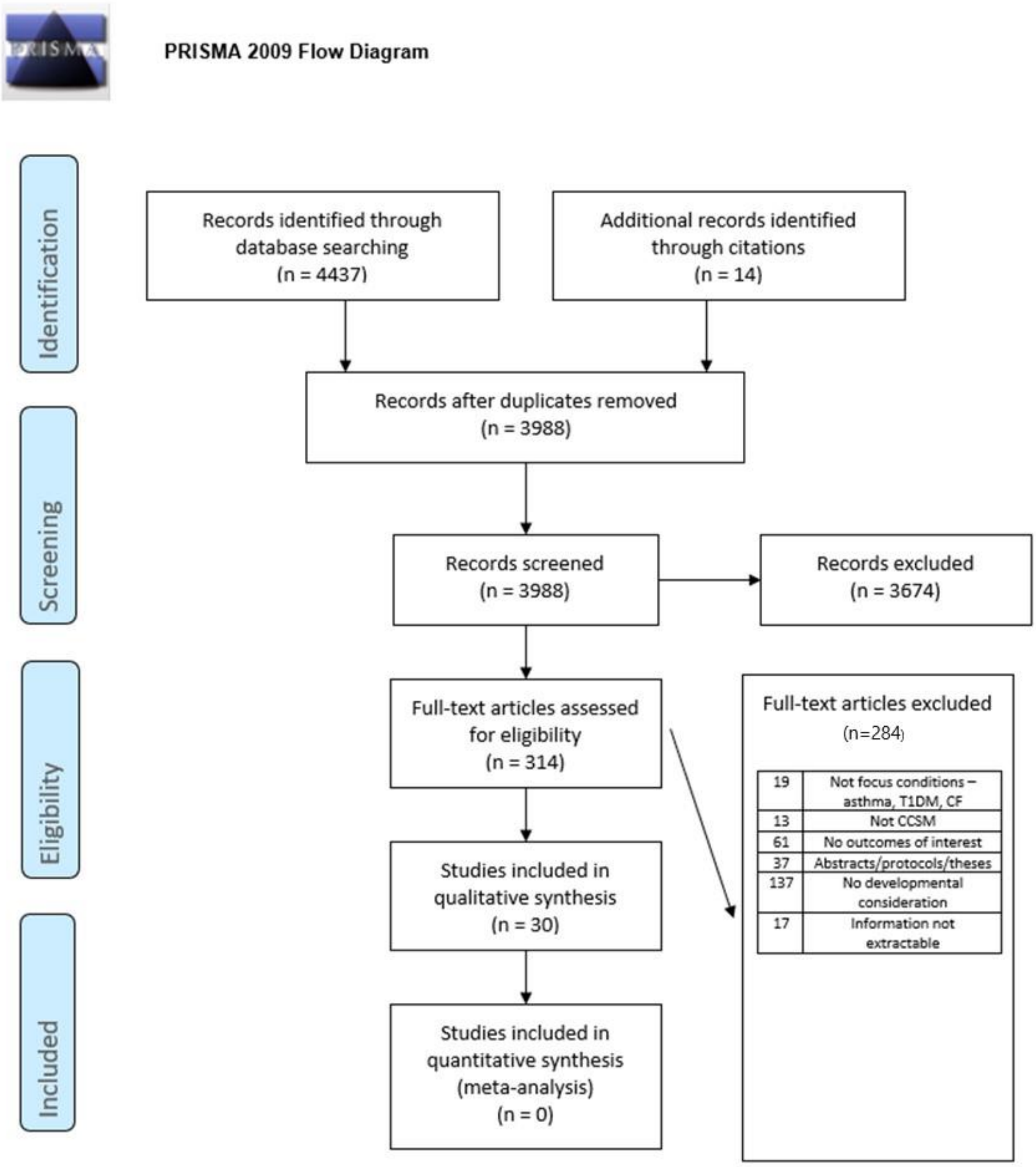
7.4.1. Search results

The search strategy yielded 4451 potential abstracts (including 14 studies identified through citations), from which 314 studies were retrieved for full-text review. Further screening excluded 283 studies for a variety of reasons. Overall, the search identified 20 developmentally appropriate supported self-management educational strategies for 4406 children with asthma, T1DM or CF across 30 studies. Two studies used the same population group, which accounted for 167 shared participants [316, 317].

Figure 10 on the next page shows the search tree, including the reasons why studies were excluded.

A conservative screening approach ensured that the maximum numbers of studies were included, as it was often difficult to identify educational components that were based on developmental theories or age appropriate teaching approaches. The three most difficult challenges encountered by the authors extracting data were the multicomponent nature of each educational intervention, individual education components not being articulated and limited information provided about the developmental theories on which the educational interventions were based.

FIGURE 10 SEARCH TREE FOR DEVELOPMENTALLY APPROPRIATE CHRONIC CONDITION SELF-MANAGEMENT EDUCATION INTERVENTIONS



7.4.2. General characteristics

The 30 included studies were heterogeneous. Studies varied in population size (range 15–491 participants), focus condition (asthma n=27, T1DM n=2 and CF n=1) and targeted age groups (infancy n=1 study, early childhood n=3 studies, school-aged children n= 24 studies, younger adolescents n=6 studies, older adolescents n=5 studies and adolescents of unspecified ages n=1 study). Several studies were designed to target more than one age grouping [80, 126, 129, 130, 318, 319]. Furthermore, in regards to the country of origin, there was a disproportionally high number of studies conducted in the USA n=20/30 [123-126, 128, 129, 133, 136, 187, 306, 307, 319-326].

Most studies were conducted in schools (n=19/30), with only a small number of studies taking place in hospitals (n=8/30) [80, 136, 306, 307, 318, 319, 327, 328] and community settings (n=4/30) [124, 133, 135, 324]. Interventionists tended to be health professionals (n=23/30) and teachers (n=4/30). Prior training about the education interventions was provided to interventionists in 54% of cases.

The summary characteristics of included educational interventions can be seen in Table 14, on the next page.

TABLE 14 SUMMARY CHARACTERISTICS DEVELOPMENTALLY APPROPRIATE SELF-MANAGEMENT EDUCATIONAL INTERVENTIONS

Intervention, Country	Study type, NHRMC ranking and quality (participants)	Underling developmental theories	Intervention description	Manual/detail to reproduce	Setting	Age group	Interventionist	Training provided	Relevant outcomes
ASTHMA									
'Asthma education program' USA	Parcel et al. 1980 [123] Cross over cohort study III–3Ø (n=104)	Unspecified	• Child- and family-centred • 24x 40-minute sessions for children o Children/young people and caregivers come together at the end of each session • Small groups (unspecified) • Developmentally appropriate tool/s: o Children's book *Teaching my parents about asthma* and concept related stories • Teaching approaches o Directive learning o Active and experiential learning o Interactive play (stories) o Enquiry-based learning	YES	School	Middle childhood	Teachers and health professionals (psychologist, nurses)	NO	1980 (Parcel et al.) Following the 24-week program compared to controls: • ↑ knowledge of younger† and older school children† • ↑ children's perception of having more control over their asthma† • A trend towards ↓ in children's anxiety levels but NS
'Asthma Care Training – For Kids' USA	Lewis et al. 1984 [124] RCTII- (n=76)	Bandura	• Child- and family-centred • 5 x 60-minute sessions for children and caregivers o Children and caregivers s taught in separate groups for first 45 minutes of each session o Children and caregivers come together at the end of each session • Small groups (4–7 children) • Teaching approaches o Directive learning o Active and experiential learning o Interactive play (games) o Enquiry-based learning o Cooperative and peer learning	YES	Community	Middle childhood	Teachers, and health professionals (asthma educators, nurses, doctors)	NO	1984 (Lewis et al.) At 12 months compared to controls (non-developmentally appropriate lectures): • ↑ compliance with self-management tasks (children's self-report)* • ↓ impact of asthma symptoms (caregiver report)* • ↑ communication between children and their caregivers* At 12 months for both intervention and control groups: • ↑ children's positive beliefs about self-management and asthma†

‘Open Airways for Schools’ USA	Evans et al. 1987 [125] RCT II+ (n=239) Horner 1998 [320] Pre-post IV+ (n=15) Spencer et al. 2000 [326] Pre-post IV- (n=364) Evans et.al 2001 [187] RCT IIØ (n=239) Bruzzese et al. 2001 [128] Pre-post IVØ (n=54) Clark et al. 2004 [323] RCT IIØ (n=291)	Piaget and Bandura	• Child-centred • 6 x 40-minute group sessions for children • Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Integrated play (stories, games) ○ Cooperative and peer learning	YES	School	Middle childhood	Social scientists and health professionals (unspecified)	YES	1987 (Evans et al.) At 12 months compared to controls (usual care): • ↑ children’s self-management skills† • ↑ children’s self-efficacy† • ↑ children’s influence on parental decision making† • ↑ children’s number of actions taken by children in managing their asthma† 1998 (Horner) Following 6-week program intervention group (pre-post): • ↑ children’s knowledge† 2000 (Spencer et al.) Following 6-week program intervention group (pre-post): • ↓ children’s symptoms of asthma‡ 2001 (Evans et al.) At 12 months compared to controls (usual care): • ↑ caregivers self-management skills† • ↑ communication between children and caregivers re: self-management†, which was associated strongly with parental CCSM skills 2001 (Bruzzese et al.) At 12 months compared to controls (usual care): • Children's/young people’s communication was positively associated with parental self-management behaviours† 2004 (Clark et al. 2004) At 24 months (pre-post) intervention group:

									• ↑ children's/young people's self-management skills† At 24 months compared to controls (usual care): • ↓ children's/young people's symptoms of asthma‡
'Modified Open Airways for Schools' USA	Bowen 2013 [321] RCTII- (n=32)	Piaget and Bandura	As above for Open Airways for Schools, with the following changes: • Program content synthesised into 3 x 60-minute sessions	NO	School	Middle childhood	Unspecified	Unspecified	2012 (Bowen) Following 3-week program compared to controls (usual care): • ↑ children's/young people asthma knowledge† • A trend towards higher QOL but NS

'Huff and Puff'
USA
	Detwiler et al. 1994 [324]
	Pre-post IV+
	(n=148)
		Piaget and Bandura	• Child- and family-centred
			• 3 x 90-minute group sessions for children/young people and caregivers
			• 2 x 120-minute group sessions for caregivers
			• Teaching approaches
			  ○ Directive learning
			  ○ Active and experiential learning
			  ○ Integrated play (games, children's imagination, sensory involvement)
			  ○ Cooperative and peer learning
				YES	Community	Early and middle childhood	Health professionals (nurses, doctors)	YES	1994 (Detwiler et al.)
									At 12 months (pre-post) intervention group:
									• ↑ children's asthma knowledge‡
									• ↑ children's self-management ability in 4/5 items‡ (stop and rest, breathe slowly, relax, drink fluids)
									• ↑ children's confidence to manage their asthma‡

'The Roaring Adventures of Puff'
Canada
	McGhan et al. 1998 [329]
	Descriptive paper
	Cicutto et al. 2005 [188]
	RCT IIØ
	(n=256)
	McGhan et al. 2010 [316]
	RCT II+
	(n=176)
		Bandura	• Child-, family- and teacher-centred
			• 6 x 60-minute group sessions for children
			• 1 x parent and teacher asthma awareness event
			• Teaching approaches
			  ○ Directive learning
			  ○ Active and experiential learning
			  ○ Interactive play (games, model building)
				YES	School	Middle childhood	Health professionals (nurses, physios, healthcare students)	YES	1998 (McGhan et al.) – no outcome data
									2005 (Cicutto et al.)
									At 2 months compared to controls (usual care):
									• ↑ children's/young peoples self-management skills†
									• ↑ children's/young peoples self-efficacy†
									• ↑ QOL†

	Mandhane et al. 2010 [317] RCT II+ (n=287)		○ Cooperative and peer learning						2010 (McGhan et al.) At 6 months compared to controls (usual care): • ↑ caregiver's knowledge† • ↑ children's/young people's self-efficacy† • ↑ QOL† 2010 (Mandane et al.) No significant results • trends to improvement in QOL and parent assessment of child's symptoms
'Young Children Managing Asthma' & 'What's That Noise' Australia	Holzheimer et al. 1998 [135] RCT IIØ (n=80)	Piaget and Bandura	• Child-centred • Developmentally appropriate tool/s ○ Videotape 4 minutes long 'Young children managing asthma' ○ Picture book *What's that noise*? • Teaching approaches ○ Interactive play (stories) ○ Enquiry-based learning	N/A	Community	Early childhood	Health professionals (unspecified)	NO	1998 (Holzhimer et al.) At 3 months compared to controls (usual care): • asthma video and asthma book ↑ children's knowledge about condition‡ • asthma video only ↑ children's knowledge about condition† • asthma book only ↑ children's knowledge of condition†
'Wee Wheezers' USA	Wilson et al. 1996 [136] RCT IIØ (n=76)	Bandura	• Family-centred • 4 x 120-minute group for caregivers • Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Cooperative and peer learning	YES	Hospital (outpatient clinics)	Infancy, early childhood	Health professionals (nurses)	NO	1996 (Wilson et al.) At 1 month compared to controls (usual care): • Reduction in child health morbidity†
'Asthma Self-Management for Adolescents Program (ASMA)'	Bruzzese et al. 2004 [126] RCT IIØ (feasibility) (n=45)	Bandura	• Adolescent-centred • 5- to 8-week group sessions PLUS individual coaching sessions for adolescents • Teaching approaches	NO	School	Younger and older adolescents	Health professionals (psychologist)	NO	2004 (Bruzzese et al.) Following completion of 8-week program (pre-post):

USA	Bruzzese et al. 2011 [127] RCT II+ (n=345)		○ Directive learning ○ Active and experiential learning ○ Enquiry-based learning ○ Cooperative and peer learning						• ↑ understanding for the young person of the chronic nature of asthma (86%) • ↑ knowledge for the young person of asthma medications and controlling symptoms (100%) • ↑ knowledge for the young person of medication side effects and triggers (100%) No control data reported 2011 (Bruzzese et al.) At 6 months relative to controls (usual care): • ↑ young person self-efficacy‡ • ↑ self-management behaviours taking more steps to prevent symptoms at 6 months† • ↑ use of a written action plan‡ At 12 months relative to controls (usual care): • ↑ young person self-efficacy† • ↑ use of a written action plan‡
'It's a Family Affair Program' USA	Bruzzese et al. 2008 [129] RCT IIØ (n=24)	Bandura	• Child- and family-centred • 6 x 75-minute adolescent group self-management education sessions • 5 x 90-minute parental group sessions ○ Parental sessions focused on child rearing skills to support children's growing autonomy • Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Cooperative and peer learning	NO	School	Adolescents (unspecified)	Health professionals (psychologist)	NO	2008 (Bruzzese et al.) At 2 months compared to controls (usual care): • ↑ adolescents knowledge of asthma† • ↑ self-management beliefs (self-efficacy)† • ↑ positive self-management attitudes and behaviours†

‘Asthma 411 Initiative’
 	
USA
	Pike et al. 2011 [325]
	Clinical trial III–2-
	(n=236)
		Grade appropriate school curriculum	• Child-centred
			• 15 standard school lessons
			• Teaching approaches
			  o Integrated learning – asthma concepts included in 3 primary education subjects
			    ▪ Maths
			    ▪ Science
			    ▪ Communication arts
				NO	School	Middle childhood	Teachers	YES	2011 (Pike et al.)
									At the completion of program (pre-post) intervention group:
									• ↑ knowledge - individual‡, combined students‡
									
									Intervention vs. comparator group = differences were NS

‘Coping with Asthma at Home and at School’
 	
The Kingdom of the Netherlands
	Colland 1993 [328]
	RCT IIIØ
	(n=195)
		Bandura and Piaget	• Child-centred
			• 10 x 60-minute group sessions
			  o Combination of self-management training, cognitive behaviour therapy and developmentally based education
			  o Caregiver’s invited for short periods each session
			• Developmentally appropriate tool/s
			  o Games designed to match developmental level of concrete operational thinking (asthma quarter, asthma quiz, asthma floor puzzle)
			• Teaching approaches
			  o Directive learning
			  o Active and experiential learning
			  o Interactive play
			  o Cooperative and peer learning
				YES	Hospital (outpatient clinics)	Middle childhood	Health professionals (unspecified)	NO	1993 (Colland et al.)
									At 6 months and 12 months follow-up compared to placebo and control groups:
									• ↑ children’s self-management coping skills‡
									• ↑ children’s self-management knowledge‡

‘Let’s talk about asthma’
 	
USA
	Mammen et al. 2018 [133]
	Pre-post IV+
	(n=42)
		Grade appropriate school curriculum	• Adolescent-centred
			• 12-hour program, 4 sessions (delivered over 2 to 3 days)
			• Teaching approaches
			  o Directive learning
			  o Active and experiential learning
			  o Integrated learning
			  o Enquiry-based learning
			  o Cooperative and peer learning
				YES	Community	Older adolescents	Health professionals (unspecified)	NO	2018 (Mammen et al.)
									Following 4 sessions (pre-post) intervention group:
									• ↑ young person self-efficacy†
									• ↑ young person self-maangement knowledge and problem solving skills‡
									Most significant effects were seen in:

									the awareness of long-term consequences of uncontrolled asthma, ability to recognise symptoms, correctly monitor symptoms and identify if asthma was uncontrolled

'Rural Children with Asthma – Interactive Educational Intervention'
USA
	Butz et al. 2005 [322]
	II RCT+
	(n=221)
		Unspecified	- Child-centred
			- 2 x 120-minute sessions for children PLUS
			- 1 parental education workshop
			- Teaching approaches
			  ○ Direct learning
			  ○ Active and experiential learning
			  ○ Interactive play
			  ○ Enquiry-based learning
			  ○ Cooperative and peer learning
				N/A	School	Middle childhood	Health professionals (asthma educator)	NO	2005 (Butz et al.)
									At 10 months or a full school year compared to controls (usual care):
									- ↑ knowledge –caregiver's‡, children/young people‡
									- ↑ child self-efficacy† (NS caregivers)
									- No significant differences seen in QOL measures

'Asthma Visual Mapping' Iran	Bozorgrad et al. 2013 [327] III-1- (n=80)	Unspecified	Self-management education to use asthma inhaler devices via the visual concept mapping (i.e., use of diagrams which are understandable to children without them needing the ability to read or write) - Use of pictures showing how to use spray 3 to 7 links - Prepared in 2 versions (boys and girls) Teaching approaches - Integrated learning	N/A	Hospital (outpatient)	Middle childhood	Unspecified	NO	2013 (Bozorgrad et al.) Immediately post-program relative to controls: - ↑ QOL† In the intervention group before and after the program: - ↑ activity‡ - ↑ symptom awareness‡ - ↑ emotional management‡

'Modular Education Program for Chronically Ill Children and Their Families (ModuS)'
- This intervention
	Ernst 2016 [80]
	Descriptive study
	Ernst 2017 [318]
	Clinical trial III–1+
	(n=491)
		Unspecified	- Child- and family-centred
			- 30x 45-minute sessions
			  ○ Separate curricular and didactic approach for children and caregivers
			  ○ 6 joint sessions for caregivers and children,
			  ○ 12 age appropriate sessions for children
			  ○ 12 sessions for caregivers
				YES	Hospital	Middle childhood, younger adolescents, older adolescents	Health professionals (paediatricia, psychologist plus other disciplines as required)	YES	2016 (Ernst 2016)
									N/A
									2017 (Ernst 2017)
									Assessed in children and young people with asthma at 6 weeks both in the modular and conventional care programs delivered:
									- ↑ knowledge of caregivers

can be altered to suit a variety of chronic conditions Germany			• Separate groups for different age groups o 6 to 12 years, o 13 to 17 years • Small groups (4–8 caregivers) • Teaching approaches o Directive learning o Active and experiential learning o Differential learning o Cooperative and peer learning						• ↑ QOL of children/young people • ↑ life satisfaction • ↓ disease burden of caregivers When intervention group outcomes at 6 weeks were compared to controls, only children's reported asthma knowledge was significantly different.
'Children with Chronic Illnesses' • Asthma and epilepsy intervention Argentina	Tieffenberg et al. 2000 [186] RCT IIØ (n=188)	Piaget and Bandura	• Child- and family-centred • 5 x 120-minute sessions • Family reinforcement sessions at 2 and 6 months post-intervention • Teaching approaches o Directive learning o Active and experiential learning o Interactive play o Cooperative and peer learning	YES	School	Middle childhood, younger and older adolescents	Teachers	YES	2000 (Tieffenberg et al.) Asthma results only – At 6 months compared to controls (usual care): • ↑ knowledge† • ↑beliefs (self-efficacy) † • ↑ positive attitudes and behaviours †
CYSTIC FIBROSIS									
'Building life skills with cystic fibrosis' USA	Christian et al. 2006 [307] RCT IIØ (n=116)	Bandura and Piaget	• Child-centred • Individual home-based session (assessing children's current knowledge and how they manage in home environment) PLUS • Group program • Teaching approaches o Differential learning (content individualised to each child's experience of CF using their own life experiences)	YES	Hospital	Middle childhood	Health professionals (unspecified)	YES	2006 (Christian et al.) At 9 months compared to controls (usual care): • ↓perceived impact ‡ • ↓perceived loneliness ‡
DIABETES									
'In Control' USA	McNabb et al. 1994 [306] RCT IIØ (n=24)	Bandura	• Child-and family-centred • 6 group education sessions o Separate children and caregiver groups o caregivers also taught parenting skills • Teaching approaches	NO	Hospital	Middle childhood	Health professionals (unspecified)	YES	1994 (McNabb et al.) At 3 months compared to controls (usual care), children: • ↑ responsibility (insulin)† • ↑ response to symptoms† • ↑ maintaining records‡

			○ Directive learning ○ Active and experiential learning ○ Cooperative and peer learning						• ↑ communicating with others †
'Care Ambassador and family-based psychoeducation' USA	Katz 2014 [319] RCT IIIØ (n=153)	Unspecified	• Child- and family-centred • Family-focused teamwork intervention (split into two age groups 8 to 12 years, 13+ years) • 30-minute session with child and their parent//guardian on the day of their quarterly clinic visit • Teaching approaches ○ Active and experiential learning ○ Enquiry-based learning ○ Cooperative and peer learning	No	Hospital	Middle childhood, young adolescents	Lay people	YES	2014 (Katz) There were no significant differences at 12 months in self-managemen tskills and behaviours, QOL or family conflict At 2 years, compared to the control group, the intervention group: • Greater parental involvement in self-management†

RCT= Randomised controlled trial. QOL = Quality of life.

Denotes study quality: + = high quality, Ø = neutral and - = low quality. Denotes significance †p ≤ 0.05 and ‡ p ≤ 0.01, * clinical p ≥ 0.05, NS= not significant. Denotes: ↑ increase, ↓decrease.

7.4.3. Developmentally appropriate theory, teaching approaches and educational components

A total of 21 out of the 30 studies specifically mentioned the developmental theories that were incorporated into their educational interventions for asthma, T1DM and CF. Of these, Bandura's social learning and cognitive theories were routinely used either alone n=9 [124, 126, 129, 136, 188, 306, 316, 317, 329] or in combination with Piaget's cognitive constructivist theory n=12 [125, 128, 135, 186, 187, 307, 320, 321, 323, 324, 326, 328]. Influences from other theorists, including those of Ausubel and Vygotsky, are also apparent across the included studies.

Study authors used a range of teaching approaches and, thus educational components:

- *Directive learning* (n=26/30 studies)
    - Directive learning was incorporated into supported self-management educational interventions for asthma [80, 123-126, 128-130, 133, 136, 186-188, 316-318, 320-324, 327, 329, 330] and T1DM [306] through the use of structured and sequential learning curricula.
- *Reinforcement methods* (n=26/30 studies)
    - Reinforcement methods were used in almost all educational interventions), except for five studies [155, 282, 299, 309, 311]. Methods included: homework activities, teach-back methodology, written support material, repeated demonstrations, child demonstrations of skills learned to caregivers, child and caregiver debriefing at the end sessions and take home supported self-management action plans.
- *Active and experiential learning* (n=25/30 studies)
    - Active and experiential learning was incorporated in interventions for asthma [80, 320] and T1DM [306]. Educational components included hands-on participation, skill training, observation, symptom monitoring and role modelling through children/adolescents asking health professionals questions directly and by providing opportunities for children to practise newly learnt supported self-management skills and behaviours, and to get feedback. Multiple exposures to supported self-management skills training were also evident in 10 studies [77, 125, 126, 128, 136, 186, 318, 323, 326].

- ***Cooperative and peer learning*** (n=21/30 studies)
    - Cooperative and peer learning were incorporated in interventions for asthma [77, 124-126, 129, 130, 133, 136, 172, 186, 187, 318, 321-324, 326] and T1DM [306, 319]. Educational components included teamwork activities, group processing, communication strategies, case-based learning and sharing of personal experiences and perceptions.
- *Interactive play* (n=19/30 studies)
    - Interactive play activities were included in asthma [123-125, 128, 187, 188, 269, 270, 316, 317, 321-324, 326, 328, 329] and T1DM [319] educational interventions. Play techniques were primarily used with school-aged children through the use of games, stories, videos, model building and role-playing. Two studies also used role-playing in adolescent age groups [186, 319], and one study used play methods in children in the early childhood years [324].
- *Enquiry-based learning* (n=8/30 studies)
    - Enquiry-based learning was incorporated through practical demonstrations, problem solving and decision-making activities in asthma [126, 130, 133] and T1DM [319] interventions.
- *Differential learning* (n=3/30 studies)
    - Differential learning was used in two asthma [80, 318] and one CF [307] educational intervention/s. All the interventions that used this particular teaching approach were targeted at adolescents (younger and older). Individualisation was made possible through the use of supported self-management assessments and one-on-one sessions where individual problems and challenges could be discussed.
- ***Integrated learning*** (n=3/30 studies)
    - Integrated learning was only used in asthma interventions. In two studies, asthma concepts were integrated into standard school curricula that were taught to all children in the class [133, 325]. In another study, how to use asthma inhalers was integrated into visual diagrams [327].

7.4.4. Developmental considerations

Table 15 on the next page shows the individual education components broken down by developmental stage and specific methods used.

For infants and very young children, educational interventions were directed at caregivers [136, 324]. As children reached school age, the interventions increasingly became child-focused and promoted children's autonomy [124, 125, 128, 135, 186, 306, 307, 316, 317, 319, 321-324, 326, 328, 329]. Integrated play and reinforcement were common for children of school age [123-125, 128, 186-188, 316, 317, 319-324, 326, 328, 329]. Adolescent interventions placed greater emphasis on communication, problem solving and role division [80, 126, 129, 130 133, 318, 319].

TABLE 15 EDUCATIONAL COMPONENTS BROKEN DOWN BY DEVELOPMENTAL STAGE AND SPECIFIC METHODS USED

Educational component	Developmental stage	Skill/ method/ topic	Selected practice example
1. Structured and sequenced curriculum (directive learning) [80, 123-126, 128-130, 133, 136, 186-188, 306, 316-318, 320-324, 327, 329, 330] n=26/30 studies	Infancy	Parent-focused curricula covering all aspects of self-management, plus stress management.	Detail of an individual curriculum was too long to include in this table – see Ernst et al. [80] p.1154 for an excellent example
	Early childhood	Parent-focused curricula covering all aspects of self-management, plus stress management, young children from ages 4 years up included in some sessions.	
	Middle childhood	Curricula were generally targeted at increasing children's basic knowledge of their chronic condition and coping strategies. Topics covered: • basic information about the chronic condition and children's feelings • recognising and responding to symptoms • treatments and when to seek help • living a healthy lifestyle (e.g. being physically active, eating well, hand-hygiene) • handling problems related to the chronic condition at school	
	Younger adolescence	Adolescent curricula were aimed at increasing self-management autonomy and independence. Topics are similar to those covered in the middle childhood age grouping, with increased emphasis placed on problem solving, decision making, and coping with negative impacts of having a chronic condition.	

	Older adolescence	As per information listed for younger adolescence, with additional importance placed on reaching independence prior to transition to adult healthcare services.	

2.	Reinforcement methods [80, 123-126, 128-130, 133, 135, 187, 188, 306, 316-318, 320-324, 327-329] n=26/30 studies	Infancy	-	Middle childhood example: Colland et al. [328] used reward systems as a way of motivating children towards positive health behaviours. Individuals or small groups were able to "earn rewards". Each time a child completed their self-management homework activities then he/she was able to colour in a line on a big poster (sowing a giant thermometer), on which 100 lines were drawn. Lines were also able to be coloured in when group work was completed to a satisfactory level. When 25 lines had been coloured in, then the entire group received a reward, in the form of a small game. Younger and older adolescence example: In the 2008 intervention by Bruzzese et al. [129], homework activities were given to both the adolescent and caregiver groups. Adolescent homework activities focused on self-management skills to build self-efficacy, and caregiver homework activities focused on childrearing and positive support approaches. Homework activities were structured to allow caregivers and children/adolescents to interact in positive ways, and to practice relevant skills together.
		Early childhood	Take home self-management action plans (for caregivers)	
		Middle childhood	Homework activities for children and caregivers, written support material for caregivers, children's demonstrations of skills learned, debriefing for both children and caregivers at the end of education sessions, take home self-management action plans (for caregivers), earning of reward, promotion of /internal incentives, goal setting for children	
		Younger and older adolescence	Homework activities for adolescents and caregivers, teach-back methodology, take home self-management action plans, and summaries of education sessions (for adolescents), earning of rewards, promotion of internal incentives, goal setting for adolescence	

3.	Active participation (active and experiential learning) [80, 320] n=25/30 studies	Infancy	No direct engagement of children	Early and middle childhood example: Detwiler et al. [324] used puppets to actively engage children in self-management. The use of puppets draws on children's imaginations. Children were asked to identify with the puppet "Huff", who ignores early symptoms, forgets what to do to manage his asthma, and wheezes. Children observe the negative consequences of what happens to Huff because of his poor self-management behaviours. But, the children are also given a positive role model to observe called "Puff" who is very good at managing his asthma. After learning about asthma management through the use of these puppets, children then get the opportunity to practice their newly learnt self-management skills.
		Early childhood	Skills training, hands on participation, use of stories and characters to teach skills (books/videos), observation, modelling (puppets, actors, cartoons), opportunities to practice self-management skills	
		Middle childhood	Skill training, hands on participation, case- based learning, observation, role playing, children's demonstration of skills learned at the end of each education session, interactive game playing to practice decision making, use of stories to initiate discussions around the chronic condition, arts based activities and model building, behaviour modelling (caregivers, facilitators, book characters, puppets), goal setting. Interventions involving active participation for children in the middle years of childhood tended to have a particular focus on preventing, identifying and controlling symptoms.	
		Younger and older adolescence	Skill training, hands on participation, modelling (facilitators), case-based learning, home visits to identify triggers (asthma), role playing, goal setting	

4.	Collaboration [80, 124-126, 129, 130, 133, 136, 172, 186, 187, 306, 318-324, 326, 328] n=21/30 studies	Infancy	-	Middle childhood example: The 1987 study by Evans et al. [125] promoted child to caregiver communication. This intervention (i.e. the "Open Airways for Schools" program) was provided directly to children; caregivers did not attend. Children's autonomy and independent actions as self-managers were encouraged, with children being given the responsibility to recognise and respond to their own symptoms (whether or not their caregiver was present). The program also encouraged children to provide information to their caregivers to help caregivers make informed asthma management decisions.
		Early childhood	-	
		Middle childhood	Collaboration between children, their caregivers, and clinicians are encouraged, communication strategies promoted, children given opportunities to directly ask health professionals questions, caregivers encouraged to support and supervise children's self-management activities, teamwork activities, group processing, sharing of perceptions and experiences, peer group learning	
		Younger and older adolescence	Collaboration between adolescents, their caregivers, and clinicians are encouraged, communication strategies promoted, teamwork activities, group processing, increased focus on peer group learning and sharing of experiences	

5.	Autonomy n=20/30 studies	Infancy	Infants are completely dependent on adult caregivers for all self-management activities	**Younger and older adolescence example:** The intervention described by Bruzzese et al. [129] strongly promotes adolescent self-management autonomy. Autonomy is promoted using two complementary but separate strategies: • Adolescent sessions focused on prevention and management of asthma – behavioural based program; • Parental sessions focused on child rearing skills to support the adolescent's growing autonomy. Co-joint sessions were not offered, as the focus was on increasing the autonomy of adolescent participants.
		Early childhood	Young children are completely dependent on adults for self-management activities; however, some education interventions encouraged children's involvement in simple self-management tasks (e.g. using an asthma puffer).	
		Middle childhood	Interventions become child centred in this age group. Most interventions acknowledged that children could begin to be autonomous for some self-management activities. Some interventions specifically mentioned that children and caregivers should be treated as equals and partners in the self-management learning and caring process.	
		Younger and older adolescence	Strong encouragement of adolescents to be autonomous in their own self-management, where possible. Caregivers encouraged to take on an advocacy and support role (separate caregiver only training provided to teach this role). The need for negotiation and clear self role delineation between adolescents and caregivers was mentioned in some interventions.	

6.	Feedback [125-127, 129, 136, 186-188, 316, 317, 320, 323, 324, 326, 329] n=16/30 studies	Infancy	-	Older adolescence example: Mammen et al. [133] integrate feedback mechanisms into their intervention. After self-management activities were modelled by facilitators (e.g. inhaler techniques, use of peak flow meters and spaces, decision making during asthma attaches), adolescents practiced self-management skills with feedback being provided on the spot until fluency was attained.
		Early childhood	Encouragement given when good self-management behaviours or knowledge are demonstrated (positive approach), timely feedback	
		Middle childhood	Symptom diary interpretation, encouragement given when good self-management behaviours or knowledge are demonstrated (positive approach), timely feedback	
		Younger and older adolescence	Opportunities to practice self-management skills and get feedback during education sessions, caregiver praise, timely feedback	

7.	Multiple exposures [77, 125, 126, 128, 136, 186, 318, 323, 326] n=10/30 studies	Infancy	-	Middle childhood example: The papers by Ernst et al. [80] and Ernst et al. [318] describe the MoDuS program (Modulares Schulungsprogramm). This program exposes children to self-management related information and skills multiple times to help them internalise the information. Multiple exposures were coupled with giving children adequate time to practice doing the self-management skills they had learned to do. In this program, feedback was also given during practice rehearsals to ensure that children retained the correct information. The MoDuS program is a generic self-management program that can be used across a variety of conditions due to similarities in the need to monitor symptoms and manage treatments.
		Early childhood	-	
		Middle childhood	Repeated demonstrations and multiple opportunities to practice newly learnt self management skills	
		Younger and older adolescence	Repeated demonstrations and multiple opportunities to practice newly learnt self-management skills	
8.	Problem solving [123, 124, 126, 130, 133, 135, 319, 322] n=8/30 studies	Infancy	-	Middle childhood example Lewis et al. [124] put children in the "driver's seat", emphasising that asthmatic children could take control of their condition (this represents a simple paradigm). An analogy was drawn between maintaining health and safely driving a car. Obeying traffic light signals was a key message, i.e. green for go, yellow for caution, and red for stop. Children controlled their asthma by using the colour system: • Green coloured medications indicated keep going and prevent symptoms • As mild symptoms develop, it is time for children to slow down and take a more cautious approach using medications coloured yellow • If/when severe symptoms occur it is time to take red medications to stop the asthma episode
		Early childhood	-	
		Middle childhood	Use of simple paradigms to communicate messages, colour coding of key concepts, practical demonstrations, collaborative discussions between children/young people and caregivers	
		Younger and older adolescence	Practical demonstrations, collaborative discussions, individualisation where possible (e.g. their use of self-management assessments and one-on-one sessions where individual problems and challenges can be discussed)	

7.4.5. Study design and quality rankings

Randomised controlled trials accounted for the largest subgroup of literature published in this area (n=20/30 studies, 67%) [124-126, 128-130, 135, 136, 186, 187, 306, 307, 316, 317, 319, 321-323, 328, 329]. Other study designs used were clinical trials (not randomised) [80, 123, 325] and pre- and post-tests [128, 133, 324, 326], and these represented lower levels of evidence. This review also included two descriptive papers [80, 329] that were followed up with outcome data in subsequent studies.

The quality rankings of the included studies were mostly positive (n=10/30 studies, 33%) and neutral (n=14/30 studies, 47%). There was good agreement between the two reviewers in regards to study design and quality rankings. Quality rankings of three studies [186, 317, 329] differed between the reviewers; however, a consensus was easily reached through discussion, and quality rankings for these three studies were later confirmed as being positive. There were no differences between the reviewers in the rankings of study designs.

7.4.6. Outcomes reported in the included studies

Outcome measures used in studies were highly variable and not comparable. Furthermore, the length of follow-up (on completion of intervention to 24 months post-intervention) and the proportion of participants with complete follow-up (range=50–100%) were mixed.

7.4.6.1. Intervention versus usual care

When the outcomes from education interventions with developmental considerations were compared to usual care, significant improvements arising from the former were seen across multiple domains (Table 16).

TABLE 16 SELF-MANAGEMENT OUTCOMES FOR EDUCATIONAL INTERVENTIONS WITH DEVELOPMENTAL CONSIDERATIONS COMPARED TO USUAL CARE.

Children's and young people's	Number of studies reporting significant improvements when compared to usual care	Associated references
Self-management skills, abilities and behaviours	11	[124, 125, 129, 130, 186, 188, 306, 327, 328]
Knowledge	10	[123, 129, 133, 135, 186, 316, 318, 321, 324, 325] [328]
Cooperation/communication	5	[124, 125, 187, 306, 319]
Sharing in decision making	3	[125, 187, 306]
Monitoring and responding to symptoms	5	[124, 130, 136, 306, 323]
Managing the impact of the condition	4	[123, 124, 307, 328]
Self-efficacy	8	[125, 129, 133, 186, 188, 316, 322]
Quality of life	2	[188, 322]

7.4.6.2. No comparison

Positive outcomes in children's supported self-management skills, healthcare behaviours, knowledge, confidence and ability to manage their chronic conditions were also reported in the four observational pre-post studies [280, 307, 311, 316] and in the one randomised control trial which did not report any control data [292].

7.5. Discussion

This review synthesised data from 20 unique educational interventions with developmental considerations, published across 30 studies. Educational interventions were grounded in psychology, with most interventions being derived from the developmental theories of Bandura (social learning and cognitive theories) and Piaget (cognitive constructivist theory). Influences from other theorists, including Ausubel and Vygotsky, were also apparent across studies. Teaching approaches used included: directive learning, active and experiential learning, cooperative and peer learning, integrated play, enquiry-based learning, differential learning and integrated learning. Unfortunately, all of the reviewed interventions included multiple teaching approaches. Thus, it was not possible to attribute causality or effectiveness to any particular educational component. Nevertheless, identification of educational components was still achievable.

Positive study outcomes indicate that the children who took part in supported self-management educational interventions that were tailored to be developmentally/age appropriate were more apt to deal with everyday life. In the case of asthma, T1DM and CF, children and adolescents who participated in these tailored interventions knew more about their condition and what they could do themselves to minimise the effects their condition had on them, as demonstrated by significant improvements in knowledge [123, 129, 133, 135, 186, 316, 318, 321, 324, 325, 328], supported self-management skills and healthcare behaviours [124, 125, 129, 130, 186, 188, 306, 327, 328], and symptom monitoring and control [124, 130, 136, 306, 323] when compared to children receiving usual care in the included randomised controlled trials studies. Some studies also showed significant improvements in children's ability to communicate openly about their condition with their peers, caregivers and health professionals [124, 125, 187, 306, 319].

7.5.1. Overarching concept – developmentally appropriate learning

The matching of teaching approaches to children's developmental stage was identified as an overarching concept in supported self-management educational interventions. It is important that knowledge and skills are taught to the right level of complexity. Younger children appear to benefit from the use of interactive play and cooperative and peer learning in both the studies included in this review and educational literature [331]. Teaching approaches that support deeper learning (and, thus, are more appropriate for adolescents) included collaborative learning and enquiry-based learning. The educational literature suggests that older adolescent learners are more likely to respond to teaching methods that have genuine relevance to their own experiences [332, 333]. Clinicians should tailor educational interventions to the needs of infants, school-aged children, younger adolescents and older adolescents.

7.5.2. Key findings – educational components

Children's supported self-management education was found to be more than just imparting knowledge. Clinicians can best support children to develop supported self-management skills, healthcare behaviours and mastery by utilising multiple educational components.

The first key component that clinicians should include in children's and young people's supported self-management educational interventions is *structured and sequenced curricula* (promoted in n=30/30 studies). Lessons should be sequential to build on skills and healthcare behaviours previously mastered by children. Moreover, the structure of lessons should enforce daily supported self-management routines. In his theoretical work on childhood development, David Ausubel stresses the importance of acknowledging and using the previous learnings of children [103]. Ausubel also advocates for learning to take place in meaningful ways through disciplined organising and connecting of concepts [103]. The effectiveness of structured sequenced curricula is well proven in the educational literature, as demonstrated by large scale meta-analyses [332, 333].

Similar to proven adult chronic condition self-management models [26, 46], children's supported self-management educational interventions need a varied curriculum. Topics to cover are: **K**nowledge of condition, children's active **I**nvolvement in their own healthcare activities, **C**are plan, **M**onitoring and **R**esponding to symptoms, **I**mpacts of the chronic condition(s) (e.g. physical, emotional and social impacts), **L**ifestyle aspects (e.g. diet and exercise) and **S**upport Services (e.g. caregivers including parents, clinicians, teachers and community). An easy way for clinicians and children to remember these topic areas is through the use of the acronym **KIC-MR-ILS** [46].

Reinforcement came in as the second most important key educational component (promoted in n=26/30 studies). People facilitating supported self-management educational interventions need to reinforce children's and young people's curiosity, problem identification (e.g. symptom monitoring) and problem-solving skills [334]. Methods such as children's/young person's demonstration of skills learnt, debriefing at the end of sessions (children and caregivers), written support materials, take home supported self-management action plans and homework activities were regularly included in the educational interventions. Homework activities seem to have been designed to provide children with the opportunity to develop further the supported self-management skills and healthcare behaviours they had just learnt [334]. Evidence suggests that reinforcement strategies are important components of effective education [334, 335]. Research is sparse with regard to the importance of debriefing [334, 335].

Active participation was identified as the third key component (promoted in n=21/30 studies that used active, experiential and interactive play teaching approaches). Children need to be active participants rather than spectators in the supported self-management learning process. Active learning aims to provide authentic, experiential and hands-on learning experience [336]. The included studies acknowledged that learners needed time to interact with their peers and facilitators as well as time to practise and adapt their newly learned supported self-management skills and healthcare behaviours. Active participation is a well-known evidence-based strategy for educating children and adolescents and is promoted to teachers by government agencies [332, 333, 336].

The fourth key educational component was found to be *collaboration* and is inclusive of participation (promoted in n=21/30 studies). Developmental theorist Lev Vygotsky was an advocate for the use of collaborative group activities to assist learning [83, 103]. Ways that clinicians can promote collaboration include using teamwork activities (strategically choosing children that will work well together) and encouraging everyone to participate in the same learning task. According to the education literature, collaborative learning takes place when children actively participate in negotiating roles, responsibilities and outcomes [332, 333]. In the educational setting, collaborative learning approaches are generally viewed as being effective, although effect sizes vary across studies [332, 333].

Placing fifth in order of importance of key educational components was learner *autonomy* (promoted in n=17/30 studies). Jean Piaget's belief that children are independent and development is guided by self-centred activities [83, 103] strongly influenced the design of most of the studies included in this review, as evidenced by almost all included studies being child or adolescent focused. Placing the child/young person at the centre of the supported self-management educational intervention acknowledges their growing autonomy and allows them to be trained to assume a leading role in their condition management. It is also essential that clinicians support self-efficacy as recommended by developmental theorist Albert Bandura when promoting the autonomy of children and adolescents [83, 103].

Feedback was identified as the sixth key educational component needed to deliver children's and young people's supported self-management programs [125-127, 129, 136, 186-188, 316, 317, 320, 323, 324, 326, 329]. A high level of facilitator–student interaction is required to teach children and young people to be involved in supported self-management and feedback is critical. Feedback is important to both children/young people with chronic conditions and facilitators, because it informs how progressing towards anticipated educational goals is going [336]. Timely feedback provides opportunities for immediate correction and improvement. Feedback can be provided by a variety of people including caregivers, educational facilitators and peers. Methods of providing feedback can be oral or written as long as the feedback includes specific advice that children can use to improve their supported self-management skills and healthcare behaviours. Appropriate feedback is a well-proven educational component for children and their teachers [332, 333].

Unexpectedly, *multiple exposures* were identified as the seventh key educational component (promoted in n=10/30 studies). A well-cited educational article (>70 citations) states that it takes ‘three or four experiences involving interaction with relevant information for a new knowledge construct to be created in working memory and then translated to long-term memory’ [337]. Multiple exposures are more than simple repetition or drill work [336]. They provide children with many opportunities to learn and practise supported self-management skills and healthcare behaviours over time through repeated learning opportunities [336]. Educational research demonstrates that multiple exposures have significant positive impacts on children being able to retain newly learnt knowledge [332, 333].

The eighth key educational component was *problem solving* (promoted in n=8/30 studies). Children with chronic conditions often face an uncertain, complex and challenging future. Learning how to make well-informed decisions and solve problems can help children and adolescents better prepare for their futures [40, 83]. Collaborative discussion is a complementary strategy to problem-based learning. Research of problem-based learning has found that positive gains in knowledge are equal to or better than gains that employed traditional lecture-style instruction [338].

7.5.3. Strengths and limitations

This review addresses gaps in knowledge about children’s and young people’s supported self-management educational interventions. While other paediatric research groups have identified and acknowledged the importance of developmentally appropriate supported self-management educational components for children [182, 339, 340], this review marks the first time that components have been systematically classified. A well-recognised and structured process for conducting systematic reviews was followed. Moreover, each of the included studies were assessed for evidence hierarchy level and quality by two reviewers.

Several limitations are also apparent. Firstly, only studies published in English were included. Secondly, due to large heterogeneity between study parameters and outcomes measured, a meta-analysis could not be conducted. Thirdly, some studies may have not been included due to the reviewers experiencing difficulty when trying to identify studies that included developmental aspects of supported self-management education (see section 3.1 for more information). Lastly, it was impossible to attribute causality to individual education components because each of the included supported self-management educational interventions used multiple teaching approaches.

7.5.4. Conclusions and next steps

Self-management education interventions that are tailored to a child's developmental stage help children with asthma, T1DM and CF to develop effective skills, attitudes and behaviours to manage their health. The effectiveness of these interventions was secured by including the following educational components: *structured and sequenced curricula*, *reinforcement*, *active participation*, *collaboration*, *autonomy*, *feedback*, *multiple exposures* and *problem solving*. Different components are relevant to specific life stages. Further research is needed to be able to attribute causality and effectiveness to individual educational components. For example, research teams may consider conducting randomised controlled trials where the intervention group receives *structured and sequenced curricula* or *reinforcement methods* and the control group does not.

7.5.5. Practice implications

Clinicians should educate children with a variety of chronic conditions using developmentally appropriate teaching approaches. An additional contribution of this review was that it provides clinicians with the range of educational components that they can use to assist their young patients with learning 'support self-management' skills and healthcare behaviours. However, practical tools still need to be developed to guide clinicians in how to do this.

7.6. Synopsis

Chapter 8 presented a second literature review that identified the components of effective self-management educational interventions for children and young people, relevant to their developmental status. Twenty education interventions were identified, published across 30 studies. Most studies were based on the developmental theories of Piaget and Bandura. Eight key educational components were identified: *structured and sequenced curricula*, *reinforcement*, *active participation*, *collaboration*, *autonomy*, *feedback*, *multiple exposures* and *problem solving*. Components were relevant for use with varied chronic conditions; however, different components were relevant to different developmental stages. Overall, this chapter acknowledges that while effective educational interventions are available, translation of education components into paediatric clinical practice is elusive.

In the next chapter (Chapter 9) the opinions of clinical academics with expertise in supported self-management, from a developmental perspective, are presented.

7.6.1. Summary of contributions to the literature

- Effective education for children's and young people's supported self-management that is developmentally appropriate exists; translation to practise is elusive.
- Education should include sequenced curricula and active, problem-based learning.
- Multiple exposures, feedback and reinforcement strategies are also valuable.
- Different education components are relevant to specific life and developmental stages.
- Similar teaching approaches were used across asthma, CF and T1DM.

7.7. Educational interventions acknowledgements

I would like to thank Ms M. Frasier (Librarian, Tasmanian Health Service) for her assistance in the completion of the literature searches presented in this chapter.

8. A Delphi survey of developmentally appropriate supported self-management for children and young people with chronic conditions

In union there is STRENGH ~ ***Author unknown***

This chapter concludes my program of research for my PhD. The Delphi study presented in this chapter fills a knowledge gap by focusing on the developmental aspect of teaching and support approaches to chronic condition self-management not found in previous literature. Please note that this Delphi study was completed in parallel with the Concept analysis study presented in Chapter 6.

Highlighted in this chapter:

- The need for tools to guide tailoring self-management teaching and support approaches to different developmental stages
- The development of new definitions of supported self-management for children and young people with chronic conditions
- Establishment
- The establishment of realistic supported self-management endpoints that children and young people should be able to complete.

Chapter 8 directly relates to the following publications:

Supplementary data and other information related to this chapter can be found in Appendix G

- N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn, Developmentally appropriate supported self-management for children and young people with chronic conditions: a consensus. **Patient Educ. Couns.** (2020) https://doi.org/10.1016/j.pec.2019.09.029

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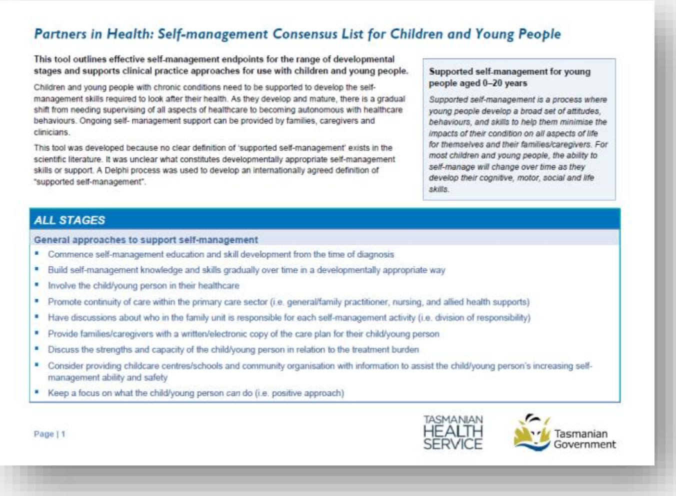
Developmentally appropriate supported self-management for children and young people with chronic conditions: A consensus

Nicole Saxby, Karen Ford, Sean Beggs, Malcolm Battersby, Sharon Lawn

The following clinical tool was also produced for paediatric clinicians working across Tasmania:



Partners in Health: Self-management Consensus List for Children and Young People

This tool outlines effective self-management endpoints for the range of developmental stages and supports clinical practice approaches for use with children and young people.

Children and young people with chronic conditions need to be supported to develop the self-management skills required to look after their health. As they develop and mature, there is a gradual shift from needing supervising of all aspects of healthcare to becoming autonomous with healthcare behaviours. Ongoing self- management support can be provided by families, caregivers and clinicians.

This tool was developed because no clear definition of 'supported self-management' exists in the scientific literature. It was unclear what constitutes developmentally appropriate self-management skills or support. A Delphi process was used to develop an internationally agreed definition of "supported self-management".

Supported self-management for young people aged 0–20 years

Supported self-management is a process where young people develop a broad set of attitudes, behaviours, and skills to help them minimise the impacts of their condition on all aspects of life for themselves and their families/caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills.

ALL STAGES

General approaches to support self-management

- Commence self-management education and skill development from the time of diagnosis
- Build self-management knowledge and skills gradually over time in a developmentally appropriate way
- Involve the child/young person in their healthcare
- Promote continuity of care within the primary care sector (i.e. general/family practitioner, nursing, and allied health supports)
- Have discussions about who in the family unit is responsible for each self-management activity (i.e. division of responsibility)
- Provide families/caregivers with a written/electronic copy of the care plan for their child/young person
- Discuss the strengths and capacity of the child/young person in relation to the treatment burden
- Consider providing childcare centres/schools and community organisation with information to assist the child/young person's increasing self-management ability and safety
- Keep a focus on what the child/young person *can* do (i.e. positive approach)

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TASMANIAN HEALTH SERVICE

Tasmanian Government

8.1. Background

Developmentally appropriate recommendations about supported self-management and divisions of self-management responsibility between children/young people and their caregivers are scarce and are usually limited by a focus on a specific chronic condition. Practical tools are needed to guide clinicians to provide developmentally appropriate self-management support. In the current study, the Delphi technique was used to draw on practical experience and expertise needed to guide the development of a practical tool for use in this field.

It is important to note that this Delphi analysis study was completed in parallel with the concept analysis study presented in Chapter 7. This was a deliberate methodological decision because I wanted to explore the concept of supported self-management of chronic conditions in children and young people in the literature and in contemporary clinical practice.

8.2. Study design and aims

8.2.1. Aims

The aims of this Delphi study were to define supported self-management for children and young people with chronic conditions, and to create a consensus list of developmentally appropriate self-management tasks that can be completed by children and young people, and self-management teaching support approaches for clinicians.

8.2.2. Study design

The method chosen for this study was the Delphi consensus technique. The Delphi consensus technique is a validated method of gathering data from experts in their field of expertise [59, 60].

8.2.3. Rationale using the Delphi consensus technique in this study

Within the current literature, there is a lack of consensus on the best approach to teaching supported self-management skills and healthcare behaviours to children and young people with chronic conditions. Furthermore, the supported self-management endpoints children and young people may be expected to reach by the end of each developmental stage are undefined. In situations such as this, when there is little or confusing evidence to guide healthcare practices, gaining consensus is an important step to aid decision making [341]. Consensus brings about common understanding among experts to advance practice [342, 343]. Consensus refers to the achievement of 'general agreement' [342, 343]. The origin of consensus in health care is unclear; however, it starts to regularly appear in the literature from the 1970s [342].

There are many ways that clinicians and researchers can go about gaining consensus. Methods for gaining consensus can be either informal or formal [342]. Depending on the method chosen, different methodological issues emerge [342]. Up until about 10 years ago, informal consensus methods were favoured [342]. Informal methods include ‘free discussions’, ‘free interaction’ or simply ‘talking to reach consensus’ [342]. Large gatherings, such as international scientific meetings, often provided an opportunistic setting to run informal consensus processes. Once involved, participants were able to take part in discussions with very few rules or procedures [342]. Limitations of informal consensus methods include potential domination of the discussion by some individuals, having no explicit definition of consensus, and only one person being able to speak at a time. There is also potential for people being afraid to share their personal views, which may, in turn, lead to group conformity [344]. An example of a healthcare document created by an informal consensus process is the 1992 ‘Nutritional assessment and management in cystic fibrosis: a consensus report’ [344].

There is a variety of formal consensus methods now available and these are preferable to informal methods [342, 343]. Formal methods include ‘consensus development conferences’, ‘nominal group techniques’, and the ‘Delphi consensus technique' [342, 343]. Table 17 highlights the main differences between these three formal consensus methods and the informal methods previously mentioned.

TABLE 17 INFORMAL AND FORMAL CONSENSUS METHODS

	Face-to-face contact?	Decisions made in private?	Formal feedback of group ideas?	Interaction structured?	Participants anonymous?	Explicit definition of consensus?
INFORMAL	Yes	No	No	No	No	No
FORMAL						
- Delphi consensus technique	No	Yes	Yes	Yes	Yes	Yes
- Nominal technique	Yes	Yes	Yes	Yes	No	Yes
- Consensus development conference	Yes	No	No	Yes	No	No

Source: Table adapted from Murphy et al. 1998 [342]

Originally developed in the 1950s to forecast new technologies, the Delphi consensus technique is a validated method of gathering data from experts in their field of expertise [341, 342]. There are many examples in the healthcare literature of the Delphi consensus technique being used [355, 356]. The iterative nature of the Delphi consensus technique means that although the participants are anonymous to each other, they are identifiable to the researcher [341, 342].

A Delphi study was used in this PhD research program to create a consensus list of supported self-management definitions, recommendations and endpoints for children and young people with chronic conditions. The Delphi consensus technique was chosen for three main reasons: (1) it allowed easy access to international participants; (2) it is inexpensive to conduct the research due to its internet-based nature (compared to needing to have participants attending face-to-face); and (3) participants were able to stay anonymous to each other [341, 342]. Furthermore, the use of the Delphi consensus technique allowed the correlation of informed judgements of supported self-management and developmentally appropriate self-management teaching and support approaches across a wide range of clinical academic disciplines.

8.2.4. How this study connects with the theoretical work presented in this thesis (systematic reviews and concept analysis) and future research directions

This Delphi study provides guidance development which allows the novel and testable part of the conceptual theory in practice. Previously in this thesis I have presented developmentally appropriate self-management support from a theoretical perspective through the use of systematic reviews chapters (Chapters 4 and 6) and a concept analysis study (Chapter, 7).

Following the submission of this thesis, a small comparison study looking at the theoretical and practical themes identified for supported self-management will be completed. Implementation and testing of the consensus guidance tool from this Delphi study is another logical next step.

8.3. Methods

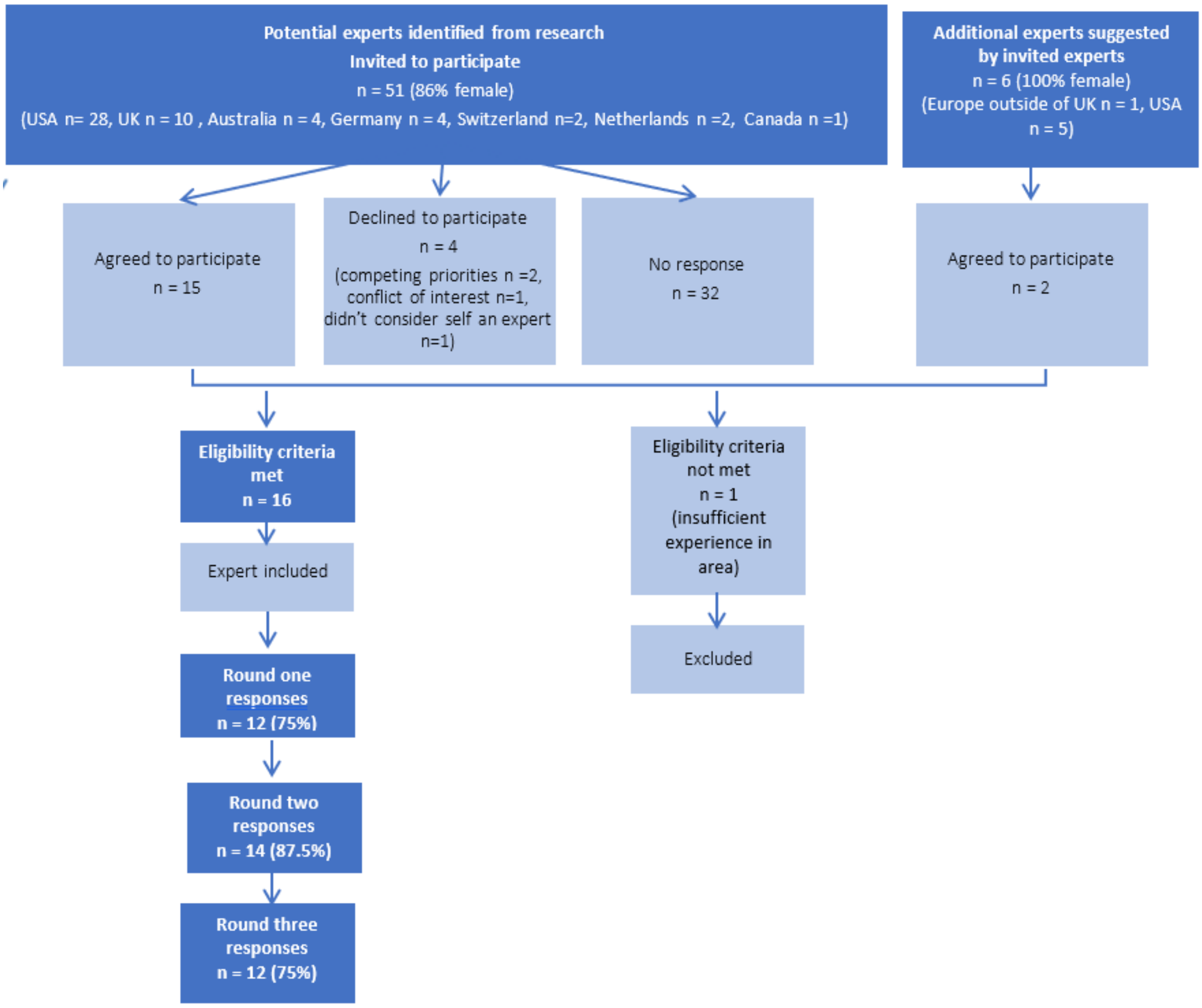
8.3.1. Expert panel selection

As children’s and young people’s supported self-management is a relatively small and emerging research area (particularly from a developmental perspective), prior to commencing this study it was anticipated that recruitment of appropriate experts would be challenging and that expert panel numbers would be small. Delphi expert panel sizes are known to range from four to more than 1000 participants [342, 345], with Linstone et al. suggesting that seven participants is the minimum panel size to conduct a successful Delphi study [346].

Clinical academics from around the world with backgrounds in medicine, nursing, allied-health, including developmental/paediatric psychology, or teaching were invited to be part of the expert panel. Clinical academics are important as they offer a bridge between research and practice. Experts were initially identified in a Medline search as authors with the highest number of peer reviewed publications specifically related to children’s/young people’s self-management from a developmental perspective. Conflict of interest declarations were reviewed by me prior to confirming inclusion of experts. No honoraria were paid to experts for their participation. Experts were also invited to suggest additional potential experts.

Participants were included as experts if they met the following criteria: had authored two or more relevant peer-reviewed papers (first, second or last author published within the last 10 years), held related postgraduate qualifications; and were recognised as an expert in the field by peers (e.g. invitation to participate in a relevant symposium, focus group, conference or other event). Participants were excluded if they had insufficient experience, did not consider themselves to be experts, had an identified conflict of interest, or were unable to commit enough time to complete the Delphi process. Figure 11 on the next page shows the recruitment process.

FIGURE 11 RECRUITMENT AND DELPHI ROUNDS FLOWCHART



Developmental stages

This Delphi study uses the five pre-determined developmental stages as outlined previously (Section 1.2).

8.3.2. Definition of consensus and statistical analysis

Expert consensus was pre-defined as rating *moderately* or *extremely satisfied* by at least 70% [347, 348].

Descriptive statistics were calculated for each statement presented in the Delphi. For the statements, median values are included as a measure of central tendency. Mean and standard deviations (SD) help to show the spread of the data presented.

Using Microsoft Excel for Macintosh [349] for the quantitative analysis, Likert scale responses were coded numerically as: *extremely dissatisfied*=1, *moderately dissatisfied*=2, *slightly dissatisfied*=3, *neither satisfied nor dissatisfied*=4, *slightly satisfied*=5, *moderately satisfied*=6, *extremely satisfied*=7. Statistics are presented as: round, consensus%, median mean, and SD. Likert scale equivalents in words are included for mean and median values.

8.3.3. Enhancing response rates

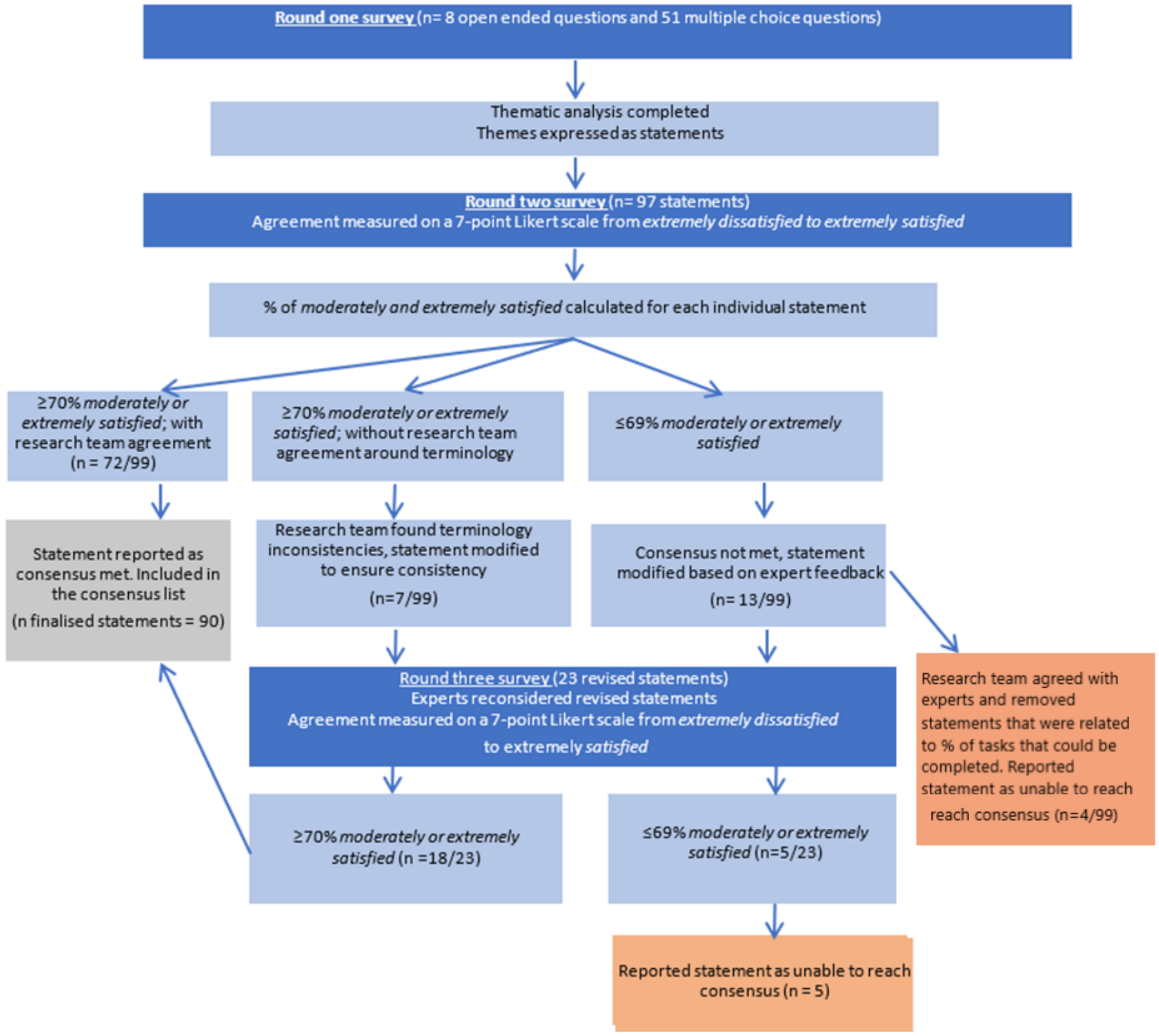
To prevent participant fatigue, the expert panel had 10 days to complete each Delphi round. After seven days, participants were sent a friendly reminder or a thank you email.

8.3.4. Data collection

It was forecast by me that three or four Delphi rounds would be required. At the end of Delphi round three, the research team agreed that a sufficient quantity of consensus had been attained (i.e. >80% of statements had reached consensus), see

Figure 12 on the next page. The 16 eligible experts were invited to participate in each Delphi round, regardless of whether they had participated in a previous round. Each round was administered via Qualtrics: Online Survey Software & Insight Platform [350].

Figure 12 Flowchart to illustrate the process of the three rounds of the Delphi



8.3.4.1. Round one

SURVEY DESIGN

Round one included eight open-ended questions that broadly covered the known domains of self-management: **K**nowledge, **I**nvolvement, **C**are plan, **M**onitor and **R**espond to symptoms, **I**mpacts, healthy **L**ifestyle, **S**upport services (Table 18, next page), and 51 multiple choice questions related to these domains. These domains of self-management originate from previous work completed by our research unit (https://www.flindersprogram.com.au) [46].

Survey questions were developed by me with the assistance of my primary PhD supervisor (S. Lawn), informed by literature review and their respective expertise in paediatrics and chronic condition self-management, then reviewed further by all remaining members of my PhD team (M. Battersby, S. Beggs, K. Ford), and finalised through discussion. The aim of round one was to elicit opinions about general concepts related to supported self-management for the pre-defined developmental stages (Table 15).

TABLE 18 OPEN-ENDED QUESTIONS PRESENTED TO EXPERT PANEL IN DELPHI ROUND 1

Domain	Definition	Open ended question asked
N/A	N/A	We need a definition of children's [and young people's] chronic condition self-management. The suggested definition is: *'Children's self-management is a process that includes a broad set of attitudes, behaviours and skills. It is directed towards managing the impact of the disease or condition, on all aspects of living by the child/young person and their family. Children and young people's ability to self-manage their condition will change over time as they develop cognitive, motor, social and life skills. Self-management, includes but is not limited to, self-care and it may also encompass prevention.'* Do you have any suggested modifications to the proposed definition?
Knowledge (K)	Knowledge is about children and young people knowing about their chronic conditions.	Please briefly explain how you would teach children and young people about their chronic conditions for the predefined developmental stages?*
Involvement (I)	Involvement is about children and young people being involved in the decisions around the management of their condition/s with their caregivers, family members, and the healthcare team.	Please briefly explain how you approach getting children and young people involved in the management of their own chronic conditions for the predefined developmental stages?*
Care plan (C)	Care plan is about children and young people, together with their family unit, following the agreed-upon care plan (which may also be known as a chronic condition action plan). It also incorporates role division between children and their caregivers in relation to self-management tasks.	Please briefly explain how you approach developing a care plan for children and young people for the predefined developmental stages (e.g. who are the plans directed at, what format do you use etc.)?*
Monitor and respond to symptoms (MR)	Monitoring and responding to symptoms is about children/young people developing an awareness of the symptoms of their chronic conditions, communicating these symptoms to other people that can help, and acting on their symptoms if they have the appropriate skills and abilities.	What signs and symptoms do you think that children and young people should be aware of and be able to respond for each predefined developmental stage?*
Impacts (Im)	Impacts relate to how children and young people manage the physical, emotional and social impacts their condition has on their everyday life. Of particular importance is the division of responsibility between children/young people and their caregivers in	For each of the predetermined developmental stages, how much independence would you expect the child to have in relation to managing the physical, emotional and social impacts of their chronic conditions?*

	managing perceived and actual impacts (i.e. how much does the parent step in and out in helping the child/young person to cope)	
Healthy lifestyle (L)	Healthy lifestyle is about children and young people being involved in activities as their age and chronic conditions allows. Lifestyle factors can include having a healthy diet, playing sport with others, and being able to stay overnight at friends and families houses.	Please briefly explain how you approach getting children and young people to follow a healthy lifestyle for each predefined developmental stage?*
Support services (S)	Support services is about children and young people knowing where they can get support in managing their chronic conditions. Supports may include teachers at schools, their caregivers, and their friends.	Please briefly explain how you encourage children and young people (with/without their caregivers) to access support services for each predefined developmental stage?*

* Expert participants were asked to answer questions for all developmental stages that applied to their experience

Key: KIC MR TILS [8] = Knowledge – Involvement – Care plan – Monitor and Respond – Transition - social Impact(s) – healthy Lifestyle – Support service

SURVEY ADMINISTRATION

I administered survey round one to expert participants in late August 2018.

DATA SYNTHESIS AND ANALYSIS

Results from survey round one were thematically analysed by myself, and confirmed by a second person (K. Ford). Content was coded according to the self-management domains, with an extra category created for transition. Together with all members of my PhD supervisor team I then discussed the proposed themes until any differences were resolved. Analysis of round one was then used to develop statements to present to expert participants in round two.

Appendix 4G shows an example of analysis and theming completed Delphi round 1.

8.3.4.2. Rounds two and three

Survey design

In Delphi survey round two, 99 statements were presented to the expert participants. These statements originated from the thematic analysis completed in round one. Round two statements were divided into three sub-sections: (1) proposed definitions; (2) self-management teaching support approaches; and (3) endpoints. Expert participants were asked to rate their level of agreement to each step using a 7-point Likert scale from *extremely dissatisfied* to *extremely satisfied*.

In survey round three, participants were presented with 23 revised statements where consensus was not reached in the previous round (feedback incorporated), plus seven statements where the research team had found terminology inconsistencies. All revised statements had consistent numbering with the results report from Delphi round two.

Survey administration

I administered the Delphi round two survey in September 2018 and the Delphi round three survey in October 2018.

8.3.4.3. Consensus list development

Statements were considered finalised when both the following criteria were met: expert consensus reached, and research team in agreement with the expert consensus. Where participants agreed that a statement was relevant across developmental stages, these statements were collated under the heading ‘all stages’. Finalised statements were then synthesised into the Partners in Health: Consensus List for Children and Young People. This list defines supported self-management for the range of developmental stages and supports clinical practice approaches.

A consultancy company (Literally Inspired, Hobart, Australia) reviewed the finalised consensus list in relation to health literacy. This review ensured that the final list was easy to read, clearly understandable, and suitable for use across paediatric primary, secondary, and tertiary healthcare settings.

8.3.5. Ethics

Prior to being undertaken, and under the research title ‘Children’s Chronic Condition Self-Management Study’, this Delphi study was approved by:

- **Flinders University Social and Behavioural Research Ethics Committee** – Project identification 7205 (Appendix 1G)
- **Tasmanian Health and Medical Human Research Ethics Committee** – Project identification H0017044 (Appendix 2G)

8.4. Results

8.4.1. Interdisciplinary expert panel

Sixteen experts participated in this Delphi study. The participant information sheet can be found in Appendix 3G.

Figure 13 (below) outlines the recruitment process, and Table 19 (next page) shows the expert panel participant characteristics. In total, 101 statements were presented to the interdisciplinary experts.

FIGURE 13 INTERDISCIPLINARY EXPERT PANEL LOCATIONS

TABLE 19 INTERDISCIPLINARY EXPERT PANEL CHARACTERISTICS

		Number	Percentage
Age	40–49 years	5	31.25
	50–59 years	7	43.75
	60–69 years	4	25
Gender	Female	16	100
Location	United States of America	10	62.50
	Australia	3	18.75
	United Kingdom	3	18.75
Health profession or background	Medical researcher or scientist	4	25
	Medicine	3	18.75
	Nursing	4	25
	Allied health (3 paediatric/developmental psychologists, 1 dietitian)	4	25
	Teacher (primary school)	1	6.25
Years of experience working with children and young people	Under 5	1	6.25
	5–10	0	0
	11–20	4	25
	21–30	6	37.50
	31–40	3	18.75
	41+	2	12.50
Types of chronic conditions* *n=42 responses*	Asthma	8	19.05
	Overweight and obesity	6	14.29
	Diabetes	5	11.90
	Cerebral palsy	4	9.25
	Cystic fibrosis	4	9.25
	Developmental disabilities	3	7.14
	Epilepsy	2	4.76
	Consequences of low birth weight and prematurity	2	4.76
	Mental illnesses	2	4.76

	Physical disabilities	1	2.38
	Inflammatory bowel disease	1	2.38
	Cancer	1	2.38
	HIV	1	2.38
	Renal	1	2.38
	Polycystic ovaries	1	2.38
Age groupings of children and young people worked with by experts* *n= 50 responses*	Infancy	5	10
	Early childhood	8	16
	Middle childhood	9	18
	Younger adolescence	13	26
	Older adolescence	15	30

** Experts were able to answer for multiple categories*

8.4.2. Definitions

Six statements presented to the experts related to definitions. In survey rounds one and two, the expert panel disagreed with the proposed definition of supported self-management for all developmental stages, but suggested modifications in the free text comments. After incorporating expert feedback, the experts agreed on the refined definition for ‘all stages’ in round three.

Similarly, in round one, experts did not reach consensus for definitions of supported self-management for any of the individual developmental stages. Round two saw experts reaching consensus for infancy, early childhood, and the younger adolescence stages. The defining statements were revised to reflect the expert feedback. Final consensus definitions for each stage were achieved in round three. All finalised definitions are shown in Table 20, on the next page, and are accompanied by descriptive statistics.

Table 20 Finalised statements, Partners in Health: Self-Management Consensus List for Children and Young People

Developmental stage definitions	Recommended approaches to support self-management	Endpoints for this stage
ALL STAGES		
■ 'Supported self-management is a process where children and young people develop a broad set of attitudes, behaviours, and skills to help them minimise the impacts of their condition on all aspects of life for themselves and their caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills.' [Round three, 100% consensus, median=7 extremely satisfied, mean=6.67 extremely satisfied, SD=±0.49)]	■ (K, C) Commence self-management education and skill development from the time of diagnosis ■ (K) Build self-management knowledge and skills gradually over time in a developmentally appropriate way ■ (I) Involve the child/young person in their health care ■ (I) Promote continuity of care within the primary care sector (i.e. general/family practitioner, nursing, and allied health supports) ■ (I) Have discussions about who in the family unit is responsible for each self-management activity (i.e. division of responsibility) ■ (I) Keep a focus on what the child/young person *can* do (i.e. positive approach) ■ (C) Provide caregivers with a written/electronic copy of the care plan for their child/young person ■ (C, I) Discuss the strengths and capacity of the child/young person in relation to the treatment burden ■ (S) Consider providing childcare centres/schools and community organisation with information to assist the child/young person's increasing self-management ability and safety	N/A
INFANCY (aged under 2 years)		
■ 'Infants are dependent on family/caregivers for all healthcare behaviours.' [Round three 91.67% consensus, median=7 *extremely satisfied*, mean=6.75 *extremely satisfied*, SD=±0.62]	■ (K, C) Regular review of caregivers' self-management knowledge, skills and abilities ■ (K, C) Use integrated play approaches to help the child to develop self-management skills and motivate them towards positive healthcare behaviours (e.g. use of stories and characters in books to teach skills, modelling behaviours through the use of puppets)	■ (C) Child is moderately accepting of daily treatments (e.g. take medications, participate in self-care related activities with limited resistance.

	(I) Have the child help with simple jobs associated with their condition (e.g. taking medications when asked) (L) Encourage positive interactions around food (including exposures to food play, tastes, and different textures) for developing positive health behaviours (L) Assist the child to actively wash their hands for developing positive health behaviours	
EARLY CHILDHOOD (aged 3 to 5 years)		
'Children in early childhood rely on caregivers/family for all healthcare behaviours. They are starting to become involved in simple self-management tasks as their cognitive, motor, and social skills develop.' [Round three, 100% consensus, median=7 *extremely satisfied* mean=6.75 extremely satisfied, SD=±0.45]	(K) Use simple explanations, descriptions and pictures to teach concepts (K) Support the child in learning body awareness and to name parts (K, C) Regular review of caregiver's self-management knowledge, skills and abilities (K, C) Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviours (I, C) Encourage the child to help with some aspects of managing their condition (e.g. bring blood glucose monitor to the caregiver when it is time to check levels) (I, C) Allow some choices around self-management activities (e.g. select a fun activity to do after treatments) (MR) Support the child in learning to say words for their symptoms (MR) Support the child to learn that symptoms can be directly related to their chronic condition(s)/treatments.	(C) Child helps caregivers/family with basic self-management tasks (e.g. setting up for equipment/treatments, bringing blood glucose monitor when it is time to have levels tested). (L) Child understands the importance of proper handwashing.
MIDDLE CHILDHOOD (aged 6 to 11 years)		
'Children in middle childhood have increasing autonomy for healthcare behaviours and decisions. Responsibility and supervision for self-management remain with family/caregivers.' [Round three 91.67% consensus, median=7 *extremely satisfied,* mean=6.67 extremely satisfied, SD=±0.65]	(K, I, C , MR) Have an individualised and evidence-based teaching plan to build self-management knowledge and skills. Focus on the basics around the chronic condition(s), functions of the body, symptom awareness, and treatments (K, MR) Use simple pictures and diagrams to explain health concepts and stimulate problem-solving	Child: (K) can describe their chronic condition(s) in 2 to 3 simple sentences (K) can communicate their contact information

	■ (K, C) Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviours (e.g. use stories to initiate discussions around the chronic condition(s), use games to promote decision making) ■ (K, C) Use active and experiential learning to teach the child self-management skills (i.e. authentic and hands-on experiences) ■ (K, C) Revisit the child's understanding of the chronic condition(s) and how their treatments work ■ (K, C) Correct any misconceptions a child may have around health, illness, and their treatments ■ (I, Im, S) Start promoting cooperative and peer learning as appropriate for the individual (i.e. learning with and from other children) ■ (I) Encourage caregivers to give the child increasing responsibility in communicating with their clinicians ■ (C, L) Encourage caregivers to model daily self-care and health activities ■ (Im, S) Coach the child to communicate with their family, teachers, friends, and clinicians about their concerns.	■ (K) knows the equipment they need for treatment and what they are used for ■ (K) is familiar with their regular tests and why they need to have them ■ (K) can name their medications and simple reasons for taking them ■ (K, S) knows who to contact in case of an emergency ■ (I) knows the names of people in their healthcare team that they see regularly ■ (I, C) assists their caregiver with setting up treatment equipment/areas ■ (MR) understands their normal health level ■ (MR) can describe changes in their health to their caregivers/family and healthcare team ■ (MR) can describe how they feel when asked ■ (L) understands the importance of self-care activities such as hygiene and dressing ■ (L) knows how the body uses food ■ (L) understands what is good food/nutrition to promote health ■ (S) can talk to their family and friends about their chronic condition(s).
YOUNGER ADOLESCENCE (aged 12 to 15 years)		
■ 'Young adolescents become increasingly autonomous for healthcare behaviours and decisions, with their caregivers/family having oversight for self-management. The responsibility for self-management is negotiated and shared between the young person and their caregivers/family' [Round three 91.67% consensus, median=6 *moderately satisfied,* mean=6.25 moderately satisfied, SD=±0.87]	■ (K, I, C, MR) Use a variety of teaching approaches to develop self-management skills – including active and experiential learning, directive learning, and enquiry-based learning (i.e. learning directed by questions, problems and challenges) ■ (K, I) Actively promote co-operative and peer learning (i.e. learning with and from other adolescents) ■ (K) Correct any misconceptions the young person may have around health, illness and their treatments ■ (C) Provide a written/electronic copy of their individualised care plan to the young person ■ (T) Discuss the move to adult healthcare services	Young person: ■ (K) knows the names of their medications, dosages, and what the medicines are for ■ (K. I) understands their rights to privacy and decision making ■ (K) knows if they have allergies and how to manage them ■ (I) answers questions independently at clinic appointments and be comfortable bringing up issues ■ (C, MR) monitors and responds appropriately to their symptoms independently

	▪ (K, S) Encourage interaction with technology as a communication platform and a source of support information	▪ (C, MR) knows what to do when they become unwell or need urgent medical assistance ▪ (MR) has an awareness of their mental health ▪ (Im) begins to discuss teenage issues including – boyfriends/girlfriends, choices around alcohol, drugs and smoking ▪ (Im, S) discuss school issues – friendships, talking with teachers about their chronic condition, impacts of living with a chronic condition ▪ (L) knows about the general principles of a balanced diet and exercise ▪
OLDER ADOLESCENCE (aged 16 to 20 years)		
▪ *'In older adolescence transition to self-management autonomy occurs for most young people with chronic conditions. By the end of this period, the goal is that caregivers/family are acting as advocates, offering support and guidance as needed.* [Round three 83.33% consensus, median=6 *moderately satisfied*, mean=6 *moderately satisfied*, SD=±0.87]	▪ (K, I, C, MR) Use a variety of teaching approaches to help the young person develop self-management skills, including active and experiential learning, directive learning, enquiry-based learning, and cooperative peer-based learning ▪ (I) Encourage the young person to attend clinic appointments by themselves ▪ (I) Encourage caregivers to step back into a self-management advocacy and support role ▪ (C) Provide a written or electronic copy of their care plan to the young person ▪ (T) Actively work with the young person to facilitate the transition to adult services ▪ (K, S) Encourage interaction with technology as a communication platform and source of support information.	Young person: ▪ (K) has a comprehensive knowledge of their chronic condition(s) ▪ (K) is aware of side effects and restrictions of the medications they take ▪ (I) knows how to reorder/arrange medications and other treatments ▪ (K) understands implications associated with comorbidities of their condition ▪ (K) knows the basics around sexual and reproductive health ▪ (K, S) knows where to get more information about health topics from reputable sources ▪ (I) knows the names of their healthcare team and understand what they do ▪ (I) knows how to make or reschedule their appointments ▪ (I) starts communicating directly with their healthcare team via phone/email ▪ (T) initiates discussions about their transfer to adult care ▪ (T) starts meeting members of the adult healthcare team.

		■ (Im) discusses their future employment options with the healthcare team

Key: KIC MR TILS[8] = Knowledge – Involvement – Care plan – Monitor and Respond – Transition - social Impact(s) – healthy Lifestyle – Support services

8.4.3. Agreement on the proposed criteria for self-management support and endpoints

From the total of 99 statements initially presented to the expert panel, 47 statements related to teaching and self-management support approaches and 46 statements related to endpoints. Statements were classified across seven broad domains (Table 20).

8.4.3.1. Self-management support

At the end of round two, consensus was reached for 40 out of the 47 statements (85.10%) for self-management support. Values for the statements were: *extremely dissatisfied* n=0, *moderately dissatisfied n*=0, *slightly dissatisfied* n=0, *neither satisfied nor dissatisfied* n=0, *slightly satisfied* n=2, *moderately satisfied* n=11, and *extremely satisfied* n=35. Free text comments written by the experts, offering suggestions on how to further improve/clarify the statements, informed further revision of statements by the research team, for readministering in round three.

In round three, the experts reviewed seven revised statements relating to self-management teaching and support approaches. Overall, 44 of the initially proposed 47 statements on self-management teaching and support approaches reached consensus.

Three self-management support statements did not meet the required consensus criteria. Experts agreed that these teaching and support approaches may be appropriate for some people (but not all), in some situations:

- **Early childhood**
    - use reward systems to promote positive self-management behaviours [Round three 64.2% (non)consensus, mean=5.75 *moderately satisfied*, median=7 *extremely satisfied*, SD=±1.91]
- **Middle childhood**
    - use reward systems to promote positive self-management behaviours [Round three 64.2% (non)consensus, median=7 *extremely satisfied,* mean=5.75 *moderately satisfied*, SD=±1.91]
- **Younger adolescence**
    - After creating rapport and getting permissions from the young person and their caregivers/family, the adolescent is to attend part of the consultation by themselves (preferably the first part) [Round three 66.67% (non)consensus, median=7 *extremely satisfied,* mean=5 *slightly satisfied*, SD=±1.47]

Free text comments by two experts help to explain why the use of reward systems did not reach consensus: *'Avoid the use of reward systems as these become ineffective over time'* and *'You don't necessarily want all health behaviour to be reward-oriented.'*

8.4.3.2. Self-management endpoints

At the end of round two, consensus was reached by the expert panel for 34 of the 46 statements (73.91%) on the proposed self-management endpoints. Values for the statements were: *extremely dissatisfied* n=0, *moderately dissatisfied n*=0, *slightly dissatisfied* n=0, *neither satisfied nor dissatisfied* n=0, *slightly satisfied* n=3, *moderately satisfied* n=10 and *extremely satisfied* n=33. The research team accepted the expert consensus to all 34 statements. For the 12 statements where consensus was not reached, free text comments were reviewed by the research team and a decision was made to revise and re-administer eight of these statements in Delphi round three. The remaining four statements not meeting consensus were removed by the research team at the end of Delphi round two due to ambiguity around the use of percentages of self-management autonomy (n=4 experts added in free text comments about ambiguity).

In round three, the expert panel reviewed six revised statements relating to developmentally appropriate self-management endpoints. Overall, 41 of the initially proposed 46 statements reached consensus and were accepted by the research team.

Five statements did not meet the required consensus criteria. Experts agreed that the following self-management endpoints may be appropriate for some individuals, some of the time:

- **Middle childhood**
    - Fill in a calendar with their date of birth and other important dates in their life [Round three 42.86% (non)consensus, median=5 *slightly satisfied*, mean=4.83 *slightly satisfied*, SD=±1.41]
    - Be independent with >50% of healthcare behaviours [Round two 64.2% (non)consensus, median=4 *neither satisfied or dissatisfied*, mean=5.91 *moderately satisfied*, SD=±1.00]
- **Early adolescence**
    - Contact the correct members of the healthcare team when they have questions [Round three 57.14% (non)consensus, median=5 *slightly satisfied*, mean=5.35 *slightly satisfied*, SD=±1.50]
    - Be independent with >50% of healthcare behaviours [Round two 64.2% (non)consensus, median=6 *moderately satisfied*, mean=5.91 *moderately satisfied*, SD=±1.00]

- **Older adolescence**
    - Be independent with >75% of healthcare behaviours [Round two 64.2% (non)consensus, median=6 *moderately satisfied*, mean=5.86 *slightly satisfied*, SD=±1.29]
    - Be independent with 100% of healthcare behaviours [Round two 64.2% (non)consensus, median=6 *moderately satisfied*, mean=5.5 *moderately satisfied*, SD=±1.87]

It was apparent that the experts did not want health professionals to relate level of autonomy against pre-defined percentage targets. The following expert comments written as free text provide sound reasoning: *'Independence could vary based on cognitive and physical abilities';* and *'Being independent in [X]% of health care behaviours depends on what you include in the tally'.*

8.4.4. Statement synthesis

The 90 statements on which consensus agreement was reached were combined to create Partners in Health: Self-Management Consensus List for Children and Young People as shown in Table 20. This tool includes six definitional statements, 43 self-management support statements, and 41 self-management endpoint statements.

8.4.5. Suggested changes to terminology and age groupings

Based on expert feedback, the terminology used to describe individuals within the age range of birth to 20 years changed over the three Delphi rounds. The experts agreed that using the terms 'children' and 'young people' best reflected individuals aged birth to 20 years (rather than 'children', 'children and adolescents' and 'youth'). In addition, the term 'middle childhood' was preferred over 'school-aged children'.

Demographic age groupings were also debated among the expert interdisciplinary panel, with agreement being reached in round three for the following age groupings: birth to 23 months, 2–5 years, 6–11 years, 12–15 years and 16–20 years.

8.5. Discussion

This Delphi study explored the opinions of clinical academics with expertise in supported self-management, from a developmental perspective. A three-round Delphi process was employed, with consensus being reached for 90 (out of 99) statements by the interdisciplinary expert panel. Together, these 90 statements formed the Partners in Health: Self-Management Consensus list for Children and Young People. This new tool fills an important practice and knowledge gap by providing consensus advice to clinicians about how to deliver developmentally appropriate self-management support.

Another important contribution of this study is the clear delineation from family management (i.e. in infancy and early childhood) to supported self-management by the child/young person (i.e in middle childhood, early adolescence and older adolescence) to autonomous self-management (i.e. at the point of transfer to adult healthcare services at approximately 18–20 years of age). It is important to remember, however, that children/young people are expected to achieve self-management milestones at varying rates. Thus, the age estimates suggested in the Partners in Health: Self-Management Consensus List for Children and Young People tool should only be used as an approximation as for when self-management skills and healthcare may be developed.

One of the strong messages from the expert panel was the importance of having an individualised and person-centred approach to supported self-management, provided in a positive way (i.e. what the child/young person can do), and focused on health behaviour goals that are relevant to the child/young person. It is therefore important that throughout the developmental trajectory, the child/young person is involved in the self-management of their condition/s, and that their caregivers/family are also considered [24]. Clinicians, however, need to be aware that the child's/young person's views towards self-management may be different from that of their caregivers/family [252].

The statements that did not reach expert consensus were also of interest to me, particularly in respect to reward system appropriateness. Reward systems are commonly used by caregivers and are promoted in paediatric healthcare and educational settings [336, 337]. This area requires further research given the common use of reward systems in fields such as paediatric psychology.

8.5.1. Strengths and limitations

This Delphi study has several strengths. Firstly, the consensus definition is applicable to paediatric self-management support across multiple conditions, which substantially increases potential for clinical usability. Secondly, the expert panel came from three countries and encompassed a variety of individuals with health and educational backgrounds, which supports a more globally representative definition. Thirdly, carefully worded open-ended questions in survey round one were used to avoid biasing responses. Furthermore, there were high response rates for all survey rounds.

There are also limitations to study methodology. While the Delphi technique enabled the researchers to summarise the existing knowledge of experts in the field of developmentally appropriate self-management, it is not a method that could be used to create new evidence. The type of data collected from experts in this study could have also been constrained by using the self-management domains within the Flinders Program [72] as an underlying conceptual model. Furthermore, the research team acknowledges using age guides to separate the developmental stages has limitations. Categorisation using age does not take into consideration cognitive development, experience and exposure, or age at diagnosis.

Other limitations include a low participation rate of 28.5% of invited experts (n=16/56), an all-female expert panel residing in only English-speaking high-income countries, and lengthy survey rounds (i.e. survey rounds one and two took >20 minutes for experts to complete) which may have been a barrier to participation for other experts who were approached but declined participation. It is worth noting that the consensus tool created through this Delphi study was not designed to fit absolutely every childhood chronic condition. The Partners in Health: Self-Management Consensus List for Children and Young People provides broad guidance only. Further refinement for specific areas is required, particularly in relation to complex chronic conditions (e.g. developmental delay, presence of multiple co-morbidities).

The results of this study can be used in paediatric clinical practice where it may be useful to support children/young people in developing self-management skills and positive health behaviours appropriate to their developmental stage.

8.5.2. Practice implications

Further testing is required to evaluate the appropriateness and usefulness of the new Partners in Health: Self-Management Consensus List for Children and Young People. Gathering feedback from children/young people, their caregivers and wider family members about the format and appropriateness of this new tool is a potential future research project.

A multifaceted strategy will be used to disseminate and implement this new consensus tool, initially through the Tasmanian Health Service in Australia and then more widely on request. Strategies will include use of education materials for health professionals, distribution of the tool to children/young people and their caregivers/family at paediatric clinics, and through providing a link to the tool on a purpose-built website.

8.6. Synopsis

Chapter 9 explored the opinions of interdisciplinary clinical academics with expertise in supported self-management, published [9]. A Delphi consensus process was used to define developmentally appropriate self-management teaching and support approaches, as well as the self-management endpoints for five predetermined developmental stages (i.e. infancy, early childhood, middle childhood, younger adolescence and older adolescence). Finalised statements informed development of the Partners in Health: Consensus List for Children and Young People. To my knowledge, this is the first standardised tool to guide developmentally appropriate self-management teaching and support approaches.

8.6.1. Summary of contributions to the literature:

- Developmentally appropriate recommendations about self-management are scarce.
- This Delphi study proposes a new clinical tool to guide self-management support approaches.
- The tool proposes a common set of self-management definitions, recommendations, and endpoints.
- Use of the tool may help children and young people transition from paediatric to adult health care settings.

8.7. Delphi acknowledgements

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- Pearl Pugh (Dietitian and PhD candidate, University of Nottingham, UK)
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9. General discussion

'The end of work such as this should signal neither a conclusion nor a final word, but rather a punctuation in time that marks a stop merely to take a breath [290 p. 1115].'

~N. Denzin & Y. Lincoln

Chapter 9 closes this thesis by presenting a high-level discussion on supported self-management for children and young people with varied chronic conditions (namely asthma, CF and T1DM), as seen through a developmental lens. Here, the main findings of the research are presented in the context of other existing research. Broad limitations of the research program are also discussed, as well as a plan to translate and implement the research findings into clinical practice. A strong emphasis has been placed on future directions for continuing research into this important topic.

9.1. Background

To recap, the clinical question guiding this research was:

'What are the attributes of supported self-management at various developmental stages?'

Answering this question is important because there is currently little evidence available to guide caregivers, clinicians and healthcare policy makers in how to best deliver developmentally appropriate self-management teaching and support approaches. Furthermore, within the existing literature base, the practice of transferring self-management responsibility from caregivers to children/young people appears to be complicated and not well described.

The outcomes of this research program aimed to provide children and young people, their caregivers, and their clinicians with guidance for a safe transition of responsibility for self-management tasks, from birth through to older adolescence – in turn, assisting with the young person's supported self-management capacity and the final transfer process to adult healthcare services. An additional aim of the research was to promote consistency in clinicians' and researchers' understanding of the concept of supported self-management, how it is applied in clinical practice and in research.

Four studies were completed. In the first instance, a systematic review was undertaken to determine if current clinical guidelines recommend that paediatric clinicians should provide self-management support in a developmentally appropriate way (Chapter 4). A rigorous new interdisciplinary method of concept analysis developed for this thesis and broader general use was then presented (i.e. the

Saxby–Page Concept Development Technique, Chapter 5), and was used to define the concept self-management support in children and young people (Chapter 6). The research then shifted to focus on how paediatric clinicians could translate the concept of supported self-management into practice. Another systematic review was completed at this point. This second review aimed to articulate the components of effective educational interventions and teaching approaches that help children and young people learn about managing their chronic conditions, relevant to their developmental status (Chapter 7). Finally, a Delphi study explored the opinions of clinical academics with expertise in supported self-management, from a developmental perspective (Chapter 8). The Delphi study resulted in the development of a new consensus tool to guide developmentally appropriate teaching and support appropriate for children and young people with chronic conditions (i.e. the Partners in Health: Self-Management Consensus List for Children and Young People). Please note that the concept analysis and Delphi studies were completed in parallel rather than consecutively. This was a deliberate methodological decision because I wanted to explore the concept of supported self-management of chronic conditions in children and young people in the literature and also in contemporary clinical practice.

9.2. Research significance and relevance

To date, most of the research on chronic condition self-management has been completed in adult populations with many interventions being extrapolated to paediatric settings as highlighted in the recent 2018 publication by Lozano and Houtrow [20]. In cases where research has been conducted with paediatric populations, it has often been limited to single chronic condition applications, specific settings (e.g. home, school, community, clinic, hospital), and specific developmental stage brackets.

Overall, the research presented in this thesis substantially contributes to the emerging topic of supported self-management. This thesis fills a gap in existing literature and knowledge by focusing on and detailing the developmental aspects of self-management teaching support approaches delivered to children and young people with chronic conditions across the entire continuum of childhood and adolescence.

Throughout the research program the concept of supported self-management was extensively pulled apart to look at the processes and themes underlying it, including the ever changing and complex interactions that take place between children/young people, their caregivers, and clinicians over time. Identification of the themes and sub-themes from both a theoretical and clinical perspective provides the reader with a more holistic perspective of the concept. A particular strength of the research findings presented in this thesis is that they are applicable across multiple chronic conditions, which substantially increases potential for clinical guidance and usability. In other words, this research takes the concept knowledge currently embedded within specific chronic conditions and age ranges to broader application.

9.3. Summary of the findings on supported self-management

To begin this section, I present the results of a preliminary analysis of the themes of supported self-management identified throughout my PhD research program. The aim of this simple analysis was to confirm the proof of concept both in theoretical and practical settings. I did not, in this preliminary analysis, seek to identify the degree to which the theoretical themes identified compare to the practical themes identified.

Together, the theoretical and practical findings of this research support the working hypothesis that *'children and young people are not just little adults when it comes to supported self-management.'* The specific new knowledge contributed by this thesis included:

- Exposure that current clinical guidelines promoting developmentally supported self-management lack a clearly articulated evidence base
- Insights into the processes of how children and young people develop self-management skills and healthcare behaviours across the paediatric continuum from infancy to older adolescence, including transferring of responsibility for self-management tasks between a child/young person and their caregivers
- A shared interdisciplinary and international understanding of the concept of supported self-management that can be used across international clinical and research settings
- A generic framework for developmentally supported self-management teaching and support approaches that are broadly applicable across chronic conditions

Four themes underpinning supported self-management were also identified to be true both from a theoretical and practical perspective - i.e. the themes were consistent across the two systematic reviews (Chapters 4 and 7), the concept analysis (Chapter 6) and the Delphi censuses study (Chapter 8):

1. It is a **layered** and **multi-dimensional** process.
2. **Child-centred** and **individualised** healthcare practices are essential.

3. Children/young people, caregivers and clinicians need to work together in **triadic** partnerships to promote self-management skills and healthcare behaviours that are developmentally appropriate.
4. Self-management teaching and support approaches provided by clinicians need to be **adjustable** and **responsive**.

Each of these themes is described further below and a plan for an expanded analysis is presented later in future directions (Section 9.7). Importantly, all these underpinning themes are in-line with existing research completed by internationally regarded expert groups, including those led by A. Modi, J. Mammen, I. Coyne, T. Creer, M. Kelo, K. Hanna, C. Decker, P. Lozano, A. Houtrow, and K. Lange [23, 24, 80, 98, 132-134, 266, 339, 340, 351]. Consistency with the existing literature serves to further enhance the evidence base for supported self-management.

9.3.1. A layered and multidimensional process

The concept of supported self-management was found to be a **layered** and **multidimensional** process with many characteristics that must be tailored to meet each child/young person's unique needs. For self-management teaching and support approaches to be suitable, complex issues need to be negotiated, including learning capacity, developmental needs of the child/young person, potential differences in expectations, and the shifting of responsibility between the child/young person and their caregivers for self-management tasks.

This thesis presents the first definition of *supported self-management* to be underpinned by a Delphi consensus process:

> *'Supported self-management is a process where young people develop a broad set of attributes, behaviours, and skills to help them minimize the impacts of their condition on all aspects of life for themselves and their caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills' [9]*

By incorporating the developmental trajectory for children/young people and acknowledging the subsequent shifts in their ability to complete self-management tasks, the above definition elaborates on previous attempts to define the concept [251, 263, 266, 271].

9.3.2. Child-centred and individualised practices

The need for child-centred and individualised approaches to supported self-management practices was evident in the research findings of several of the studies completed (Chapters 4, 6, 7 and 8). While it was clear that children and young people will follow a predictable developmentally related trajectory of self-management skill development and mastery, it was also clear that they will develop these skills and healthcare behaviours at different rates from each other.

Supported self-management tasks involving basic mechanical skills and rote learning are expected to be required at an earlier age (e.g. a child with a chronic condition(s) remembering the names of clinicians they see regularly, or child with T1DM manually giving an insulin dose). Other tasks learnt earlier include more complex tasks where there is a clear and temporally associated adverse outcomes (e.g. a child with T1DM and not taking insulin, or a child CF and not taking pancreatic enzyme supplements). Skills learnt later were found to be those that related to preventative strategies and skills that involved judgement, decision making and/or the manipulation of the environment and emotions, or ones that involved complex problem solving and self-regulation.

In paediatric healthcare settings (including primary, secondary and tertiary environments), self-management teaching and support approaches need to be tailored to the individual, provided in a positive way (i.e. what the child/young person can do), and focused on healthcare behaviour goals that are relevant to the child/young person. It is important to involve the child/young person in self-management of their condition/s from early childhood and to continue their involvement throughout the developmental trajectory and into adulthood. Caregivers also need to be considered and consulted. Clinicians need to be aware that the child's/young person's views towards self-management may be different from that of the caregivers (and potentially also those of the clinical team).

9.3.3. Triadic partnerships

To achieve effective self-management children/young people, caregivers and clinicians need to work together in triadic partnerships that are collaborative. As explored in detail in this thesis, children and young people (especially those in infancy and the early childhood developmental stages) cannot self-manage alone. They are on a trajectory of developing self-management skills and healthcare behaviours and, thus, the responsibility for completing self-management tasks will shift between the child/young person and their caregivers. Clinicians play an essential role in providing guidance as to the appropriate transfer of self-management responsibilities.

As clinicians play a key role in assisting children and young people to develop self-management capacity that is appropriate to their developmental stage, clinical instructions and information provided should be guided by broader considerations such as the individual's capacity to learn and their life situation. Clinicians can help caregivers set realistic expectations for their child's/young person's self-management. An important way that clinicians can achieve this is to inform caregivers of the predictable developmentally related trajectory of self-management skill development and mastery. It is, however, also important for clinicians to remember that just because a child/young person may be capable of performing supported self-management tasks does not mean that they will do these tasks. Clinicians may need to encourage caregivers to stay involved (in a supervisory capacity) with their child's/young person's self-management practices long beyond when the child/young person first begins being capable of completing them autonomously. Furthermore, clinicians should not assume that within a family unit the child/young person and their caregivers communicate about the sharing of self-management responsibilities or about the changes in expectations that each may develop over time.

9.3.4. An adjustable and responsive approach

Clinicians and healthcare policy makers need to be responsive to the complex and ever-changing interplay of healthcare roles and responsibilities between each child/young person and their caregivers. Trepidation from within the family unit needs to be actively discussed and monitored on an ongoing basis (e.g. fear of the risk of mortality with increasing self-management responsibility by their child/young person).

9.4. Methodological contributions

This thesis has also presented a rigorous new interdisciplinary method of concept analysis (Chapter 6). The Saxby–Page Concept Development Technique combines components from existing concept analysis methodology with systematic review processes, qualitative synthesis approaches, and a confidence assessment measure.

9.4.1. Further development and evaluation of the new concept analysis method

Discussions have been had with other research groups to use the Saxby–Page Concept Development Technique to investigate the concepts of *professional practice* and *compassion in mental health care*. In the future, comparative work will also need to be done to determine if the various steps apply equally, or whether there are nuances/variations for different healthcare settings (e.g. primary vs secondary vs tertiary environments), stakeholder populations, and contexts (e.g. emerging versus mature concepts). In an ideal setting, this comparative work would be completed by various research groups to help establish the credibility of the new concept analysis method.

9.5. Limitations of the work presented in this thesis

All research approaches have potential shortcomings and limitations. Acknowledging the limitations of the research presented in this thesis in no way decreases the value of the contributions made. Conversely, an accurate context to the research findings is made through the acknowledgement of the limitations. In this section, I discuss the research design, data and impact limitations.

9.5.1. Research design limitations

It is important to remember that the research presented in this thesis was predominately exploratory, theoretical and conceptual in nature and, thus, further practical interpretation and implementation of the findings within paediatric healthcare settings is required. This approach to understanding supported self-management was taken in recognition of the limited research to date on the topic. By offering a clinical perspective, the Delphi consensus study presented in Chapter 9 helped to complement and strengthen the theoretical research components.

The population groups studied in this PhD program were mostly limited to asthma, CF and T1DM as examples of paediatric chronic conditions. These three conditions vary in severity and treatment regimens but they all share a commonality in that they require children/young people and their caregivers to complete daily self-management tasks. Examination of three different chronic conditions with no restriction on settings allowed for the distillation of common themes of the current evidence that is available, allowing findings to be presented in a generalisable framework.

Mental health, developmental disability (includes learning disabilities), and culturally and linguistically diverse populations were not considered as part of this research program. A level of consideration and caution needs to be employed when generalising the findings to these specific groups. Furthermore, also not studied was the complex influence of relationships on development of children's/young people's supported self-management skills and healthcare behaviours. More focused enquiry into the role of caregivers (and wider family influences) is needed. Also, this research did not go directly to children/young people and their caregivers to gather their perspectives.

9.5.2. Data limitations

The deliberate choice in research methodology (i.e. pragmatic, mixed methods, predominately theoretical/conceptual in nature) warranted some additional data considerations. Primary data collection was limited to one study – the Delphi consensus technique presented in Chapter 8. While the Delphi study utilised clinical academics recognised for their expertise in the area of supported self-management across three developed English-speaking countries, it did not include male or developing country representation. The other three studies completed as part of this research program involved the use and interpretation of secondary data that was not specifically designed to reflect a longitudinal and developmental trajectory of how children and young people develop self-management skills and healthcare behaviours over time. Use of pooled secondary data, however, can be a powerful research tool in areas where there is little research available such as this.

Supported self-management is an emerging topic area that is also likely to be conducive to incremental research findings.

9.5.3. Impact limitations

An interdisciplinary approach, as was undertaken in this research program, has become an important aspect of paediatric health care. The interdisciplinary approach brings together the knowledge and experience from more than one discipline, in turn creating clinical teams and enhancing the supported self-management' experience for children and young people.

One of the common challenges of completing interdisciplinary research is a lack of a 'common language' and a shared understanding of a concept. It can be difficult to work on a research problem when members of the research team have been trained to approach it from different directions. This limitation was addressed through the completion of the concept analysis (Chapter 6) and Delphi (Chapter 8) studies, which sought to gain a shared understanding of the topic of supported self-management.

9.6. Recommendations

In light of the summary and discussion of findings provided in this chapter, a number of overarching recommendations pertaining to supported self-management are provided. Where possible, a discussion on the ways that clinicians can translate the new evidence into their everyday practice is presented.

Recommendations relate to four main areas:

1) Involvement of children and young people in the care of their own chronic condition(s) beginning from time of diagnosis and being a process that they undertake as part of lifelong learning to self-manage their chronic condition(s)

2) Designing and implementing teaching and support approaches that meet the developmental needs of children and young people
3) The need for updated clinical guidelines that better reflect the needs of children/young people and their caregivers
4) Suggestions to improve the transition process from paediatric to adult healthcare services

9.6.1. Lifelong supported self-management learning

Clinicians need to encourage children and young people to learn about how to manage their chronic conditions and to actively participate in supported self-management from the time of diagnosis. Learning about supported self-management needs to be lifelong and continue into adulthood. For some individuals this process will begin in the early childhood years (especially relevant for individuals with CF who are generally diagnosed during infancy).

When working with children and young people, respect is key. The findings of this research suggest that it may be advantageous to involve children/young people and their caregivers equally when discussing supported self-management. Clinicians should be clear, be honest, and keep any education provided to a developmentally appropriate level. It may be necessary to allow additional time during consultations to get to know each child/young person as an individual self-management learner, and to ascertain if there are any differences in expectations of the responsibility for the completion self-management tasks between the child/young person and their caregivers.

Use of structured and sequenced learning, timely feedback and active participation in supported self-management by the child/young person is to be encouraged by both clinicians and caregivers at all developmental stages. These approaches all need to be provided within supportive community (e.g. schools), healthcare and family environments.

For children in the earlier developmental stages (i.e. infancy, early childhood, middle childhood), appropriate strategies include use of stories, puppets and characters to teach simple self-management skills and healthcare behaviours. Educational interventions should focus on self-management tasks that involve basic mechanical skills and rote learning. When used in combination, these strategies encourage children’s imaginations and create positive learning environments.

Young people in the later developmental stages (i.e. younger and older adolescents) are particularly influenced and motivated by their desire for independence and peer acceptance. Where possible, and when infection control guidelines permit, opportunities should be provided for young people to interact with others who have the same or similar chronic conditions. If socialising isn't possible, then mobilisation of social network communities is a viable option (e.g. Facebook groups).

Caregivers are an essential factor in the success of a child/young person's ability to effectively participate in self-management. It should be recognised that the wider family unit needs just as much support, education, time and attention in parallel with the child/young person. The salience of family support during adolescence should not be underestimated to minimise sources of conflict and differences in self-management expectations. Areas of future research could include the impacts that styles of parenting, family make-up, and socio-economic demographics have on supported self-management skill and healthcare behaviour development.

9.6.2. Designing supported self-management teaching and support approaches specifically for children and young people

The benefit to the individual, their family and healthcare system of having supported self-management teaching and support approaches that are specifically designed to meet the needs of children and young people at various developmental stages is considerable. As models and frameworks for paediatric supported self-management become available, they need to be embedded within relevant medical, nursing and allied health teaching practices and included in clinical guidelines.

9.6.3. Updating clinical guidelines

Guideline recommendations with a stronger evidence-base that help guide clinicians in how to deliver supported self-management are desperately needed (Chapter 5). Through the literature-based and conceptual work completed during the later stages of this research program, it was found that there is sufficient (methodologically sound) evidence available to inform recommendations specific to self-management education and teaching approaches that are developmentally appropriate. Guideline working groups need to consider the foundational work of D. Evans, S. McGhan, G. Ernst, J. Bruzzese and others in this area [80, 85, 125-131, 187]. Conversely, there is much less available literature on the skill set paediatric clinicians need to have in order to support children and young people in developing self-management skills and healthcare behaviours, including how to assess children's and/or caregivers' knowledge about chronic conditions and treatments.

9.6.4. Improving transition practices from paediatric to adult care

It is important that adult healthcare services recognise where older adolescents and young adults are at with their capacity to autonomously self-manage at the time of transfer. One way this can be facilitated is by paediatric clinicians providing a detailed interdisciplinary handover to adult healthcare service providers that acknowledges medical management through a self-management lens. Adult services can also benefit from adoption of proven adult-based self-management models such as the Wagner Chronic Care Model [29]. Similar to the findings presented in this thesis for children and young people, proven adult self-management models include the promotion of individual active participation, collaboration between the adult and their healthcare team, and utilising an interdisciplinary workforce trained in chronic condition self-management [26].

9.7. A supported self-management framework for all?

The findings of this thesis create a conceptual framework for supported self-management. While caution must be applied when using the framework for conditions other than the focus conditions, the framework is generic in nature and thus is appropriate for use with all children and young people – including those living with developmental disability and/or mental health conditions, different cultural beliefs, language and socioeconomic disadvantage. For these groups, clinicians need to be aware that:

- developing self-management skills is an individualised process
- children and young people with special needs may have significant issues when compared to their peers in the general population. These can include:
    - reduced cognitive and motor functioning
    - sensory impairments (vision and hearing)
    - pubertal delays and sexual health concerns
    - social and financial vulnerabilities
    - multiple co-morbidities
    - antisocial and other difficult behaviours
    - increased parental concerns with achieving the right balance of protection versus independence
    - increased difficulty with peers and self-acceptance
- it is important to identify early key clinicians who can help with the supported self-management journey
    - some children and young people with chronic conditions may be eligible for paediatric health care services but may not fit eligibility criteria for transfer to adult services when then come of age
    - general practitioners are often the only consistent clinicians through the transition process from paediatric to adult care

- additional supports may be for children and young people with special needs (e.g. involve a psychologist as part of the self-management support team or consider enhanced collaboration across sections such as education, justice, welfare, youth centres).

9.8. Future directions

Following the submission of this thesis, a study will be designed to further compare the degree to which the theoretical themes of supported self-management identified through completion of the concept-analysis study (Chapter 6) align with practical opinions of the clinical academics on supported self-management identified through the completion of the Delphi consensus study (Chapter 8).

From the perspective of clinicians and healthcare policy makers, the findings of this research are relevant because they will influence how self-management support and education approaches are delivered to children and young people at various developmental stages. More work is required to evaluate whether the findings of this research program can be used broadly in a generic way across paediatric chronic conditions, including the appropriateness and usefulness of the new Partners in Health: Self-Management Consensus List for Children and Young People. Gathering feedback from children/young people, their caregivers and wider family members about the format and appropriateness of this new tool is a potential future research project. Furthermore, researchers need to test when a child/young person can actually perform each self-management task and if supported self-management results in improved quality of life/health outcomes.

Another important future research area is developing a scale that can measure the self-management capacity of children and young people at various developmental stages. Objective measurement of self-management capacity helps identify the degree of participation people have in the management of their chronic conditions and guides clinicians in determining person-centred care. The (Adult) Partners in Health Scale, a self-report generic questionnaire, has previously been developed to capture the self-management of adults and older adults with chronic conditions [352, 353]. Recent work has also seen the scale translated and validated for several other languages, including French and Dutch [353, 354]. However, a paediatric version of the Partners in Health Scale capacity assessment measure that has broad application across chronic conditions has yet to be developed. In the context of supporting children to become autonomous self-managers, it is crucial that the most effective, cost-effective, and age-appropriate capacity assessment measures are employed.

9.9. Closing statement

To conclude, the key overarching message that came from this research program is that development of self-management skills and healthcare behaviours is a complex and lengthy process. Attainment of self-management skills and healthcare behaviours occurs over time and needs to be tailored to each individual child/young person and their developmental stage, and to the needs and preferences of their caregivers and wider family. It is anticipated that using a ‘developmental lens’ will enhance clinicians’ foundational knowledge of how children and young people develop supported self-management skills and healthcare behaviours. Ultimately, supported self-management needs to be re-positioned as a central component of paediatric health care for chronic conditions, running alongside the medical, nursing and allied health clinical input.

Appendix A

Evidence of conference proceedings and invited presentations/workshops

Conference proceedings **[13]**

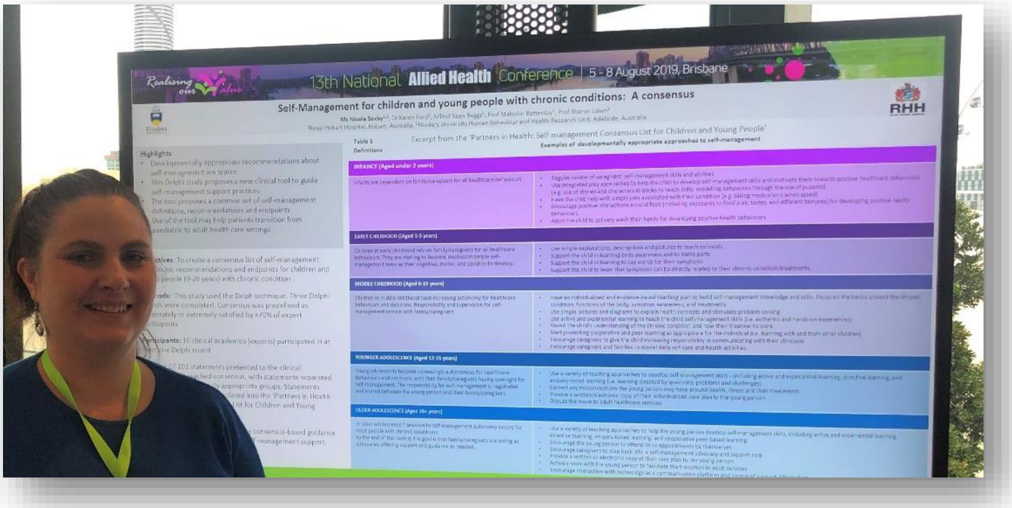
1A) N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn, Self-management for children and young people with chronic conditions: An international consensus, 13th National Conference of Allied Health, Brisbane, Australia, August 2019.

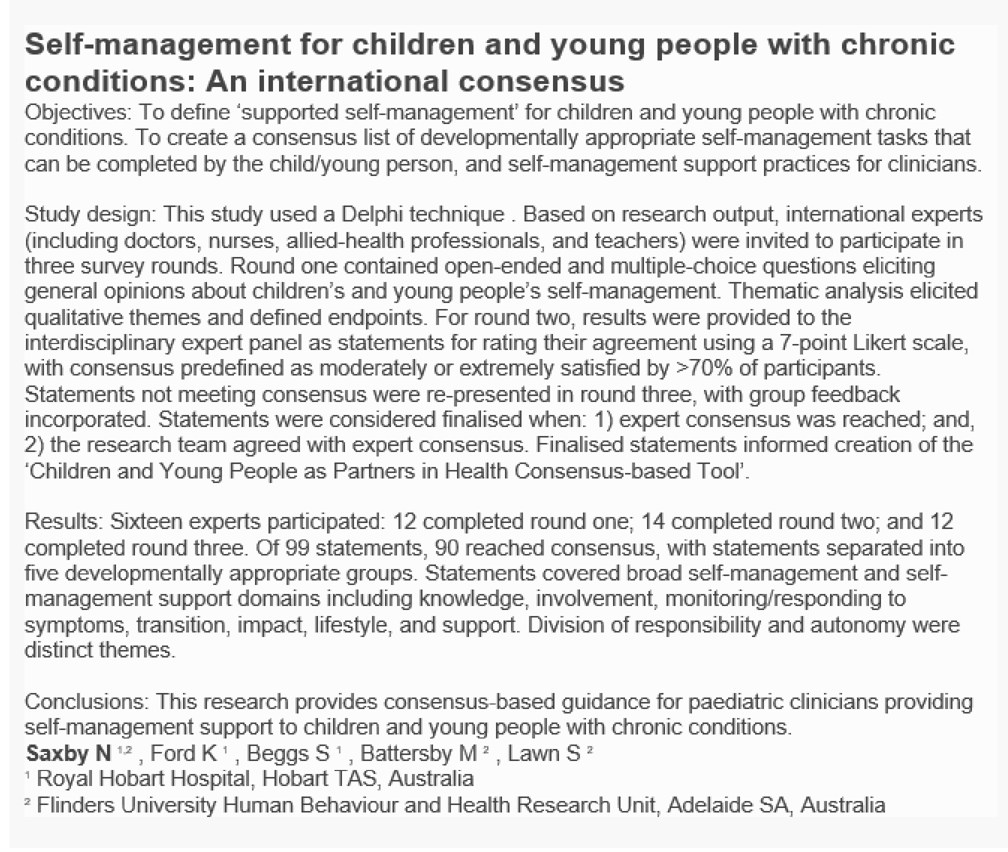
Invited presentations/workshops **[14, 15]**

2A) N. Saxby, Moving on UP: Paediatric Chronic Condition Self-Management, Grand Rounds Royal Hobart Hospital; Tasmanian Health Service South, Hobart, Australia, November 2018.

3A) N. Saxby, R. Littlewood, T. O'Sullivan, C. Collins, V. Kinghorn, Workshop – Empowering children in clinical and research settings. 36th Dietitians Association of Australia National Conference, Gold Coast, Australia, August 2019.

1A)





Self-management for children and young people with chronic conditions: An international consensus

Objectives: To define 'supported self-management' for children and young people with chronic conditions. To create a consensus list of developmentally appropriate self-management tasks that can be completed by the child/young person, and self-management support practices for clinicians.

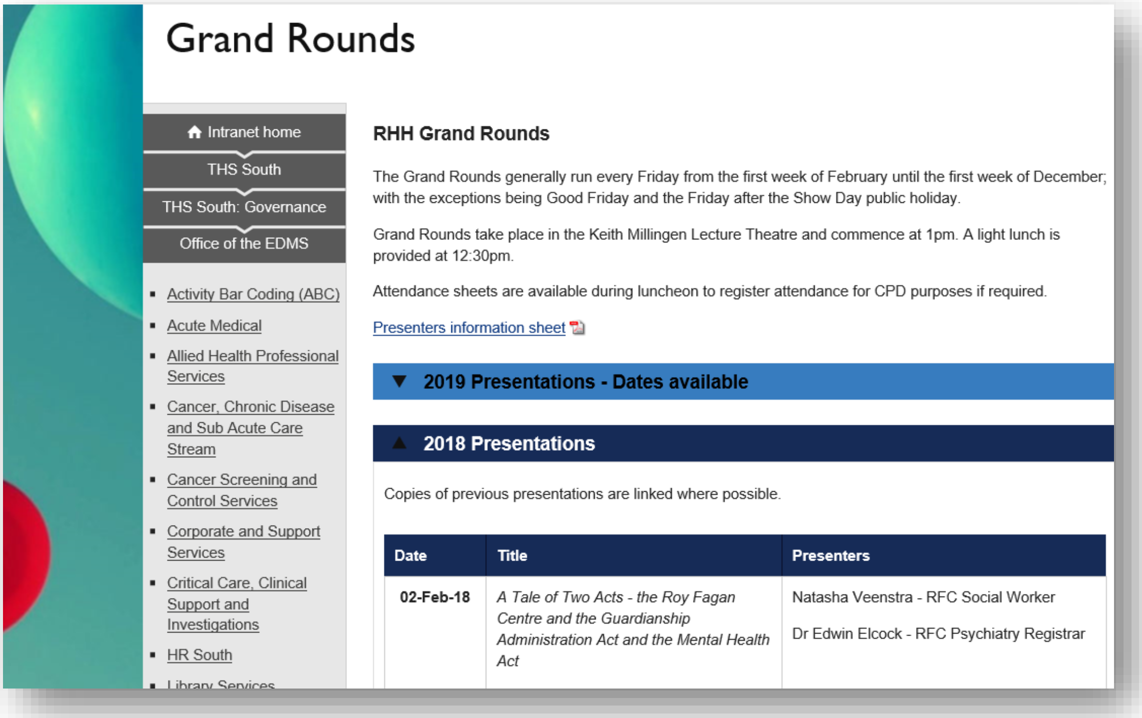
Study design: This study used a Delphi technique . Based on research output, international experts (including doctors, nurses, allied-health professionals, and teachers) were invited to participate in three survey rounds. Round one contained open-ended and multiple-choice questions eliciting general opinions about children's and young people's self-management. Thematic analysis elicited qualitative themes and defined endpoints. For round two, results were provided to the interdisciplinary expert panel as statements for rating their agreement using a 7-point Likert scale, with consensus predefined as moderately or extremely satisfied by >70% of participants. Statements not meeting consensus were re-presented in round three, with group feedback incorporated. Statements were considered finalised when: 1) expert consensus was reached; and, 2) the research team agreed with expert consensus. Finalised statements informed creation of the 'Children and Young People as Partners in Health Consensus-based Tool'.

Results: Sixteen experts participated: 12 completed round one; 14 completed round two; and 12 completed round three. Of 99 statements, 90 reached consensus, with statements separated into five developmentally appropriate groups. Statements covered broad self-management and self-management support domains including knowledge, involvement, monitoring/responding to symptoms, transition, impact, lifestyle, and support. Division of responsibility and autonomy were distinct themes.

Conclusions: This research provides consensus-based guidance for paediatric clinicians providing self-management support to children and young people with chronic conditions.

Saxby N [1,2] , Ford K [1] , Beggs S [1] , Battersby M [2] , Lawn S [2]
[1] Royal Hobart Hospital, Hobart TAS, Australia
[2] Flinders University Human Behaviour and Health Research Unit, Adelaide SA, Australia

2A)



- Activity Bar Coding (ABC)
- Acute Medical
- Allied Health Professional Services
- Cancer, Chronic Disease and Sub Acute Care Stream
- Cancer Screening and Control Services
- Corporate and Support Services
- Critical Care, Clinical Support and Investigations
- HR South
- Library Services

Grand Rounds

RHH Grand Rounds

The Grand Rounds generally run every Friday from the first week of February until the first week of December; with the exceptions being Good Friday and the Friday after the Show Day public holiday.

Grand Rounds take place in the Keith Millingen Lecture Theatre and commence at 1pm. A light lunch is provided at 12:30pm.

Attendance sheets are available during luncheon to register attendance for CPD purposes if required.

Presenters information sheet

▼ 2019 Presentations - Dates available

▲ 2018 Presentations

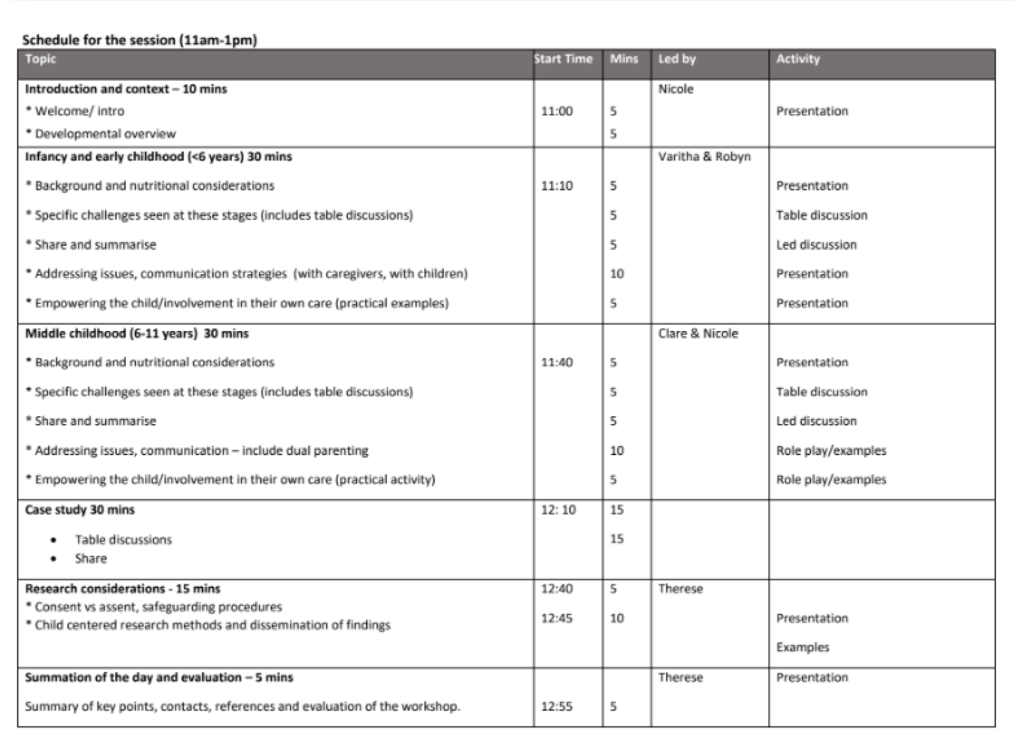
Copies of previous presentations are linked where possible.

Date	Title	Presenters
02-Feb-18	*A Tale of Two Acts - the Roy Fagan Centre and the Guardianship Administration Act and the Mental Health Act*	Natasha Veenstra - RFC Social Worker Dr Edwin Elcock - RFC Psychiatry Registrar

Dates and details of other presentations from Feb to Oct 2018 have been omitted

19-Oct-18	*Methadone - Less is More*	• *Dr Guy Bannink - Staff Specialist, Palliative Care*
2-Nov-18	*Perception of Social Support in Individuals Living with a Diabetic Foot:* *Cochlear Implants: Why is it so Hard to Predict Outcomes*	• *Joshua Palaya, Senior Podiatrist, Podiatry South* • *Lee Kethel Discipline Lead, State-wide Audiology Service*
16-Nov-18	*Radiation Oncology - Stereotactic Ablative Body Radiotherapy (SABR)* Clinical Cases - M Skala Holman Clinic SABR data descriptive analysis - R Awad SABR - M Jones	• *Dr Marketa Skala – Radiation Oncologist / Director of Radiation Oncology* • *Dr Raef Awad – Radiation Oncologist VMO* • *Dr Michael Jones – Radiation Oncologist Staff Specialist*
23-Nov-18	*HealthPathways* *Moving on Up - Presentation* *Moving on Up - Case Study*	• Catherine Spiller, Manager, Health Services Design, *Primary Health Tasmania* • Sal Bucksey, *Health Stream Lead, Primary Health Tasmania* • Nicole Saxby, *State-wide Paediatric Coordinator & Dietician, Tasmanian Cystic Fibrosis Service & THS*

3A)



Schedule for the session (11am-1pm)

Topic	Start Time	Mins	Led by	Activity
Introduction and context – 10 mins			Nicole	
• Welcome/ intro	11:00	5		Presentation
• Developmental overview		5		
Infancy and early childhood (<6 years) 30 mins			Varitha & Robyn	
• Background and nutritional considerations	11:10	5		Presentation
• Specific challenges seen at these stages (includes table discussions)		5		Table discussion
• Share and summarise		5		Led discussion
• Addressing issues, communication strategies (with caregivers, with children)		10		Presentation
• Empowering the child/involvement in their own care (practical examples)		5		Presentation
Middle childhood (6-11 years) 30 mins			Clare & Nicole	
• Background and nutritional considerations	11:40	5		Presentation
• Specific challenges seen at these stages (includes table discussions)		5		Table discussion
• Share and summarise		5		Led discussion
• Addressing issues, communication – include dual parenting		10		Role play/examples
• Empowering the child/involvement in their own care (practical activity)		5		Role play/examples
Case study 30 mins	12: 10	15		
• Table discussions		15		
• Share				
Research considerations - 15 mins	12:40	5	Therese	
• Consent vs assent, safeguarding procedures • Child centered research methods and dissemination of findings	12:45	10		Presentation Examples
Summation of the day and evaluation – 5 mins			Therese	Presentation
Summary of key points, contacts, references and evaluation of the workshop.	12:55	5		

Appendix B

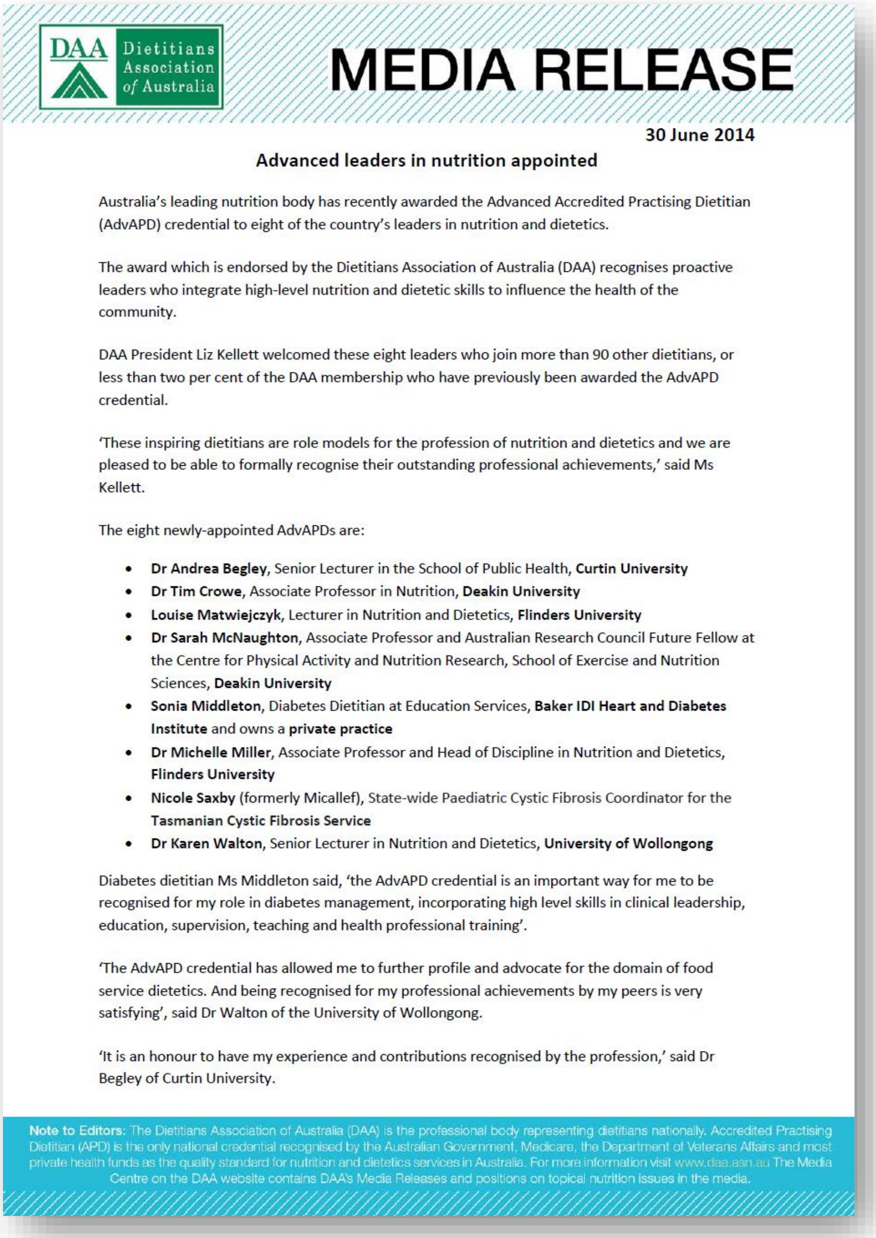
Evidence of awards received during PhD candidature

The skills learnt during my PhD candidature helped me achieve the following professional awards:

1B) Media Release – Advanced Accredited Practicing Dietitian Status, Dietitians Association of Australia, 2014

2B) Practice Evidence in Nutrition – Evidence-Based Practice Prize, Dietitians Association of Australia, 2015

1B) Advanced Accredited Dietitian Status, 2014



DAA Dietitians Association of Australia

MEDIA RELEASE

30 June 2014

Advanced leaders in nutrition appointed

Australia's leading nutrition body has recently awarded the Advanced Accredited Practising Dietitian (AdvAPD) credential to eight of the country's leaders in nutrition and dietetics.

The award which is endorsed by the Dietitians Association of Australia (DAA) recognises proactive leaders who integrate high-level nutrition and dietetic skills to influence the health of the community.

DAA President Liz Kellett welcomed these eight leaders who join more than 90 other dietitians, or less than two per cent of the DAA membership who have previously been awarded the AdvAPD credential.

'These inspiring dietitians are role models for the profession of nutrition and dietetics and we are pleased to be able to formally recognise their outstanding professional achievements,' said Ms Kellett.

The eight newly-appointed AdvAPDs are:

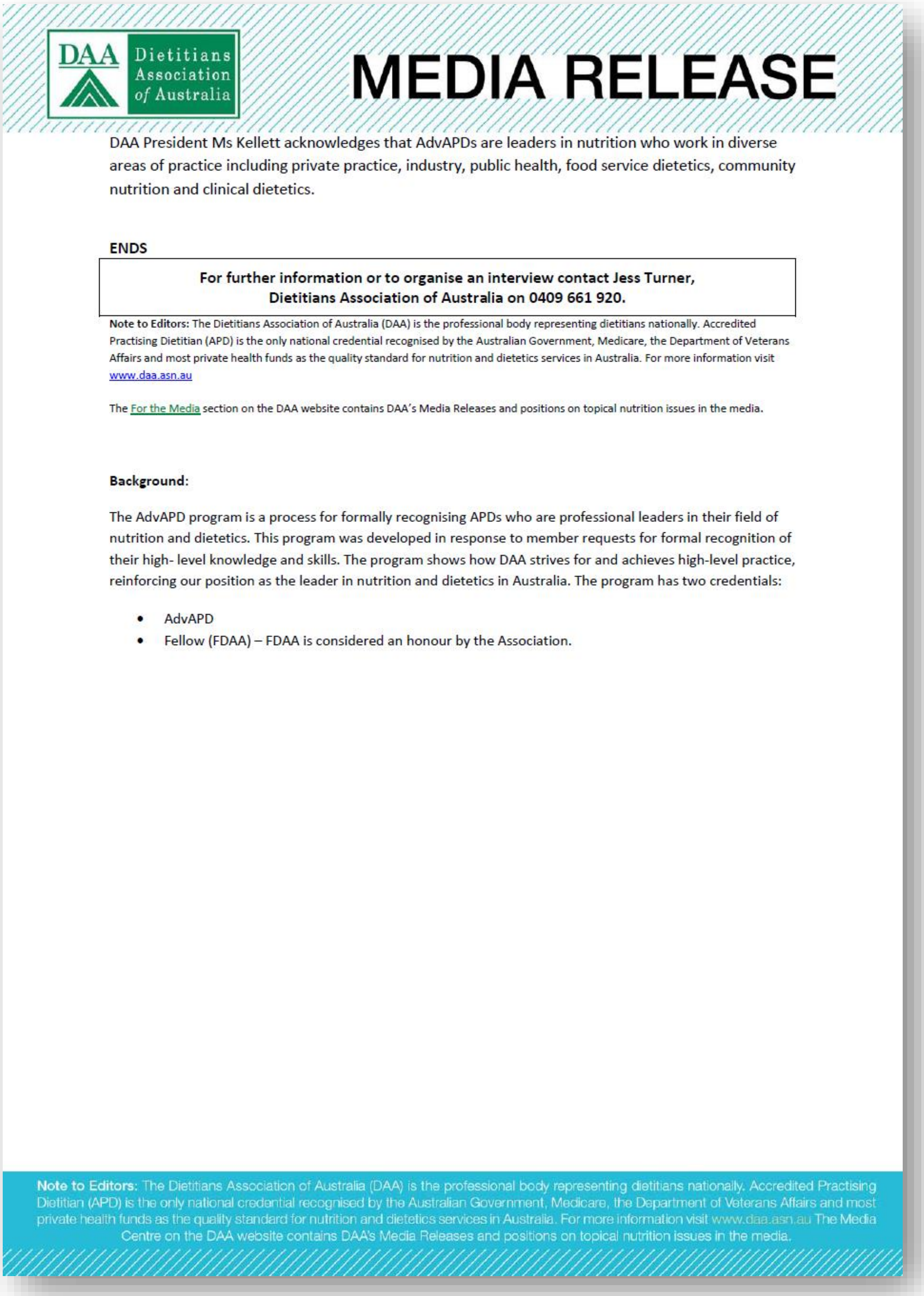
- **Dr Andrea Begley**, Senior Lecturer in the School of Public Health, **Curtin University**
- **Dr Tim Crowe**, Associate Professor in Nutrition, **Deakin University**
- **Louise Matwiejczyk**, Lecturer in Nutrition and Dietetics, **Flinders University**
- **Dr Sarah McNaughton**, Associate Professor and Australian Research Council Future Fellow at the Centre for Physical Activity and Nutrition Research, School of Exercise and Nutrition Sciences, **Deakin University**
- **Sonia Middleton**, Diabetes Dietitian at Education Services, **Baker IDI Heart and Diabetes Institute** and owns a **private practice**
- **Dr Michelle Miller**, Associate Professor and Head of Discipline in Nutrition and Dietetics, **Flinders University**
- **Nicole Saxby** (formerly Micallef), State-wide Paediatric Cystic Fibrosis Coordinator for the **Tasmanian Cystic Fibrosis Service**
- **Dr Karen Walton**, Senior Lecturer in Nutrition and Dietetics, **University of Wollongong**

Diabetes dietitian Ms Middleton said, 'the AdvAPD credential is an important way for me to be recognised for my role in diabetes management, incorporating high level skills in clinical leadership, education, supervision, teaching and health professional training'.

'The AdvAPD credential has allowed me to further profile and advocate for the domain of food service dietetics. And being recognised for my professional achievements by my peers is very satisfying', said Dr Walton of the University of Wollongong.

'It is an honour to have my experience and contributions recognised by the profession,' said Dr Begley of Curtin University.

Note to Editors: The Dietitians Association of Australia (DAA) is the professional body representing dietitians nationally. Accredited Practising Dietitian (APD) is the only national credential recognised by the Australian Government, Medicare, the Department of Veterans Affairs and most private health funds as the quality standard for nutrition and dietetics services in Australia. For more information visit www.daa.asn.au The Media Centre on the DAA website contains DAA's Media Releases and positions on topical nutrition issues in the media.



MEDIA RELEASE

DAA President Ms Kellett acknowledges that AdvAPDs are leaders in nutrition who work in diverse areas of practice including private practice, industry, public health, food service dietetics, community nutrition and clinical dietetics.

ENDS

For further information or to organise an interview contact Jess Turner, Dietitians Association of Australia on 0409 661 920.

Note to Editors: The Dietitians Association of Australia (DAA) is the professional body representing dietitians nationally. Accredited Practising Dietitian (APD) is the only national credential recognised by the Australian Government, Medicare, the Department of Veterans Affairs and most private health funds as the quality standard for nutrition and dietetics services in Australia. For more information visit www.daa.asn.au

The For the Media section on the DAA website contains DAA's Media Releases and positions on topical nutrition issues in the media.

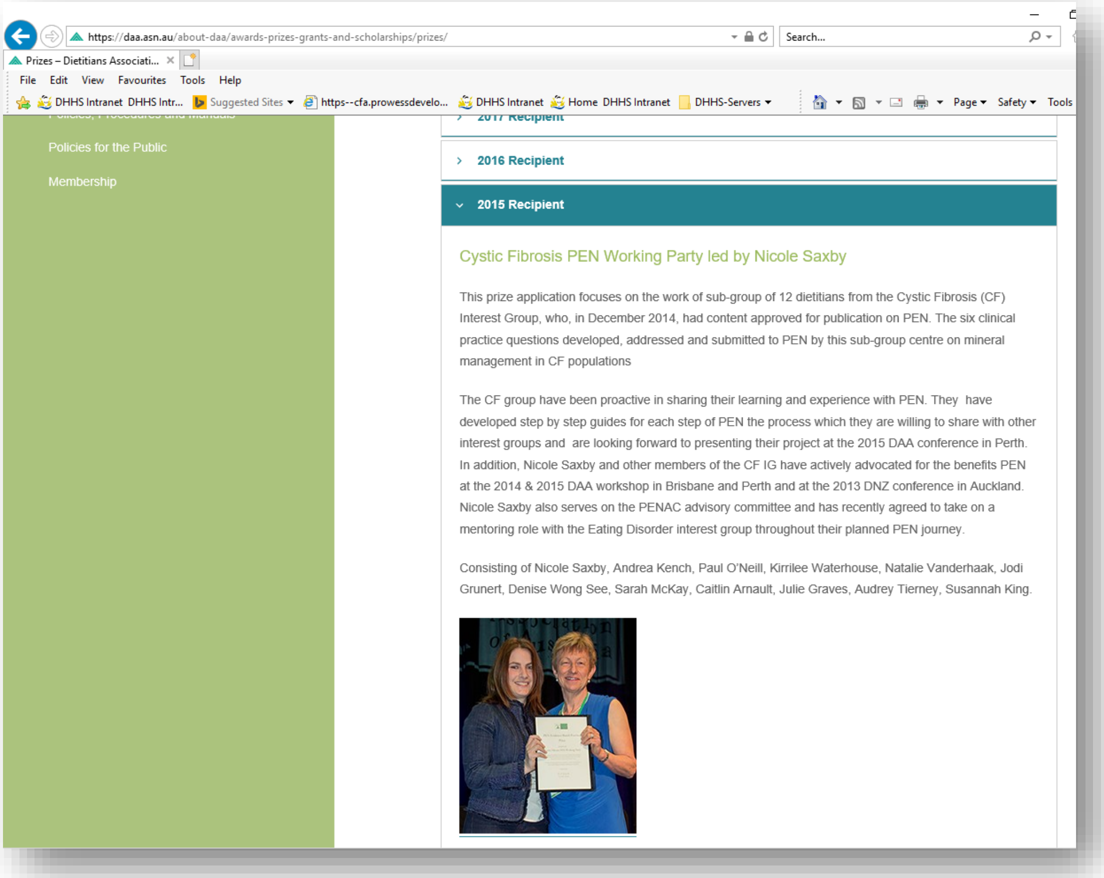
Background:

The AdvAPD program is a process for formally recognising APDs who are professional leaders in their field of nutrition and dietetics. This program was developed in response to member requests for formal recognition of their high- level knowledge and skills. The program shows how DAA strives for and achieves high-level practice, reinforcing our position as the leader in nutrition and dietetics in Australia. The program has two credentials:

- AdvAPD
- Fellow (FDAA) – FDAA is considered an honour by the Association.

Note to Editors: The Dietitians Association of Australia (DAA) is the professional body representing dietitians nationally. Accredited Practising Dietitian (APD) is the only national credential recognised by the Australian Government, Medicare, the Department of Veterans Affairs and most private health funds as the quality standard for nutrition and dietetics services in Australia. For more information visit www.daa.asn.au The Media Centre on the DAA website contains DAA's Media Releases and positions on topical nutrition issues in the media.

2B) Practice Evidence in Nutrition – Evidence-Based Practice Prize, 2015



Cystic Fibrosis PEN Working Party led by Nicole Saxby

This prize application focuses on the work of sub-group of 12 dietitians from the Cystic Fibrosis (CF) Interest Group, who, in December 2014, had content approved for publication on PEN. The six clinical practice questions developed, addressed and submitted to PEN by this sub-group centre on mineral management in CF populations

The CF group have been proactive in sharing their learning and experience with PEN. They have developed step by step guides for each step of PEN the process which they are willing to share with other interest groups and are looking forward to presenting their project at the 2015 DAA conference in Perth. In addition, Nicole Saxby and other members of the CF IG have actively advocated for the benefits PEN at the 2014 & 2015 DAA workshop in Brisbane and Perth and at the 2013 DNZ conference in Auckland. Nicole Saxby also serves on the PENAC advisory committee and has recently agreed to take on a mentoring role with the Eating Disorder interest group throughout their planned PEN journey.

Consisting of Nicole Saxby, Andrea Kench, Paul O'Neill, Kirrilee Waterhouse, Natalie Vanderhaak, Jodi Grunert, Denise Wong See, Sarah McKay, Caitlin Arnault, Julie Graves, Audrey Tierney, Susannah King.

Appendix C

Supplementary files presented with the work in Chapter 1

Limited content from this thesis (e.g. background information from Chapter 4 has been repurposed for publications associated with the 'Moving on UP' program [6, 7]. The 2019 version of the 'Moving on UP' [7] program is included here as an appendix:

Publication [7]

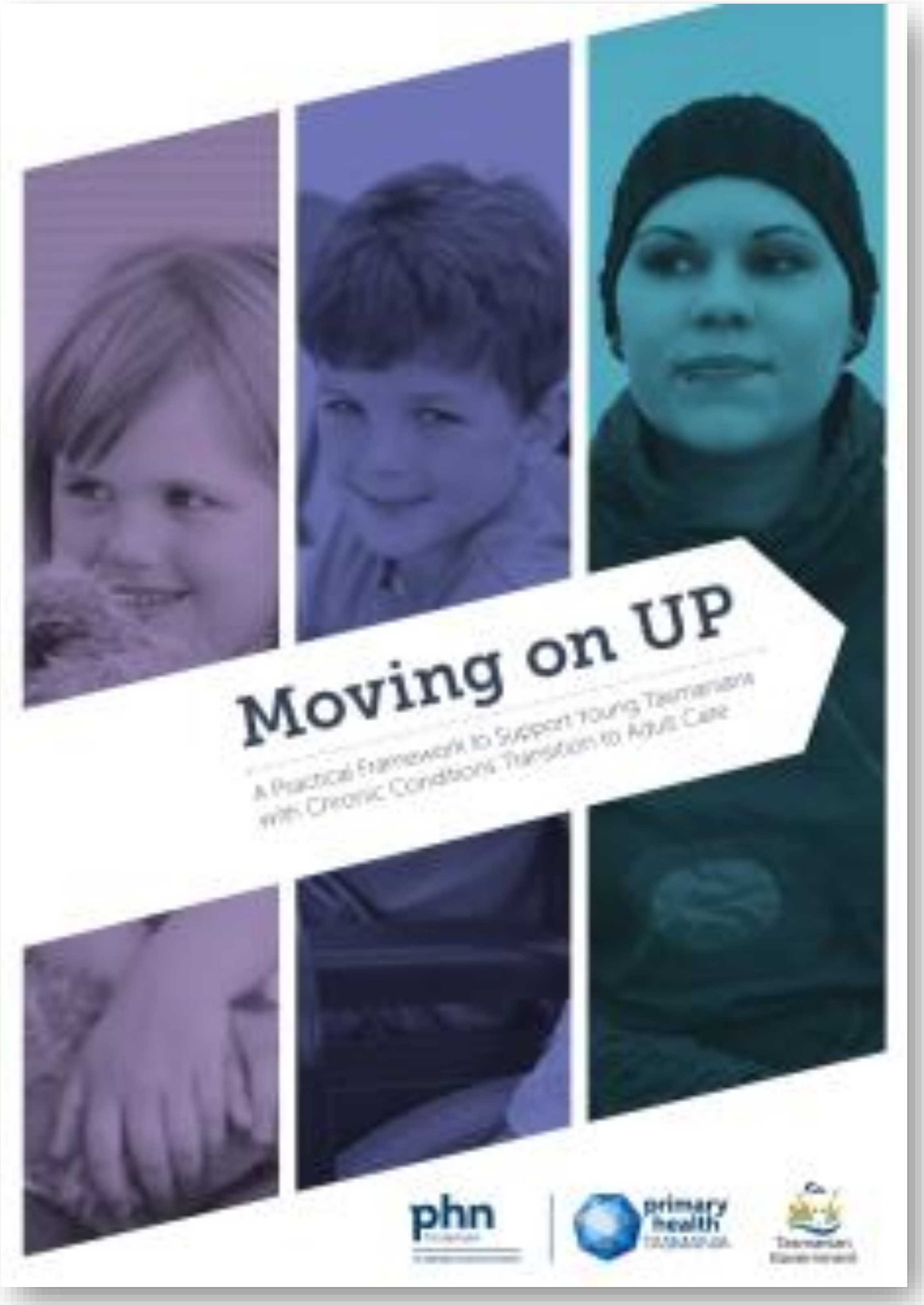
1C) N. Saxby, G. Bassett, S. Beggs, J. Cooper, A. Diffley, K. Ford, C. Hollings, G. Putts, C. Tichanow, R. Wallace, N. Zaluki, P. MacIntyre, A. MacDonald, G. Mebeza, R. Aalton, K. Waterhouse, Moving on UP: A practical framework to support Tasmanian children with chronic conditions transition to adult care, 2nd ed., Primary Health Tasmania and the Tasmanian Government, Hobart, 2019. https://www.primaryhealthtas.com.au/wp-content/uploads/2019/03/Moving-on-Up-Framework.pdf (accessed 24 July 2019)

Media coverage

2C) Media release for 'Moving on UP' (March 2019)

3C) Magazine article on 'Moving on UP' (Primary Health Matters, November 2019)

1C)



Moving on UP

A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care

Foreword

Going through adolescence is hard enough and likely more so if living with a chronic condition. It is a time of vulnerability as there are many things for the individual to sort out – social pressures, mental health, drugs, emerging sexuality, educational decisions, puberty, a growing intellect and deeper level of thinking, self-consciousness, and perhaps increased awareness of what the differences and limitations are in having a chronic health or developmental condition. At the age of 18 years, the move away from trusted wonderful paediatricians, those with whom the young person and their family have been with from the start, through the diagnosis and coping, through to treatments and management of ups and downs of the chronic condition, predisposes to a real vulnerability on emotional and physical health levels. These changes coupled with a completely differently organised adult health service structure can amplify the risk of unnecessary suffering and stress.

A considered and well-planned transition process goes a long way to alleviating some of the stress. *Moving on Up–A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care* is a marvellous initiative addressing this process in our local health services.

The first key message in this document is that transition is a process, not simply a transfer of care. Transition occurs over time and is tailored to each individual young person, their family/caregivers, their developmental stage, their chronic condition, and with appropriate cultural considerations. The second point is that it is important to identify and engage adult health professionals early in the transition process so that the young person feels comfortable with differences in service provision when the transfer occurs, and to set clear start and end points for the transition process. The third point is to allow patients and health professionals time to support a mutual task of comprehending the scope of services and manner of how young people access these in the adult world. This will include health services from adult specialists, GPs and allied healthcare professionals in adult health settings, with the aims of managing the chronic condition while at the same time facilitating getting on with the rest of emerging adult life. Managing living with a chronic condition while pursuing tertiary education, vocational or life skills training, open, supported, part time or full-time employment, sport and recreational options, managing more mature relationships, making and reaching goals are examples within this scope. Importantly for some, the re-assessment of any associated disability is paramount in this section of transition. This means a re-evaluation of the logistics of building the right disability supports required by that young person to live a financially secure, vocational, social and community rich life, to have access to healthcare including hospitalisation, aids, living healthily, visiting doctors, of being aware of carer and financial supports, and of the National Disability Insurance Scheme.

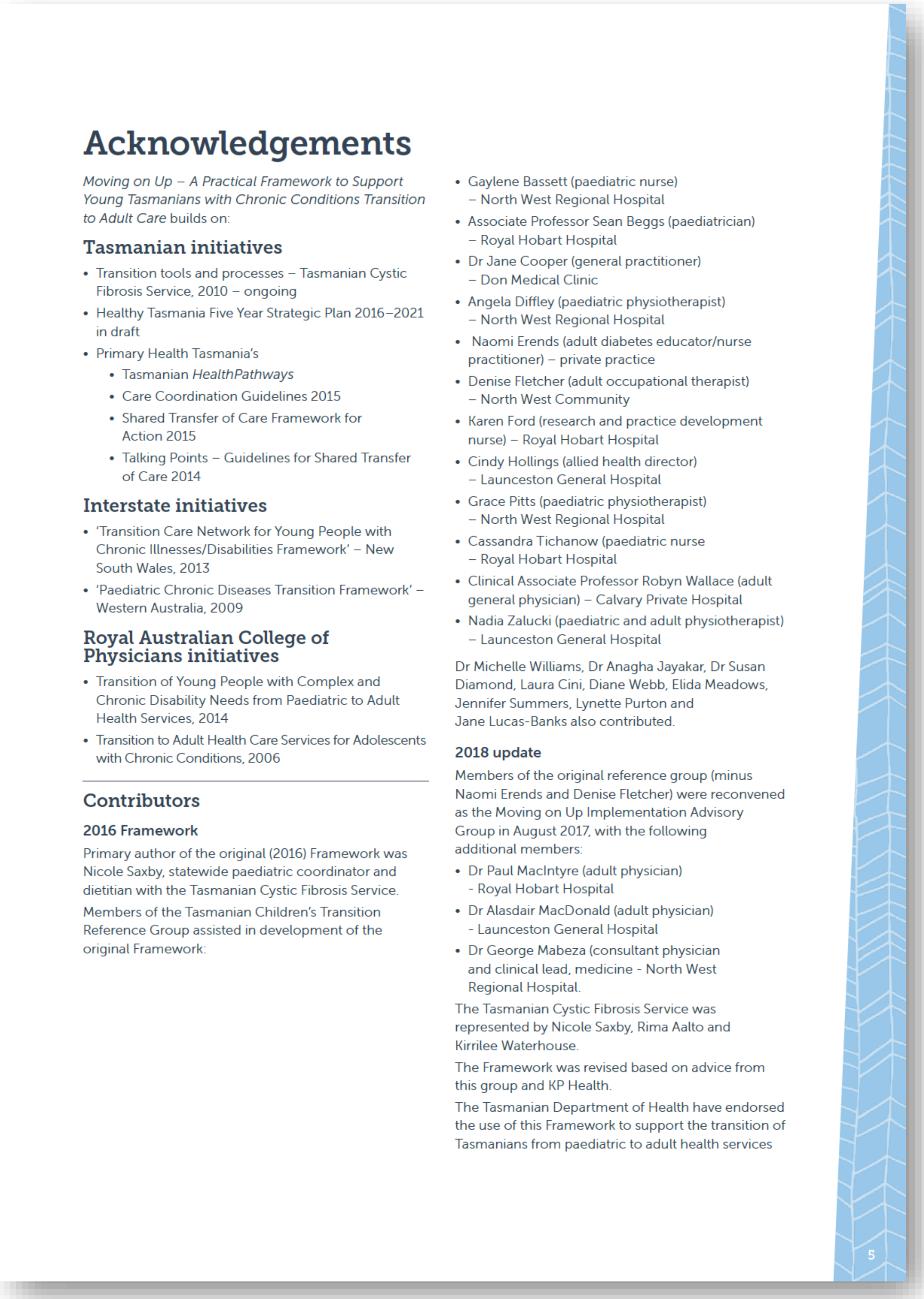
The initiators of the *Framework* have purposely consulted widely and wisely. The presented concept of transition of health care helpfully covers stages of increasing independence within the childhood period and then the critical transition through to young adulthood. The sections of the *Framework* highlighting examples of young people with specific chronic conditions are excellent. The *Framework* is sufficiently non-prescriptive to permit its use and refinement to a more detailed transition depending on differing circumstances of individuals and differing circumstances of chronic conditions. This document is a very pragmatic approach, able to be read by young people, their families and their health professionals and is a wonderful contribution to better healthcare of young Tasmanians with chronic conditions.

Wallace

Clinical Associate Professor Robyn A Wallace
Chair, Tasmanian State Committee
Royal Australian College of Physicians

Contents

4 **Moving on UP** A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care.



Acknowledgements

Moving on Up – A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care builds on:

Tasmanian initiatives

- Transition tools and processes – Tasmanian Cystic Fibrosis Service, 2010 – ongoing
- Healthy Tasmania Five Year Strategic Plan 2016–2021 in draft
- Primary Health Tasmania's
    - Tasmanian *HealthPathways*
    - Care Coordination Guidelines 2015
    - Shared Transfer of Care Framework for Action 2015
    - Talking Points – Guidelines for Shared Transfer of Care 2014

Interstate initiatives

- 'Transition Care Network for Young People with Chronic Illnesses/Disabilities Framework' – New South Wales, 2013
- 'Paediatric Chronic Diseases Transition Framework' – Western Australia, 2009

Royal Australian College of Physicians initiatives

- Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services, 2014
- Transition to Adult Health Care Services for Adolescents with Chronic Conditions, 2006

Contributors

2016 Framework

Primary author of the original (2016) Framework was Nicole Saxby, statewide paediatric coordinator and dietitian with the Tasmanian Cystic Fibrosis Service.

Members of the Tasmanian Children's Transition Reference Group assisted in development of the original Framework:

- Gaylene Bassett (paediatric nurse) – North West Regional Hospital
- Associate Professor Sean Beggs (paediatrician) – Royal Hobart Hospital
- Dr Jane Cooper (general practitioner) – Don Medical Clinic
- Angela Diffley (paediatric physiotherapist) – North West Regional Hospital
- Naomi Erends (adult diabetes educator/nurse practitioner) – private practice
- Denise Fletcher (adult occupational therapist) – North West Community
- Karen Ford (research and practice development nurse) – Royal Hobart Hospital
- Cindy Hollings (allied health director) – Launceston General Hospital
- Grace Pitts (paediatric physiotherapist) – North West Regional Hospital
- Cassandra Tichanow (paediatric nurse – Royal Hobart Hospital
- Clinical Associate Professor Robyn Wallace (adult general physician) – Calvary Private Hospital
- Nadia Zalucki (paediatric and adult physiotherapist) – Launceston General Hospital

Dr Michelle Williams, Dr Anagha Jayakar, Dr Susan Diamond, Laura Cini, Diane Webb, Elida Meadows, Jennifer Summers, Lynette Purton and Jane Lucas-Banks also contributed.

2018 update

Members of the original reference group (minus Naomi Erends and Denise Fletcher) were reconvened as the Moving on Up Implementation Advisory Group in August 2017, with the following additional members:

- Dr Paul MacIntyre (adult physician) - Royal Hobart Hospital
- Dr Alasdair MacDonald (adult physician) - Launceston General Hospital
- Dr George Mabeza (consultant physician and clinical lead, medicine - North West Regional Hospital.

The Tasmanian Cystic Fibrosis Service was represented by Nicole Saxby, Rima Aalto and Kirrilee Waterhouse.

The Framework was revised based on advice from this group and KP Health.

The Tasmanian Department of Health have endorsed the use of this Framework to support the transition of Tasmanians from paediatric to adult health services

1. Introduction

Chronic conditions affect the everyday lives of approximately 40 per cent of young Australians (1) – **that's nearly 64,000 Tasmanians!** (2) See figure 1.

A chronic condition of childhood is:

> *A medical condition of more than [6] months duration, and/or; persistent functional limitations; and/or use of healthcare services beyond usual care (beyond resolvable developmental issues – e.g. preschool speech therapy)* (3 p.1)

This definition has been amended from the 2007 Cincinnati Children's Hospital Chronic Condition Self-Management Guideline (3) to suit the Australian healthcare context. Chronic conditions can range from relatively minor conditions such as allergic rhinitis and asthma which affect up to 1 in 10 children, (1) to more complex conditions such as type 1 diabetes mellitus and cystic fibrosis which affect less than 1 in a 1000 children. (4, 5) **Of particular concern is that a large number of young people who grow up with chronic conditions of childhood fail to successfully transition to adult services.** (6, 7)

It is important for clinicians to recognise that transition is a process, not a single administrative event. (8) The transition process needs to be guided, developmentally appropriate, educational and therapeutic. (8, 9) A well accepted definition of **transition** is:

> *the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from family/child-centred to adult-oriented healthcare systems* (10 p.570)

During childhood and adolescence, there is a gradual shift from parents and other adults supervising all aspects of the child's medical care, to the child and young person taking on increasing responsibilities in self-management. While younger children cannot be expected to assume full responsibility for management of their chronic condition(s), over time they can be encouraged to become more actively involved, together with their family/caregivers and clinicians. There is a growing body of evidence that well planned transition processes, emphasising early self-management support (e.g. educational programs, skills training) and care coordination (e.g. joint clinics run by paediatric and adult clinicians, enhanced follow-up), leads to better health outcomes and quality of life, and a reduction in health service use. (11, 12)

Unlike other Australian states, Tasmania has not had a Framework to guide the transition from paediatric to adult healthcare services in place. The development of this *Framework* addresses this gap and provides healthcare practitioners with a recommended staged process to guide transition, from birth to young adulthood.

Figure 1 estimated percentage of Tasmanian young people (0 – 24 years) living with a chronic condition(1, 2)

The total population of Tasmania is approx 514,792.

Approx 159,784 Tasmanians are aged 0–24.

Approx 40% (nearly 64,000) of Tasmanians aged 0–24 have a chronic condition.

Aim

The aim of *Moving on Up – A practical framework to support young Tasmanians with chronic conditions transition to adult care* (referred to as the *Framework*) is to support successful transition of young people to adult health services. This will optimise young people's health and their ability to adapt to adult life successfully, including developing self-management skills.

Objectives

- to build the self-management skills and abilities of the young person and their family
- to improve the coordination of care of the young person during and after transition
- to strengthen communication and collaboration between service providers and consumers
- to support clinicians to understand and implement the *Framework*.

Practice Point: condition versus disease

The term 'chronic condition' is better suited to the needs of young people than the term 'chronic disease'. Despite these terms often being used interchangeably by clinicians, there are differences between them. 'Condition' refers to a state of health, whether well or ill. (13) In contrast, 'disease' denotes a condition that is characterised by functional impairment, structural change and the presence of specific symptoms, which adversely affect the individual. (13) The *Framework* uses the term 'condition' in place of 'disease', in light of this distinction.

1.1 Self-management and transition

Developing self-management skills helps to prepare young people for transition by enabling them to understand and access the services that they will need in their adult lives. (12)

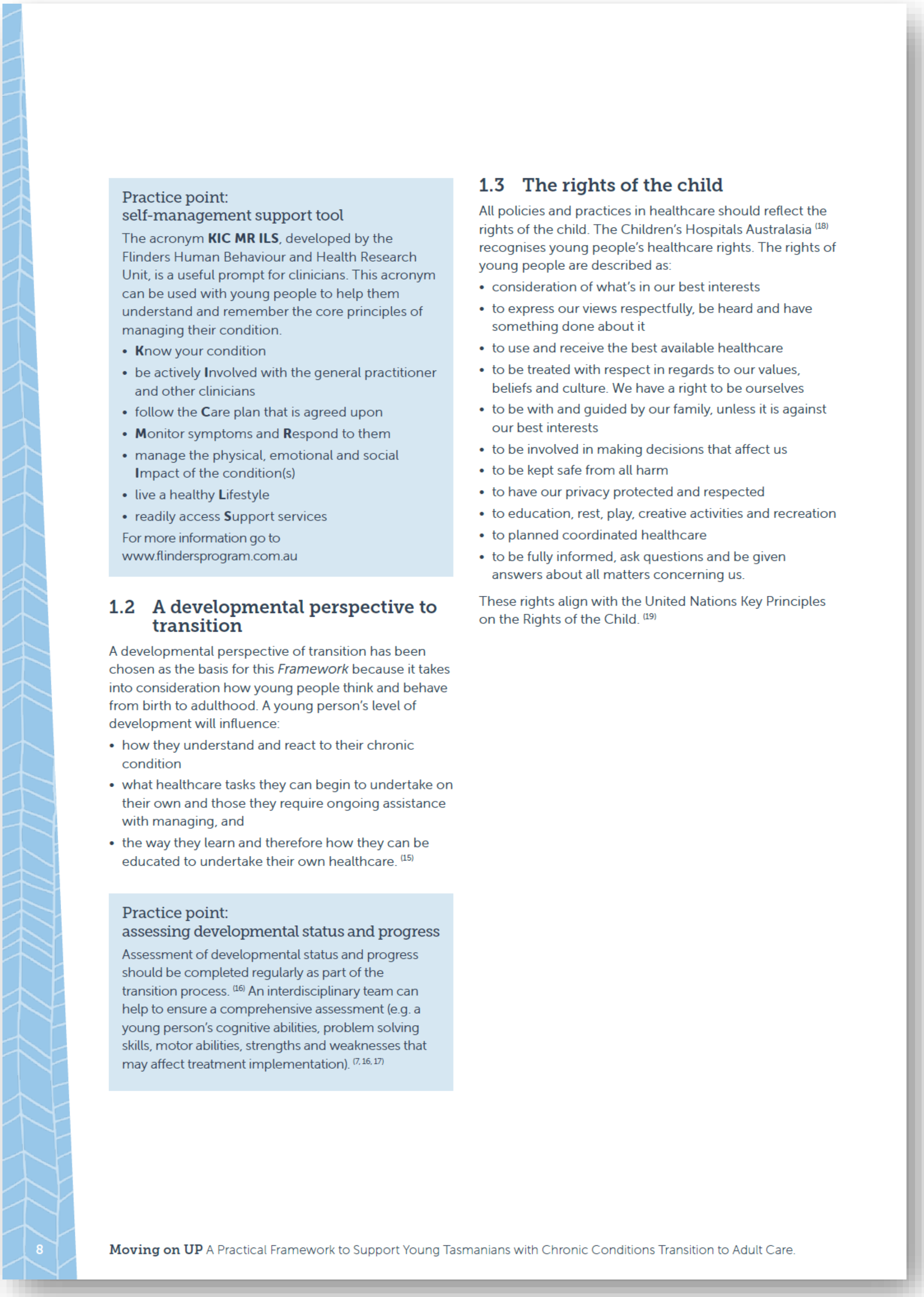
In the context of this *Framework* self-management can mean the young person solely taking on the role, but it may also mean that the ongoing assistance of family members or caregivers is required due to the nature or severity of their condition (or disability) or because it is their choice.

A young person's ability to self-manage is multi-factorial. Clinicians need to be aware of factors that are modifiable and those that are not (i.e. are non-modifiable). Modifiable factors are those that planned interventions can impact on. Non-modifiable factors are those that are not typically targeted in intervention. For more information, see table 1 below:

Table 1 Factors affecting self-management ability in young people (12)

	Modifiable	Non-modifiable
young person	• disease and treatment knowledge • child internalising/externalising symptoms • coping style • health beliefs and perceptions (e.g. self-efficacy, perceived stigma)	• age • gender • developmental level • cognitive functioning (e.g. IQ) • sociocultural factors (e.g. race/ethnicity, religion)
family/caregivers	• disease and treatment knowledge • family internalising/externalising symptoms • family coping style • health beliefs and perceptions • family functioning • relationship quality • parental monitoring and supervision • parental involvement	• parental marital status • family structure • cognitive functioning (e.g. IQ) • insurance coverage • income • education • sociocultural factors (e.g. race/ethnicity, religion)
community	• peer support • social stigma • school-based accommodations related to health • availability of social networking	• neighbourhood • availability of resources to support positive healthcare behaviours
healthcare system	• patient-provider communication • frequency of clinic visits • medical training models	• availability of healthcare resources (e.g. access, including location and frequency and health insurance)

Table above modified from Modi 2012 (12): Table 1, Examples of the influences, processes, and behaviours of paediatric self-management, p. e477



Practice point:
self-management support tool

The acronym **KIC MR ILS**, developed by the Flinders Human Behaviour and Health Research Unit, is a useful prompt for clinicians. This acronym can be used with young people to help them understand and remember the core principles of managing their condition.

- **K**now your condition
- be actively **I**nvolved with the general practitioner and other clinicians
- follow the **C**are plan that is agreed upon
- **M**onitor symptoms and **R**espond to them
- manage the physical, emotional and social **I**mpact of the condition(s)
- live a healthy **L**ifestyle
- readily access **S**upport services

For more information go to www.flindersprogram.com.au

1.2 A developmental perspective to transition

A developmental perspective of transition has been chosen as the basis for this *Framework* because it takes into consideration how young people think and behave from birth to adulthood. A young person's level of development will influence:

- how they understand and react to their chronic condition
- what healthcare tasks they can begin to undertake on their own and those they require ongoing assistance with managing, and
- the way they learn and therefore how they can be educated to undertake their own healthcare. (15)

Practice point:
assessing developmental status and progress

Assessment of developmental status and progress should be completed regularly as part of the transition process. (16) An interdisciplinary team can help to ensure a comprehensive assessment (e.g. a young person's cognitive abilities, problem solving skills, motor abilities, strengths and weaknesses that may affect treatment implementation). (7, 16, 17)

1.3 The rights of the child

All policies and practices in healthcare should reflect the rights of the child. The Children's Hospitals Australasia (18) recognises young people's healthcare rights. The rights of young people are described as:

- consideration of what's in our best interests
- to express our views respectfully, be heard and have something done about it
- to use and receive the best available healthcare
- to be treated with respect in regards to our values, beliefs and culture. We have a right to be ourselves
- to be with and guided by our family, unless it is against our best interests
- to be involved in making decisions that affect us
- to be kept safe from all harm
- to have our privacy protected and respected
- to education, rest, play, creative activities and recreation
- to planned coordinated healthcare
- to be fully informed, ask questions and be given answers about all matters concerning us.

These rights align with the United Nations Key Principles on the Rights of the Child. (19)

2. Scope

2.1 Purpose

The *Framework* is designed to:

- raise awareness among Tasmanian clinicians of the need to support young people to develop the skills, knowledge, and behaviours they and/or their families/caregivers need to manage their own condition as they transition to adult care
- embed a transition focus into everyday practice
- increase understanding of the key elements of transition
- improve transition planning and preparation
- tailor transition processes so that they are developmentally and age appropriate, and
- improve communication, coordination and collaboration between young people, families and their service providers, as well as between the different service providers.

2.2 Target users

The *Framework* has been created for Tasmanians involved in delivering health services to children and young people accessing primary services (e.g. general practitioners, community and youth health nurses, allied health professionals), secondary services (e.g. clinical specialists such as cardiologists), and tertiary services (e.g. hospital coordinated interdisciplinary healthcare team). Clinicians is the term used in this document to refer to the diverse healthcare disciplines and health professionals who are directly involved in care of young people and young adults.

2.3 Target population

The target population of the *Framework* is young people with chronic conditions who access services within the Tasmanian primary, secondary and tertiary healthcare systems. This *Framework* is applicable across life stages from infancy through to late adolescence and early adulthood (birth up to 24* years of age (20)).

The impacts that specific health-related issues, social and economic considerations, cultural influences, and geographical conditions can have for transition are considered in section five: 'Considerations for specific groups' (page 28). Examples of health conditions affecting young people include:

- asthma
- acquired childhood chronic injuries
- cancer
- cystic fibrosis
- diabetes mellitus (type 1 and type 2)
- developmental disabilities (physical, sensory and intellectual)
- eating disorders
- epilepsy
- gastrointestinal conditions
- heart conditions
- juvenile idiopathic arthritis
- mental health conditions
- obesity

* The *Framework* may also be applicable to individuals older than the target age group depending on individual circumstances and geographical isolation.

2.4 How does this *Framework* link with other initiatives?

The *Framework* aligns with the Australian health priority areas and the following documents:

- One State, One Health System, Better Outcomes Delivering Safe and Sustainable Clinical Services. Tasmanian Government White Paper June 2015
- National Statement on Health Literacy, Australian Commission on Safety and Quality in Health Care, 2015
- Primary Health Tasmania's
    - Tasmanian *HealthPathways*
    - Care Coordination Guidelines 2015
    - Shared Transfer of Care – Framework for Action 2015
    - Talking Points – Guidelines for Shared Transfer of Care 2014
- Australian Privacy Principles, Australian Government Office of the Australian Information Commissioner, 2014
- A Framework to Support Self-Management, Department of Health and Human Services, Tasmania, 2012
- The National Safety and Quality Health Services Standards, Second Edition, 2017
    - Standard 1 – Clinical Governance
    - Standard 2 – Partnering with Consumers
    - Standard 6 – Clinical Handover

  www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-second-edition
- National Strategic Framework for Chronic Conditions www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

2.5 Methodology

Primary Health Tasmania facilitated a care coordination program from 2013-16 for clients with complex chronic diseases, funded under the Tasmanian Health Assistance Package. During this time it was identified that Tasmanian clinicians needed more guidance to support young people to successfully transition to adult health care services. Anecdotal evidence for this need was collected through consultation with service providers and consumers across Tasmania.

Collaboration between Primary Health Tasmania and the Tasmanian Health Service from 2015, especially the cystic fibrosis program, led to the development of Moving on UP – *A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care.*

The *Framework* builds on a long-standing quality improvement project (since 2010), aiming to improve the transition process for young people with cystic fibrosis.

Two key authors, plus a project officer coordinated the development of the *Framework*. A reference group of clinicians working in paediatrics, primary health care, general practice and adult services was convened to assist in the development of the *Framework*.

Regular meetings were held with the reference group to discuss priority topics to be included in the Framework. Draft versions of the Framework were completed and sent to the reference group members for discussion, revision and comment. Preliminary feedback was requested from the Tasmanian Health Service Women and Children's Clinical Advisory Group.

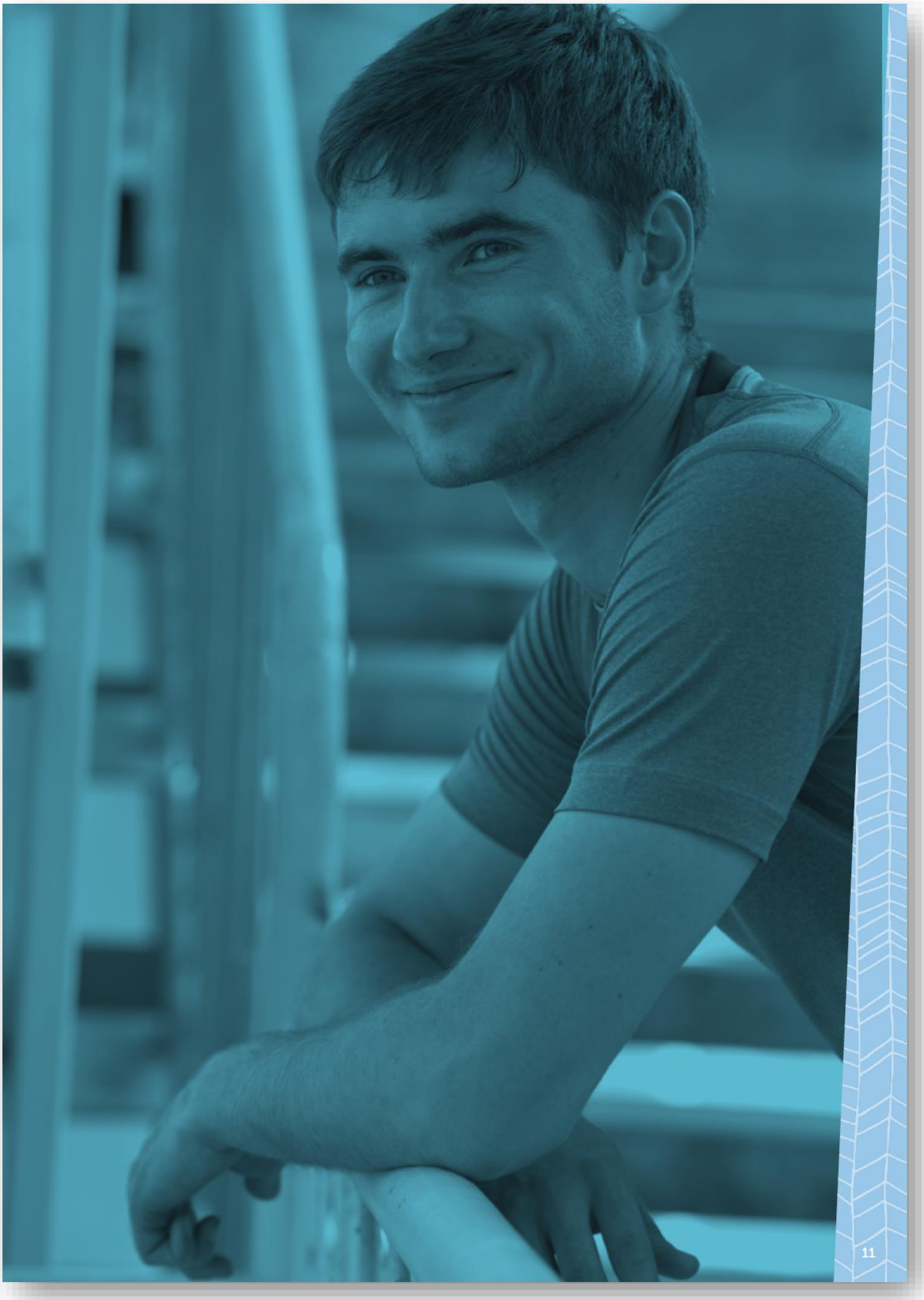
The *Framework* was released for public consultation, as recommended by the National Health and Medical Research Council,(21) from 26 October 2015 to 27 November 2015. Twelve submissions were received from health departments, non-government organisations and individual clinicians; comments were integrated into the final document.

In 2017, an external review of the *Framework* was undertaken to inform the development of resources and tools to support its implementation.

The review confirmed the *Framework* is consistent with best practice in supporting young people with a chronic condition transitioning from paediatric to adult services as reported in the international peer-reviewed literature and reflected in national and international guidelines for supporting transition.

It is important to recognise that this is an evolving area of practice, where national and international research is continuing to contribute to a policy environment that is both iterative and emerging. It is important that over time the *Framework* be reviewed to ensure continued best practice in supporting young people with a chronic condition transitioning from pediatric to adult services.

The Reference Group was reconvened as an Advisory Group to provide expert advice to support the implementation phase.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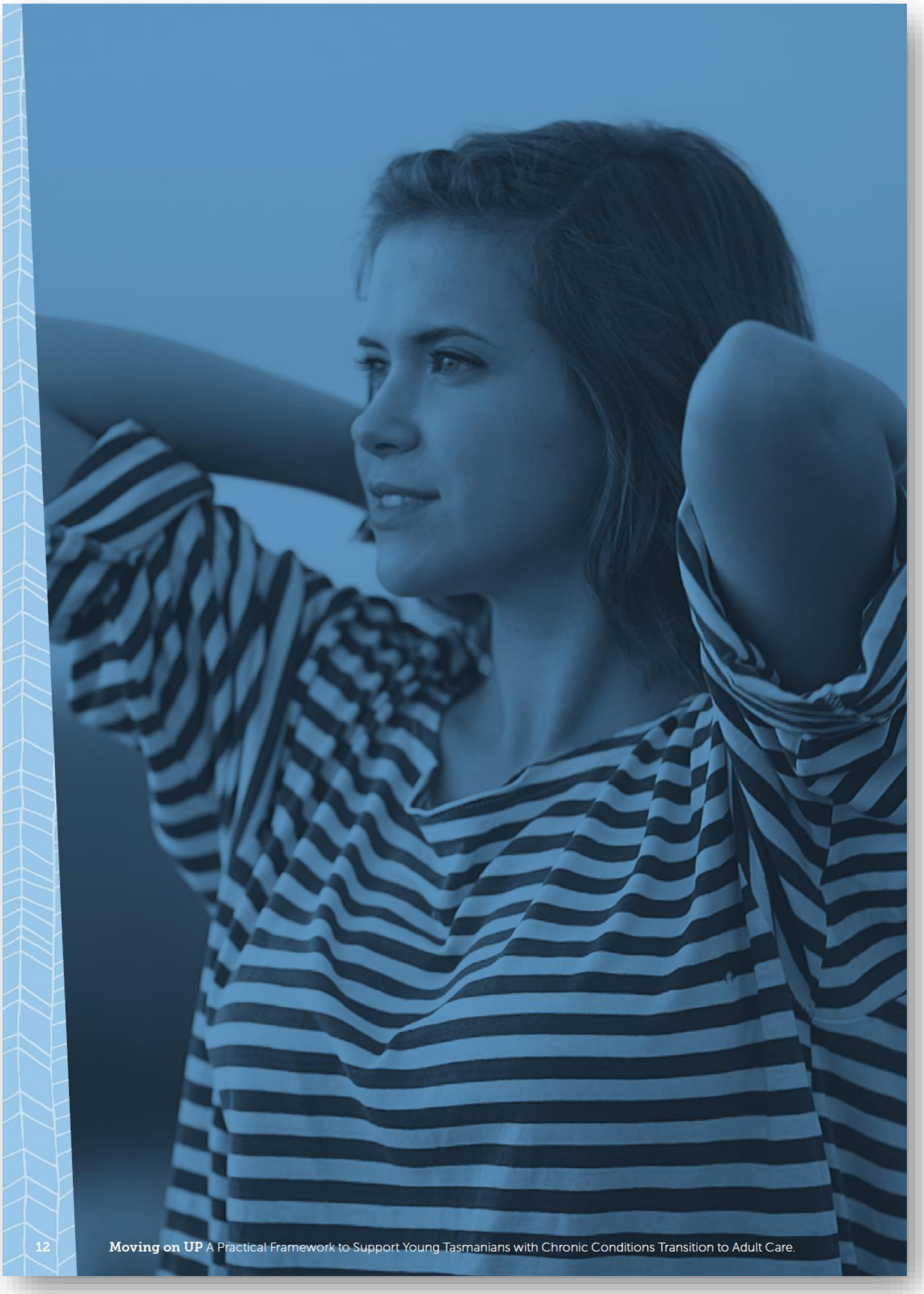


3. Moving on UP

'Moving on Up' presents a staged approach to transition that recognises health services need to take a life-course approach to working with young people with chronic conditions and their families. Preparation for transition through enabling self-management should begin at diagnosis, whatever age this may be.

Starting self-management support early enables young people to develop the skills, behaviour and confidence they need to look after their condition, over an extended period of time.

The *Framework* proposes that there are six key transition stages.

Figure 2 six key transition stages

6

Young adulthood

- signifies the need to move to adult healthcare services
- independent healthcare behaviours and self care
- acceptance of chronic condition

5

Older adolescence

- active transition phase. Primarily address the young person in healthcare interactions and encourage them to be independent in their healthcare

4

Early adolescence

- active preparation for transition. This involves providing health education, self-management support and increasingly spending time with the young person without their family/caregivers

3

Middle childhood

- the introduction of independent healthcare behaviours and self care

2

Early childhood

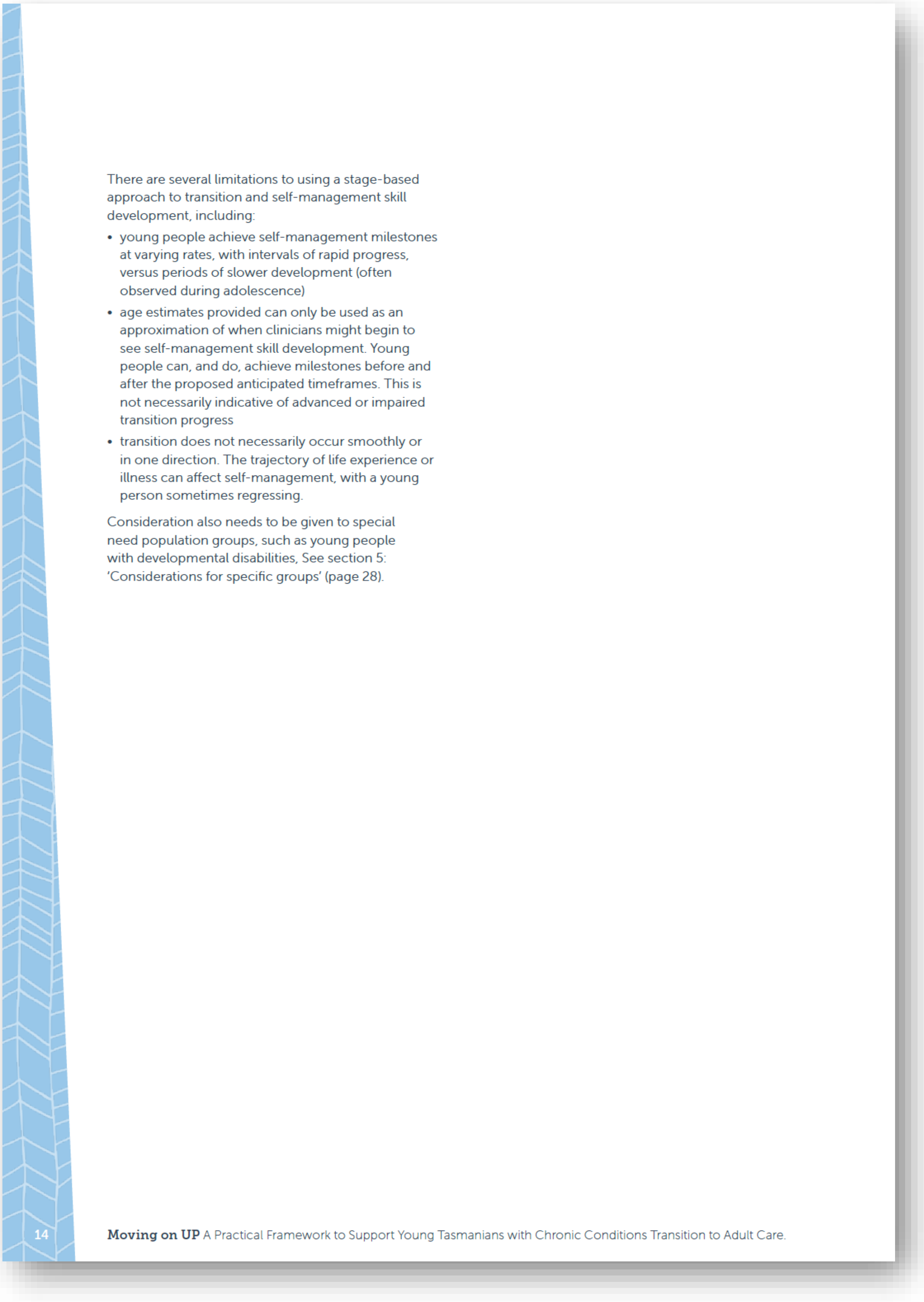
- begin self-management skill development by encouraging participation in own healthcare behaviours

1

Infancy

- self-management support directed at family/caregivers

13



There are several limitations to using a stage-based approach to transition and self-management skill development, including:

- young people achieve self-management milestones at varying rates, with intervals of rapid progress, versus periods of slower development (often observed during adolescence)
- age estimates provided can only be used as an approximation of when clinicians might begin to see self-management skill development. Young people can, and do, achieve milestones before and after the proposed anticipated timeframes. This is not necessarily indicative of advanced or impaired transition progress
- transition does not necessarily occur smoothly or in one direction. The trajectory of life experience or illness can affect self-management, with a young person sometimes regressing.

Consideration also needs to be given to special need population groups, such as young people with developmental disabilities, See section 5: 'Considerations for specific groups' (page 28).

1

Transition Stage 1
Infancy (approximately 0–3 years)

Development

Stage characterised by:

- forming of trusting relationships between the infant and their family/caregivers and any others involved in their care
- increasing body awareness
- object permanency
- stranger anxiety
- beginning to learn meaning of words and speaking
- unable to communicate needs and indicate health needs

Chronic condition considerations

Family/caregiver

- emotional adjustment to infant's diagnosis
- mental health concerns are more common in family units affected by chronic conditions

Infant

- fussy eating behaviours more common in infants with chronic conditions
- difficulty swallowing pills/taking medication
- increased potential for disturbed sleep patterns

Support approaches

Family/ caregiver

- direct self-management support to family/caregivers

Infant

- support learning body awareness and parts as well as verbal labels for symptoms
- support knowing routines and what is expected
- allow some choices (e.g. pick a story or select an activity to complete after treatments)

Self-management skills KIC MR ILS*

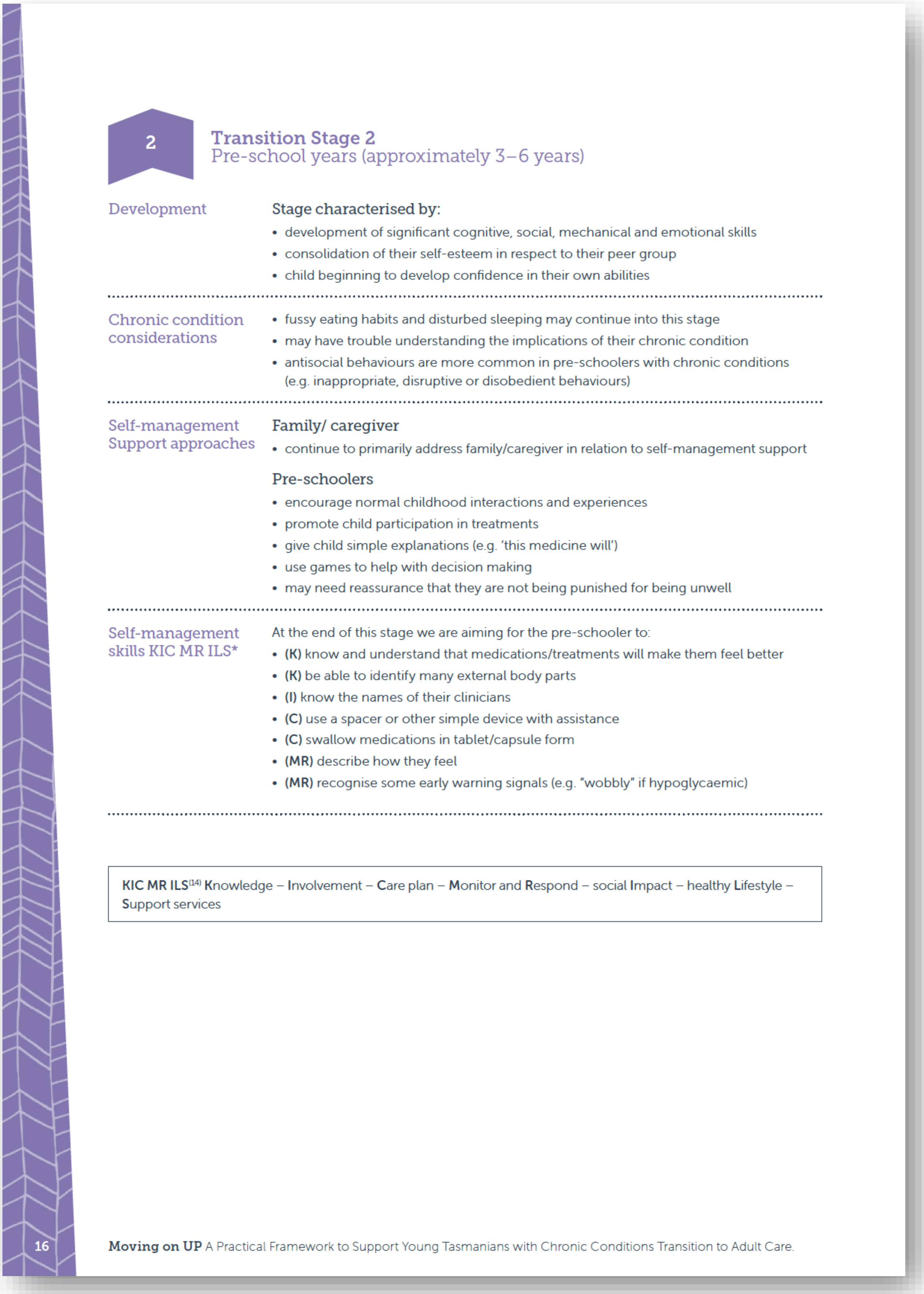
At the end of this stage we are aiming for the family/caregiver to:

- **(K)** know and understand the condition
- **(I)** work in partnership with clinicians
- **(I)** have adjusted to the diagnosis
- **(C)** administer medical and lifestyle treatments as required
- **(L)** promote active play
- **(L)** promote a diet suitable to the infant's condition

At the end of this stage we are aiming for the infant to:

- **(C)** be accepting of daily treatments
- **(C)** help family/caregiver to set up treatment areas

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services



2

Transition Stage 2
Pre-school years (approximately 3–6 years)

Development

Stage characterised by:

- development of significant cognitive, social, mechanical and emotional skills
- consolidation of their self-esteem in respect to their peer group
- child beginning to develop confidence in their own abilities

Chronic condition considerations

- fussy eating habits and disturbed sleeping may continue into this stage
- may have trouble understanding the implications of their chronic condition
- antisocial behaviours are more common in pre-schoolers with chronic conditions (e.g. inappropriate, disruptive or disobedient behaviours)

Self-management Support approaches

Family/ caregiver

- continue to primarily address family/caregiver in relation to self-management support

Pre-schoolers

- encourage normal childhood interactions and experiences
- promote child participation in treatments
- give child simple explanations (e.g. 'this medicine will')
- use games to help with decision making
- may need reassurance that they are not being punished for being unwell

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the pre-schooler to:

- **(K)** know and understand that medications/treatments will make them feel better
- **(K)** be able to identify many external body parts
- **(I)** know the names of their clinicians
- **(C)** use a spacer or other simple device with assistance
- **(C)** swallow medications in tablet/capsule form
- **(MR)** describe how they feel
- **(MR)** recognise some early warning signals (e.g. "wobbly" if hypoglycaemic)

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

3

Transition Stage 3
Primary school years (approximately 7–11 years)

Development

Stage characterised by:

- continuing development of cognitive, social, mechanical and emotional skills
- continuing consolidation of their self-esteem in respect to their peers
- increased ability to relate to others
- child beginning to initiate their own activities

Chronic condition considerations

- growing awareness of being different to their peers
- often blame themselves for their chronic condition
- may lack energy to play at the same level as their peers

Support approaches

Family/caregivers

- encourage family/caregivers to give the child increased responsibility in communicating with their clinicians
- provide family/caregivers with a copy of the care plan (treatment regimen)

Child

- encourage normal childhood interactions and experiences
- begin to address child more directly in discussion of care
- able to report and recognise symptoms
- demonstrate exercises
- take medicine when reminded (eventually without reminders)
- encourage responsibility and chores
- use reward systems (e.g. star charts)
- create choice opportunities for the child
- coach the child to communicate with family/caregivers, teachers, clinicians about concerns
- use simple pictures and stories to explain health concepts and stimulate problem solving
- encourage interaction with technology and its platform as a communication tool and source of support information

Schools/community groups

- supply with information to assist with increasing levels of self-management

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the child to:

- **(K)** be able to identify internal body structures and the function of a specific body part (e.g. lungs for breathing)
- **(K)** have a basic knowledge of their condition and treatments (e.g. why they need treatment and what it does)
- **(K)** name their prescribed treatments including order and timing
- **(I)** engage with clinicians by answering simple questions
- **(C)** know how long to perform each treatment
- **(MR)** recognise, report and respond to significant symptoms (e.g. asthma attack, hypoglycaemia, infection)
- **(I)** talk to others about their condition including their peers and teachers
- **(L)** follow a healthy diet suitable to their condition
- **(L)** be physically active at school and at home, participating in sport activities if able to
- **(S)** consider attendance at chronic condition support camps

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

4

Transition Stage 4
Early adolescence (approximately 12–14 years)

Development

Stage characterised by:

- abstract thinking (right versus wrong)
- egocentricity and mood swings
- physical, hormonal and pubertal changes
- rapid growth and significant changes in bodily appearance (body image and concern for normal growth are common)
- shift from parental influence to peer influence
- amplified intensity of emotion, which may lead to increased family/caregiver conflict
- developing a sense of their own responsibility and identity
- increasing reasoning and problem-solving skills
- increased independence and thrill seeking

Chronic condition considerations

- potential instability of condition/s
- changes in treatment requirements
- high potential for refusal to comply with treatments
- adoption of sick role as personal identifier or denial of condition
- reduced independence at a time when independence is normally developing
- risk taking behaviour more common in adolescents with chronic conditions
- social isolation

Support approaches

Family/caregiver

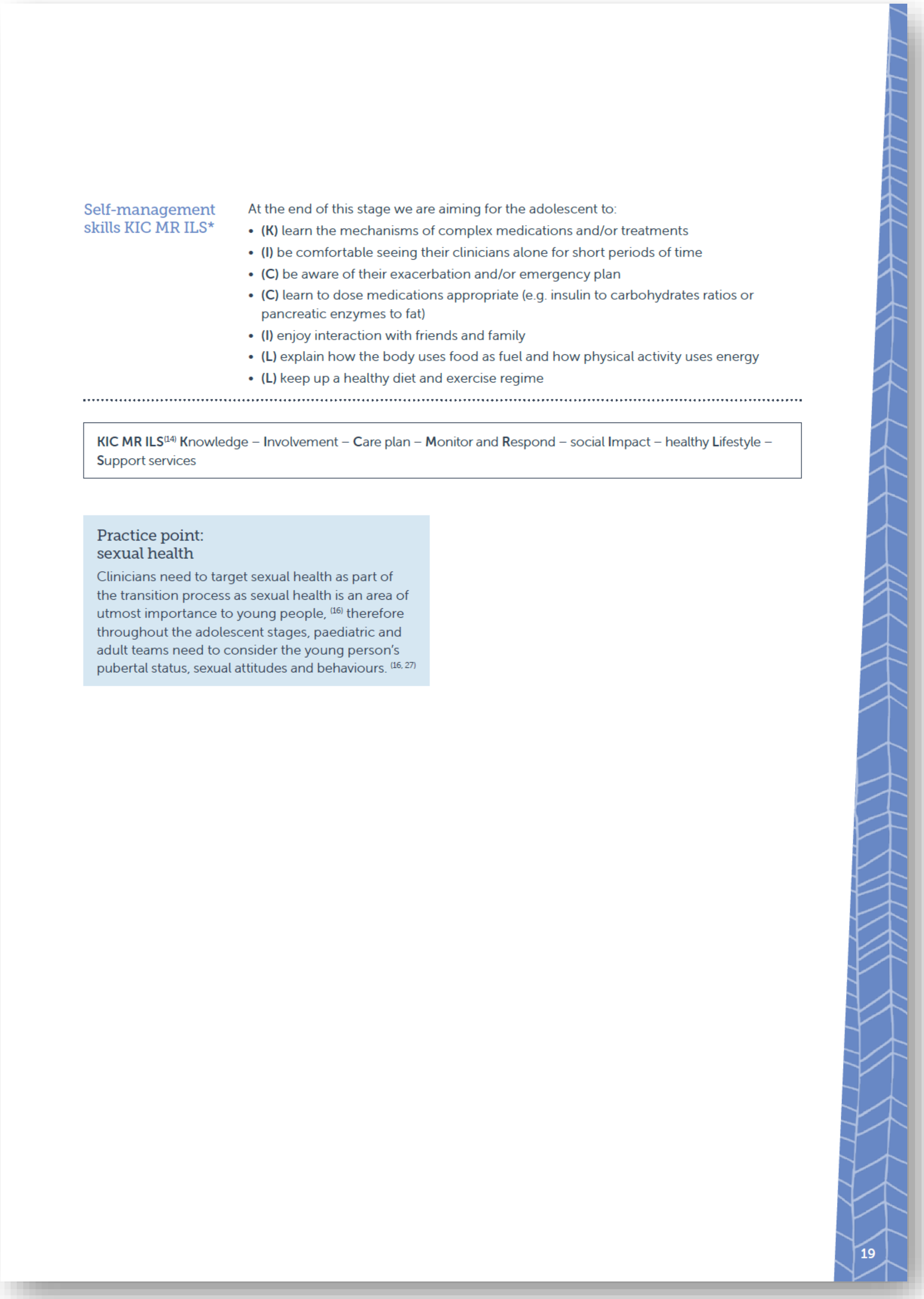
- encourage family/caregivers to be good role models, especially around forming and maintaining healthy relationships and for positive ways of dealing with difficult emotions

Adolescent

- increasingly address the young person directly in regards to their health and treatments rather than their parents
- encourage the young person to attend part of the appointment by themselves
- have open discussions about the division of responsibility of healthcare tasks with both the young person and their family/carers in the move towards independence
- long term goal would be for the young person to undertake own treatments independently (e.g. prepare and take medications and follow physical and dietary recommendations)
- anticipate possible side effects of treatments that may be bothersome
- encourage the young person to demonstrate good preparation and judgement when looking after themselves when away from home
- with guidance from their family/caregivers, encourage the young person to keep written records of medications, care plan and their symptoms as required
- a 'health contract' may be beneficial; role play occasionally helpful
- use models/diagrams when clarifying information
- encourage interaction with social media as a communication tool and source of support information

Schools/community groups

- supply external groups with information to assist with increasing levels of self-management



Self-management skills KIC MR ILS*

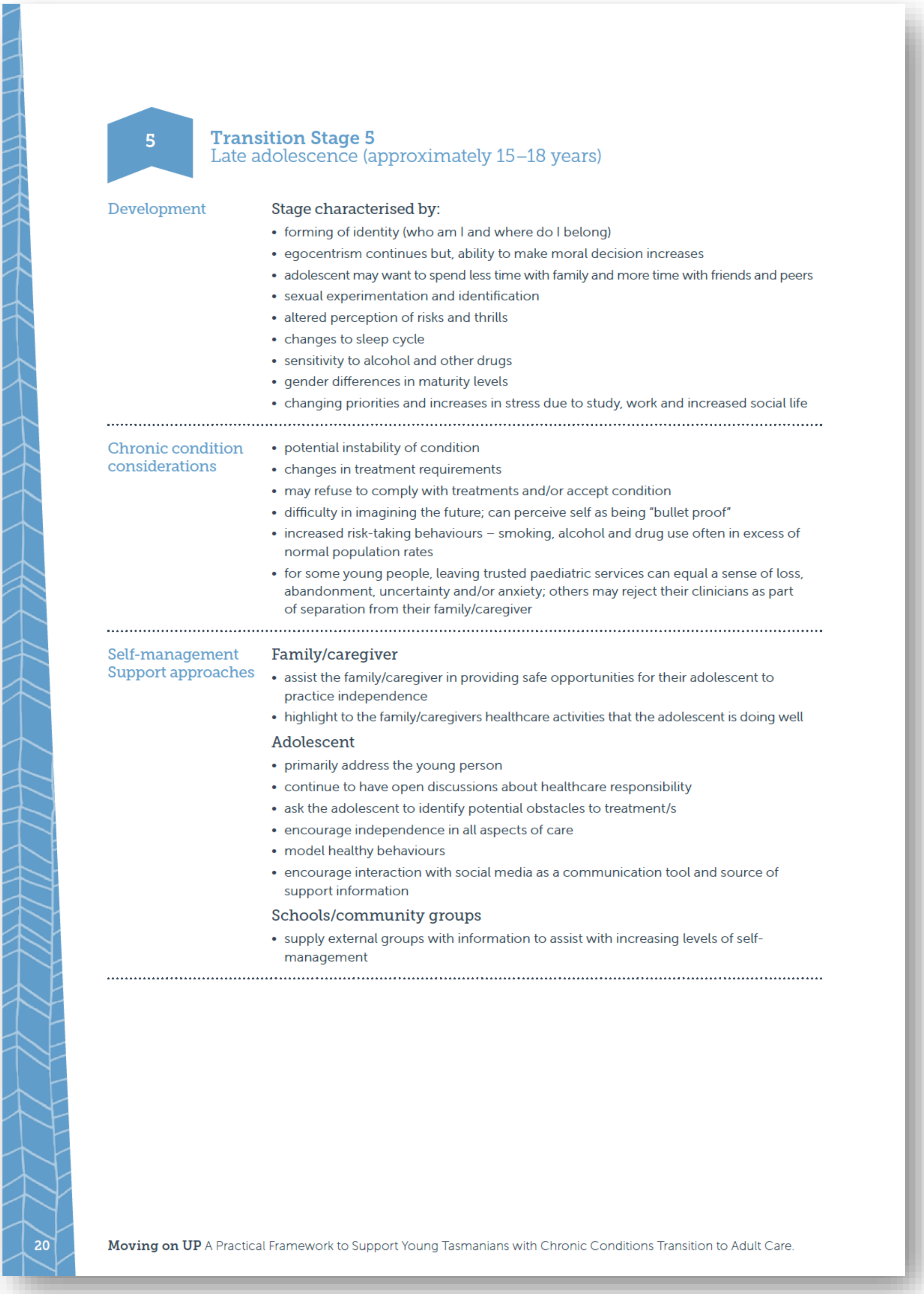
At the end of this stage we are aiming for the adolescent to:

- **(K)** learn the mechanisms of complex medications and/or treatments
- **(I)** be comfortable seeing their clinicians alone for short periods of time
- **(C)** be aware of their exacerbation and/or emergency plan
- **(C)** learn to dose medications appropriate (e.g. insulin to carbohydrates ratios or pancreatic enzymes to fat)
- **(I)** enjoy interaction with friends and family
- **(L)** explain how the body uses food as fuel and how physical activity uses energy
- **(L)** keep up a healthy diet and exercise regime

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

Practice point: sexual health

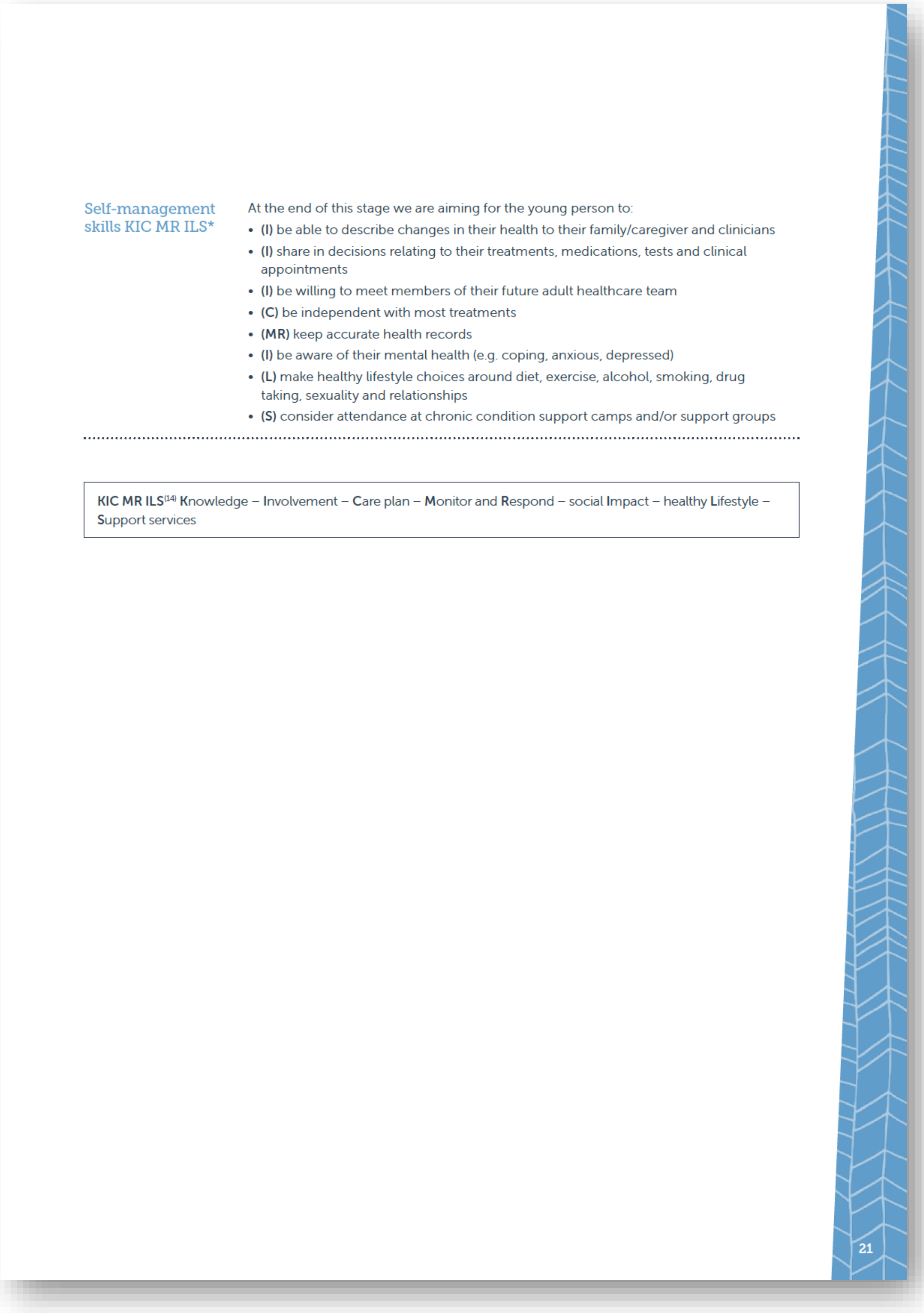
Clinicians need to target sexual health as part of the transition process as sexual health is an area of utmost importance to young people, (16) therefore throughout the adolescent stages, paediatric and adult teams need to consider the young person's pubertal status, sexual attitudes and behaviours. (16, 27)



5 Transition Stage 5

Late adolescence (approximately 15–18 years)

Development	**Stage characterised by:** • forming of identity (who am I and where do I belong) • egocentrism continues but, ability to make moral decision increases • adolescent may want to spend less time with family and more time with friends and peers • sexual experimentation and identification • altered perception of risks and thrills • changes to sleep cycle • sensitivity to alcohol and other drugs • gender differences in maturity levels • changing priorities and increases in stress due to study, work and increased social life
Chronic condition considerations	• potential instability of condition • changes in treatment requirements • may refuse to comply with treatments and/or accept condition • difficulty in imagining the future; can perceive self as being “bullet proof” • increased risk-taking behaviours – smoking, alcohol and drug use often in excess of normal population rates • for some young people, leaving trusted paediatric services can equal a sense of loss, abandonment, uncertainty and/or anxiety; others may reject their clinicians as part of separation from their family/caregiver
Self-management Support approaches	**Family/caregiver** • assist the family/caregiver in providing safe opportunities for their adolescent to practice independence • highlight to the family/caregivers healthcare activities that the adolescent is doing well **Adolescent** • primarily address the young person • continue to have open discussions about healthcare responsibility • ask the adolescent to identify potential obstacles to treatment/s • encourage independence in all aspects of care • model healthy behaviours • encourage interaction with social media as a communication tool and source of support information **Schools/community groups** • supply external groups with information to assist with increasing levels of self-management

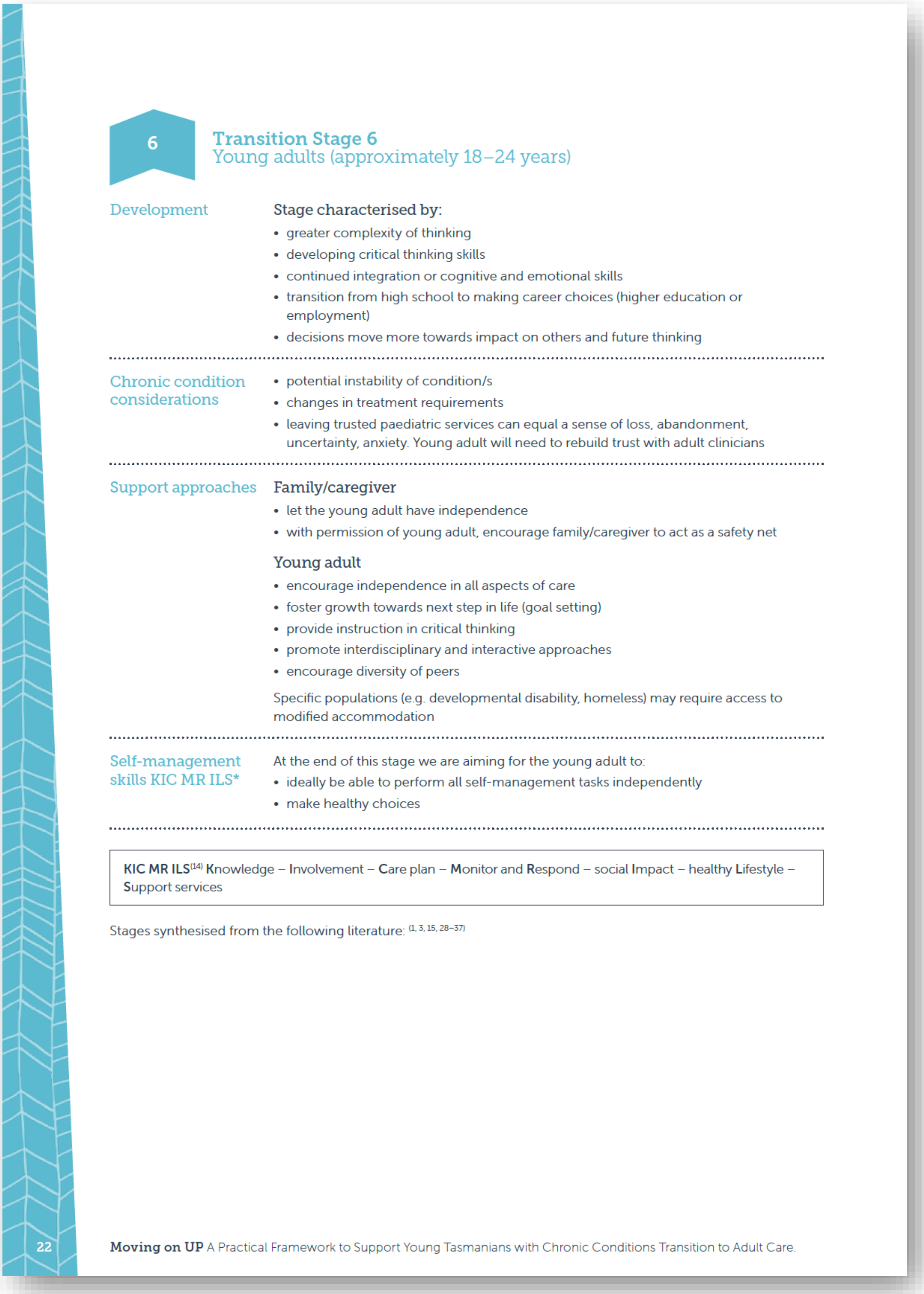


Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the young person to:

- **(I)** be able to describe changes in their health to their family/caregiver and clinicians
- **(I)** share in decisions relating to their treatments, medications, tests and clinical appointments
- **(I)** be willing to meet members of their future adult healthcare team
- **(C)** be independent with most treatments
- **(MR)** keep accurate health records
- **(I)** be aware of their mental health (e.g. coping, anxious, depressed)
- **(L)** make healthy lifestyle choices around diet, exercise, alcohol, smoking, drug taking, sexuality and relationships
- **(S)** consider attendance at chronic condition support camps and/or support groups

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services



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Transition Stage 6
Young adults (approximately 18–24 years)

Development

Stage characterised by:
- greater complexity of thinking
- developing critical thinking skills
- continued integration or cognitive and emotional skills
- transition from high school to making career choices (higher education or employment)
- decisions move more towards impact on others and future thinking

Chronic condition considerations

- potential instability of condition/s
- changes in treatment requirements
- leaving trusted paediatric services can equal a sense of loss, abandonment, uncertainty, anxiety. Young adult will need to rebuild trust with adult clinicians

Support approaches

Family/caregiver
- let the young adult have independence
- with permission of young adult, encourage family/caregiver to act as a safety net

Young adult
- encourage independence in all aspects of care
- foster growth towards next step in life (goal setting)
- provide instruction in critical thinking
- promote interdisciplinary and interactive approaches
- encourage diversity of peers

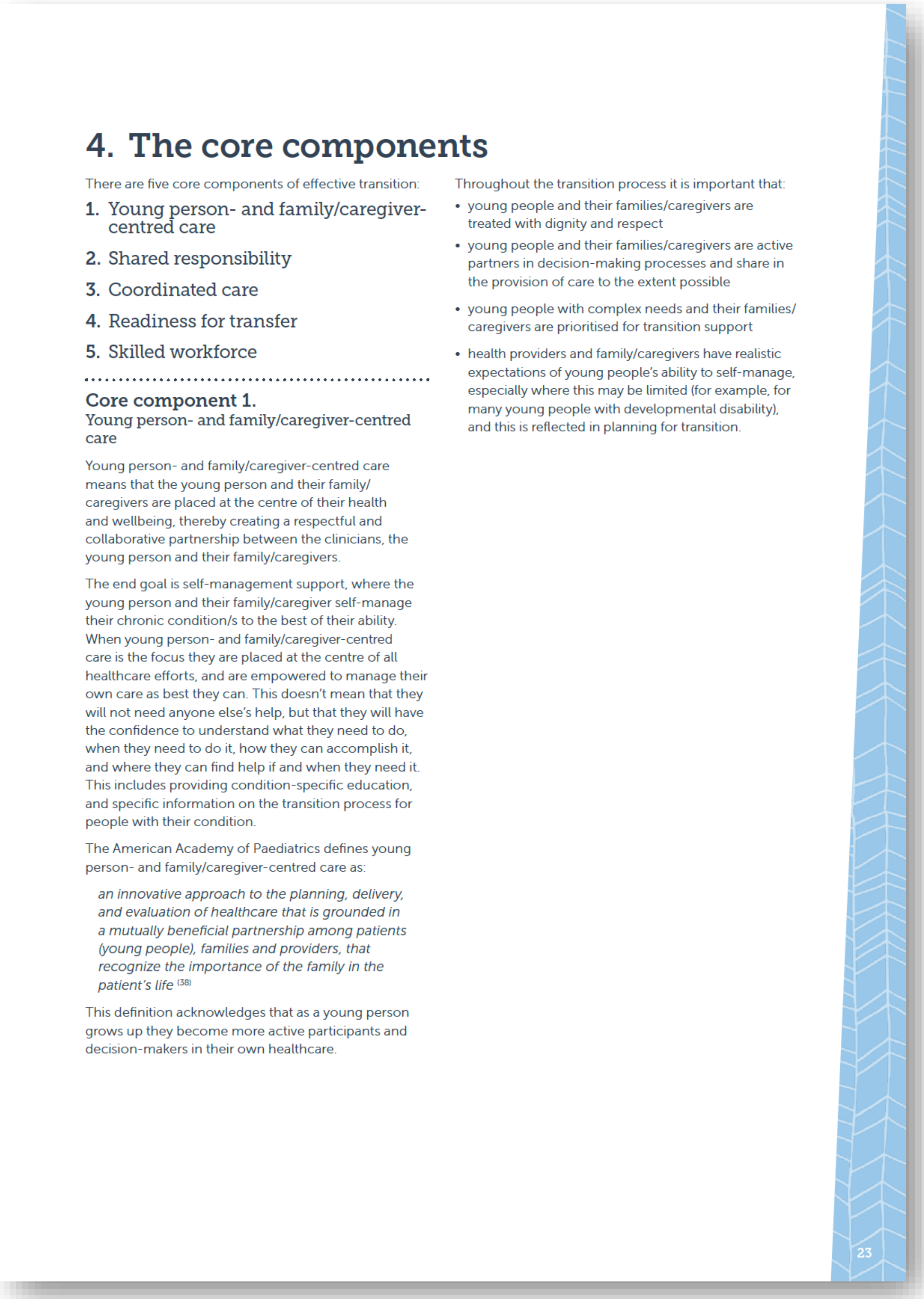
Specific populations (e.g. developmental disability, homeless) may require access to modified accommodation

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the young adult to:
- ideally be able to perform all self-management tasks independently
- make healthy choices

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

Stages synthesised from the following literature: (1, 3, 15, 28–37)



4. The core components

There are five core components of effective transition:

1. Young person- and family/caregiver-centred care
2. Shared responsibility
3. Coordinated care
4. Readiness for transfer
5. Skilled workforce

Core component 1.

Young person- and family/caregiver-centred care

Young person- and family/caregiver-centred care means that the young person and their family/caregivers are placed at the centre of their health and wellbeing, thereby creating a respectful and collaborative partnership between the clinicians, the young person and their family/caregivers.

The end goal is self-management support, where the young person and their family/caregiver self-manage their chronic condition/s to the best of their ability. When young person- and family/caregiver-centred care is the focus they are placed at the centre of all healthcare efforts, and are empowered to manage their own care as best they can. This doesn't mean that they will not need anyone else's help, but that they will have the confidence to understand what they need to do, when they need to do it, how they can accomplish it, and where they can find help if and when they need it. This includes providing condition-specific education, and specific information on the transition process for people with their condition.

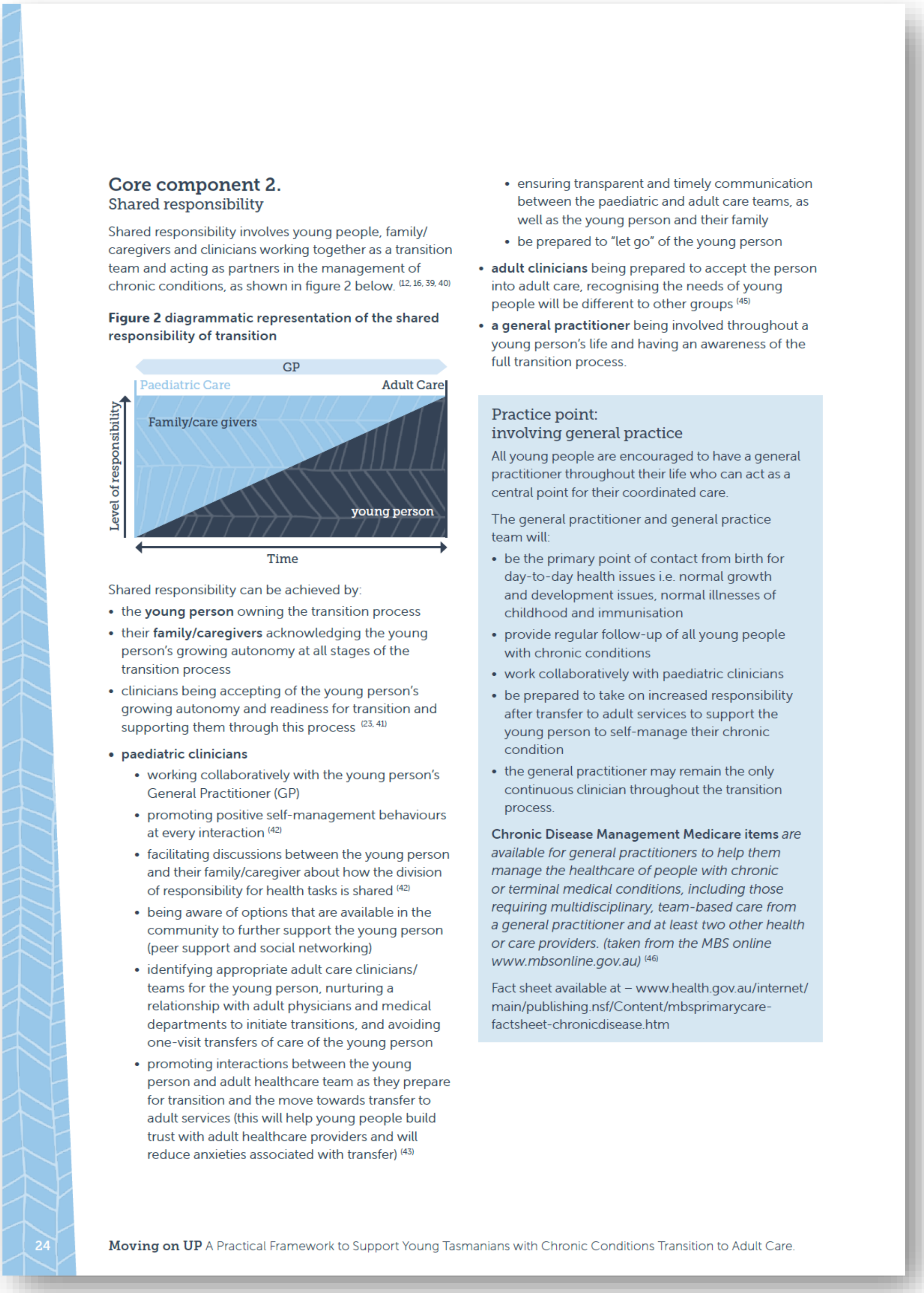
The American Academy of Paediatrics defines young person- and family/caregiver-centred care as:

> *an innovative approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients (young people), families and providers, that recognize the importance of the family in the patient's life* (38)

This definition acknowledges that as a young person grows up they become more active participants and decision-makers in their own healthcare.

Throughout the transition process it is important that:

- young people and their families/caregivers are treated with dignity and respect
- young people and their families/caregivers are active partners in decision-making processes and share in the provision of care to the extent possible
- young people with complex needs and their families/caregivers are prioritised for transition support
- health providers and family/caregivers have realistic expectations of young people's ability to self-manage, especially where this may be limited (for example, for many young people with developmental disability), and this is reflected in planning for transition.



Core component 2.
Shared responsibility

Shared responsibility involves young people, family/caregivers and clinicians working together as a transition team and acting as partners in the management of chronic conditions, as shown in figure 2 below. (12, 16, 39, 40)

Figure 2 diagrammatic representation of the shared responsibility of transition

Shared responsibility can be achieved by:

- the **young person** owning the transition process
- their **family/caregivers** acknowledging the young person's growing autonomy at all stages of the transition process
- clinicians being accepting of the young person's growing autonomy and readiness for transition and supporting them through this process (23, 41)
- **paediatric clinicians**
  - working collaboratively with the young person's General Practitioner (GP)
  - promoting positive self-management behaviours at every interaction (42)
  - facilitating discussions between the young person and their family/caregiver about how the division of responsibility for health tasks is shared (42)
  - being aware of options that are available in the community to further support the young person (peer support and social networking)
  - identifying appropriate adult care clinicians/teams for the young person, nurturing a relationship with adult physicians and medical departments to initiate transitions, and avoiding one-visit transfers of care of the young person
  - promoting interactions between the young person and adult healthcare team as they prepare for transition and the move towards transfer to adult services (this will help young people build trust with adult healthcare providers and will reduce anxieties associated with transfer) (43)
  - ensuring transparent and timely communication between the paediatric and adult care teams, as well as the young person and their family
  - be prepared to "let go" of the young person
- **adult clinicians** being prepared to accept the person into adult care, recognising the needs of young people will be different to other groups (45)
- **a general practitioner** being involved throughout a young person's life and having an awareness of the full transition process.

Practice point:
involving general practice

All young people are encouraged to have a general practitioner throughout their life who can act as a central point for their coordinated care.

The general practitioner and general practice team will:

- be the primary point of contact from birth for day-to-day health issues i.e. normal growth and development issues, normal illnesses of childhood and immunisation
- provide regular follow-up of all young people with chronic conditions
- work collaboratively with paediatric clinicians
- be prepared to take on increased responsibility after transfer to adult services to support the young person to self-manage their chronic condition
- the general practitioner may remain the only continuous clinician throughout the transition process.

Chronic Disease Management Medicare items *are available for general practitioners to help them manage the healthcare of people with chronic or terminal medical conditions, including those requiring multidisciplinary, team-based care from a general practitioner and at least two other health or care providers. (taken from the MBS online www.mbsonline.gov.au)* (46)

Fact sheet available at – www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-factsheet-chronicdisease.htm

Core component 3.
Coordinated care

Care coordination involves deliberately organising a young person's healthcare activities and sharing information among the clinicians involved. This planned and managed approach ensures that the best health outcomes are achieved for the young person and their family/caregivers and that health services are effectively and efficiently used.

The main goal of care coordination is to meet patients' needs and preferences, provide safe, appropriate and effective high-quality, high-value healthcare and:

- to ensure clients have capacity to be in control of their healthcare
- to improve access to necessary services to help support improved health outcomes – particularly for the young person with chronic and complex conditions
- to reduce inappropriate and avoidable service use across the healthcare sector – particularly in relation to potentially avoidable hospitalisations, emergency department presentations, and emergency admissions involving people with complex chronic care needs
- increase communication between healthcare providers.

Coordinated care is a comprehensive approach to achieving continuity of care for people with chronic conditions from childhood into adulthood. With the right services and clinicians engaged, young people will be able to access healthcare and supports across a range of clinicians who work collaboratively.

Clinicians can ensure a coordinated care approach by:

- identifying a key worker to support throughout the transition process. This may be a general practitioner, but could also be a nurse navigator, peer worker, or relevant allied health professional.
- ensuring that the young person and their family/caregiver are informed and involved at each life stage
- sharing information clearly and openly with the young person and their family/caregiver and ensuring that the general practitioner is kept up to date
- keeping high-quality clinical documentation that is shared across services (timely, appropriate, routine and non–routine)
- the use of secure information technology to facilitate transfer of information
- having effective channels of communication between clinicians, services, the young person and their family/caregivers, e.g.
    - family meetings
    - a written healthcare transition plan (16)
    - an accurate compilation of the patient's complex medical information which should be developed so that it is accessible and available to the young person, their family/caregiver, and adult health care providers. (16)

Core component 4.
Readiness for transfer

Services should maintain a registry of young people to identify who is ready to start the transition process as well as to track progress and outcomes. Active planning for transition should start in early adolescence.

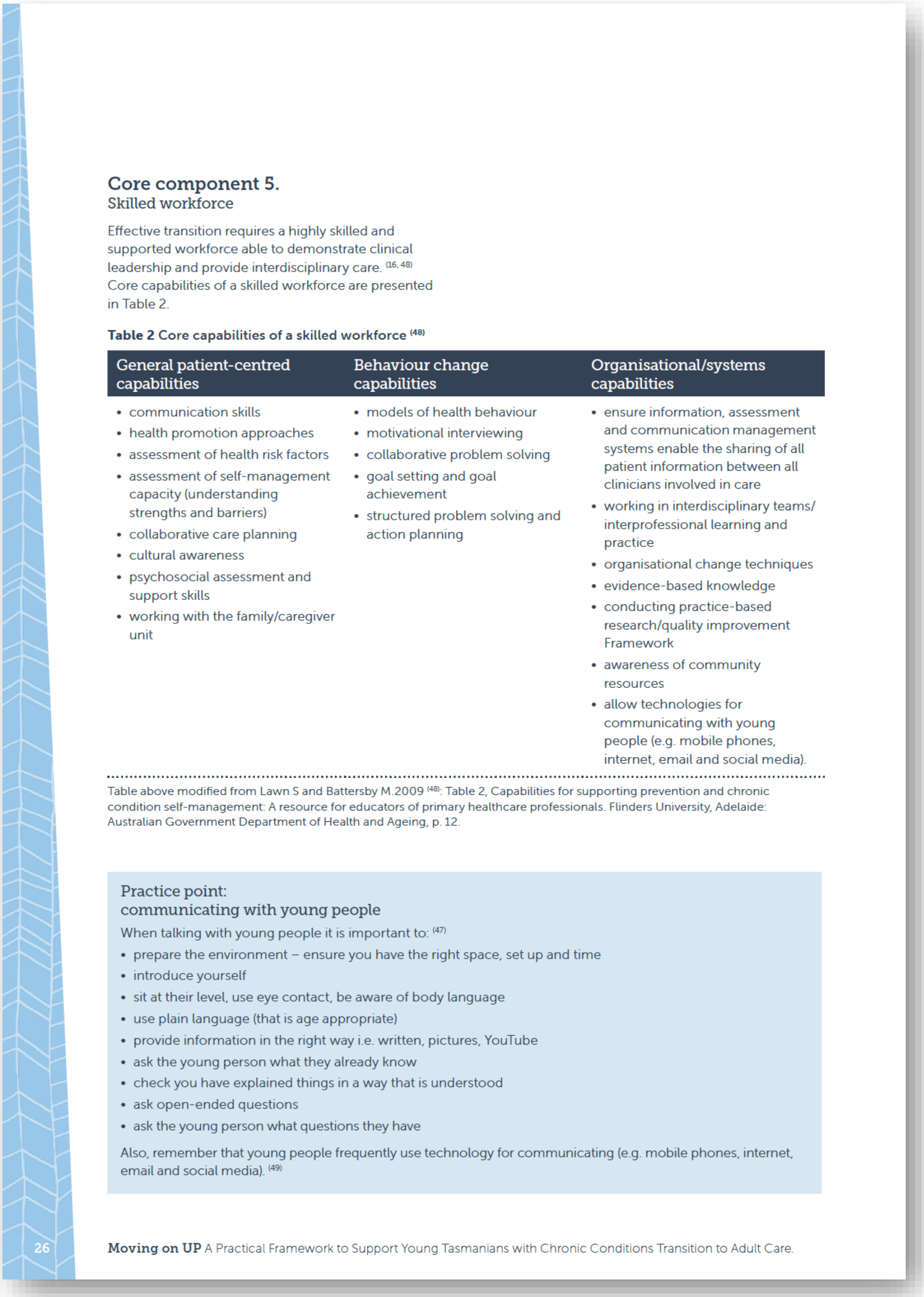
The readiness for transfer for individual young people is varied and reliant on multiple factors including age, capacity, and available services. When considering the timing of transfer it is important to ensure that it does not coincide with other major life changes such as exams, commencing employment, or starting university. (16) It is also important to consider the medical and emotional stability of the young person.

From early adolescence, clinicians should be regularly assessing the young person's self-management skills and readiness for transfer. There are a variety of generic and condition-specific 'readiness to transfer' tools available for use.(47)

Practice point:
no local adult specialist services available

Many local areas in Tasmania lack condition-specific adult services or clinics to which a young person can be transferred. Local paediatric teams, their adult physician counterparts and general practitioners must work together during this time. Adult physicians must be prepared to accept and go through the process of transition of new young adult patients, and paediatricians must be prepared to nurture a relationship with adult physicians and medical departments and to initiate transitions, and avoid one-visit transfers of care of the young person.

Because of Tasmania's relatively small population, some statewide services are centrally based. Combining use of government subsidy transport systems for face-to-face appointments with telehealth consultations offers potential to optimise access to health care for patients living in rural and regional areas. Sharing of knowledge of skills and local supports may be optimised additionally via interdisciplinary teleconferences and consultations.



Core component 5.

Skilled workforce

Effective transition requires a highly skilled and supported workforce able to demonstrate clinical leadership and provide interdisciplinary care. (16, 48) Core capabilities of a skilled workforce are presented in Table 2.

Table 2 Core capabilities of a skilled workforce (48)

General patient-centred capabilities	Behaviour change capabilities	Organisational/systems capabilities
• communication skills • health promotion approaches • assessment of health risk factors • assessment of self-management capacity (understanding strengths and barriers) • collaborative care planning • cultural awareness • psychosocial assessment and support skills • working with the family/caregiver unit	• models of health behaviour • motivational interviewing • collaborative problem solving • goal setting and goal achievement • structured problem solving and action planning	• ensure information, assessment and communication management systems enable the sharing of all patient information between all clinicians involved in care • working in interdisciplinary teams/ interprofessional learning and practice • organisational change techniques • evidence-based knowledge • conducting practice-based research/quality improvement Framework • awareness of community resources • allow technologies for communicating with young people (e.g. mobile phones, internet, email and social media).

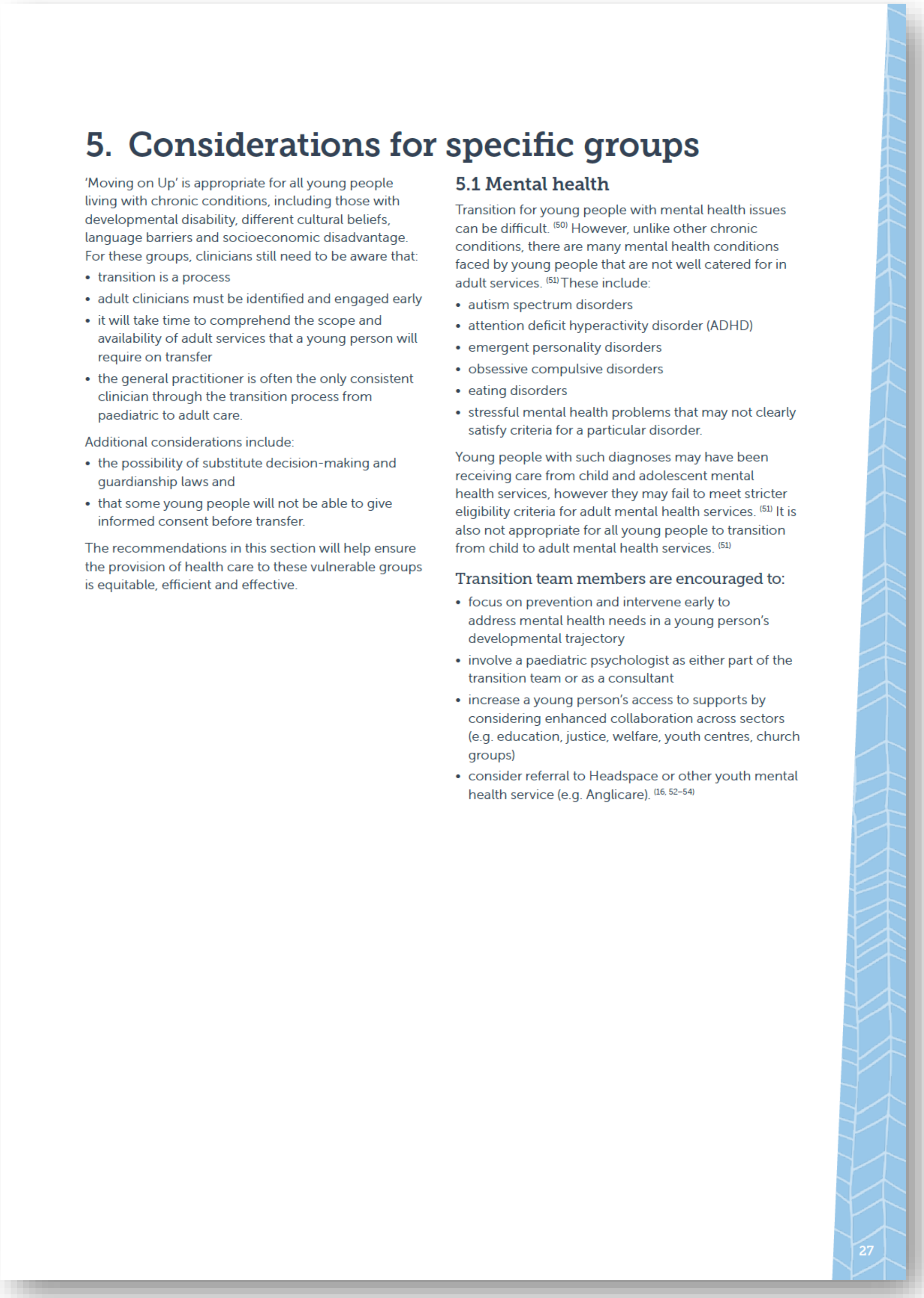
Table above modified from Lawn S and Battersby M.2009 (48): Table 2, Capabilities for supporting prevention and chronic condition self-management: A resource for educators of primary healthcare professionals. Flinders University, Adelaide: Australian Government Department of Health and Ageing, p. 12.

Practice point: communicating with young people

When talking with young people it is important to: (47)

- prepare the environment – ensure you have the right space, set up and time
- introduce yourself
- sit at their level, use eye contact, be aware of body language
- use plain language (that is age appropriate)
- provide information in the right way i.e. written, pictures, YouTube
- ask the young person what they already know
- check you have explained things in a way that is understood
- ask open-ended questions
- ask the young person what questions they have

Also, remember that young people frequently use technology for communicating (e.g. mobile phones, internet, email and social media). (49)



5. Considerations for specific groups

‘Moving on Up’ is appropriate for all young people living with chronic conditions, including those with developmental disability, different cultural beliefs, language barriers and socioeconomic disadvantage. For these groups, clinicians still need to be aware that:

- transition is a process
- adult clinicians must be identified and engaged early
- it will take time to comprehend the scope and availability of adult services that a young person will require on transfer
- the general practitioner is often the only consistent clinician through the transition process from paediatric to adult care.

Additional considerations include:

- the possibility of substitute decision-making and guardianship laws and
- that some young people will not be able to give informed consent before transfer.

The recommendations in this section will help ensure the provision of health care to these vulnerable groups is equitable, efficient and effective.

5.1 Mental health

Transition for young people with mental health issues can be difficult. (50) However, unlike other chronic conditions, there are many mental health conditions faced by young people that are not well catered for in adult services. (51) These include:

- autism spectrum disorders
- attention deficit hyperactivity disorder (ADHD)
- emergent personality disorders
- obsessive compulsive disorders
- eating disorders
- stressful mental health problems that may not clearly satisfy criteria for a particular disorder.

Young people with such diagnoses may have been receiving care from child and adolescent mental health services, however they may fail to meet stricter eligibility criteria for adult mental health services. (51) It is also not appropriate for all young people to transition from child to adult mental health services. (51)

Transition team members are encouraged to:

- focus on prevention and intervene early to address mental health needs in a young person’s developmental trajectory
- involve a paediatric psychologist as either part of the transition team or as a consultant
- increase a young person’s access to supports by considering enhanced collaboration across sectors (e.g. education, justice, welfare, youth centres, church groups)
- consider referral to Headspace or other youth mental health service (e.g. Anglicare). (16, 52–54)

5.2 Developmental disability

Developmental disability refers to a permanent cognitive and/or physical impairment that usually occurs in the early years of life but can occur any time before the age of 18 years. It results in significantly reduced capacity in three or more major life activities. (55) Activities compromised can include communication; learning; mobility; living independently; decision making; self-care; self-management and ability to seek; and management and participation in their own health. (55)

There are up to 15,000 individuals in Tasmania with developmental disabilities. (56) Although there are well developed and highly successful developmental paediatric services (paediatrician led) there are few specialised and dedicated services in the adult-health sector. (57) Many young people with numerous medical problems may be referred over to their general practitioner after turning 18 but additional referral for possible long term care to a physician specialising in Internal Medicine should be considered. (57) Physicians specialising in internal medicine, though not necessarily specialised in disability, are used to managing the healthcare of people with multiple and complex bio psychosocial histories. (57)

Transition team members need to consider:

That young people with developmental disabilities can have significant issues when compared to their peers in the general population. These can include:

- reduced cognitive and motor functioning
- sensory impairments (vision and hearing)
- pubertal delays and sexual health concerns
- social, sexual and financial vulnerabilities
- multiple physical health comorbidities
- lower healthy living habits
- antisocial behaviours and other difficult behaviours
- parental concerns over achieving the right balance of protection versus independence
- loss of many paediatric school related community programs or supports
- difficulty with peers and self-acceptance
- accessing Centrelink schemes and learning about relevant entitlements such as disability allowances and benefits, healthcare subsidy systems, leaving home options, respite, group homes, accessing National Disability Insurance Scheme, including access to equipment and appliances, seeking disability service providers for residential, day and supported employment options, and refining the roles of disability support services in all the various health settings and managing the health handover from families
- a requirement to fit into generic services instead of specialised paediatric services and facing adult health services which may not be disability aware
- the value of advocacy from the transition team to facilitate the development of resaonble adjustments to the generic adult health systems to minimise barriers in the adult health settings
- feeling intimidated and not confident to be assertive
- optimal health and healthcare access contributes to maximal social participation and opportunities
- an ongoing but variable dependence on disability support from parents, and now additionally the disability service provider sector, to access and participate in adult health services and healthy living (38, 55, 57–60)

Transition team members need to consider:

- develop a professional relationship over time with adult general physicians to oversee the range of medical problems of transitioning young people with developmental disability
- set a start and stop time for transition; complete the transition process with this group over a period of time i.e. 6 months, and prior to the completion of the transition make it clear that the young person is still considered a paediatric patient for acute ilnesses requiring hospitalisation. This allows the clinicians to learn about the young person's personality and behaviour, cognitive and motor skills, home situation, daytime activities, as well as the health issues. This facilitates development of disability supports plans for the young person to access and participate in all aspects of health care and health processes
- be prepared to make reasonable adjustments in adult health services such as longer and more frequent appointments, at least in the early stages
- spend time discussing how the management of inpatient hospital care could occur and the role of family or carers disability supports in adult hospital wards
- learn about syndromes of developmental disability and disability principles: see appendix 1
- consider referrals to other clinicians as required (e.g. occupational therapists, physiotherapists, epileptoligists (epilepsy specialist), geneticists, cardiologists and the disability and advisory team in your area)
- engage with adult disability service providers and families to establish working relationships in the healthcare of the young person with developmental disability
- become familiar with the National Disability Insurance Scheme, the role of the clinician in assessment for National Disability Insurance Scheme and the role of the support services in accessing and managing health.

5.3 Being culturally aware

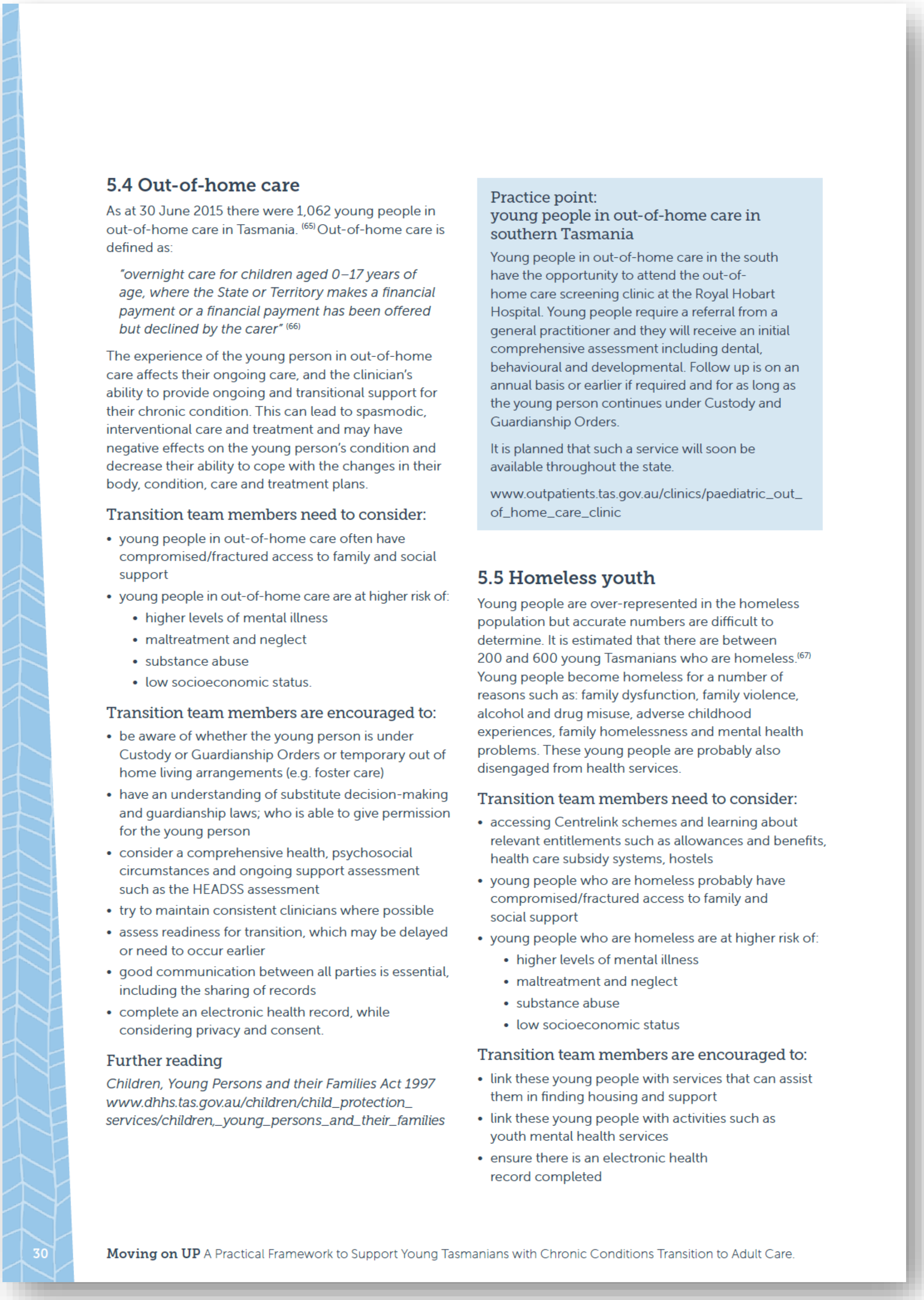
Cultural awareness is a key component in young person-and family-centred care. Being aware of a young person's background and how it will affect their ability to communicate and participate in the care partnership will help to provide better care, care that is empathetic, collaborative, inclusive and ultimately more sustainable. (61) Being culturally aware is the basis of communication between people. It involves the ability to stand back from ourselves and become aware of our own and other people's cultural values, beliefs and perceptions. (61, 62)

Tasmania is culturally and linguistically diverse with people from over 170 countries speaking more than 75 languages (63) and a growing population of people identifying as Aboriginal and Torres Strait Islanders (currently around 20,000). (64)

Young people from a culturally and linguistically diverse background have specific requirements or needs around understanding and accessing health care (63). Cultural differences may create or exacerbate issues such as poverty, poor education or barriers to continuing education, difficulty with transport and poor social support networks; each with the ability to impact the health and wellbeing opportunities of young people (63). These well-documented social determinants of health may mean that young people are not aware of the services available in their community and may not be able to access what is readily available because of language, religion or other cultural barriers. (63)

Transition team members are encouraged to:

- consider completing cultural awareness training
- use the Translating and Interpreting Service (TIS National) if clients have limited English language skills. TIS National provides several services including immediate phone interpreting available 24 hours a day, every day of the year for the cost of a local call. To register, call 131 450
- be aware of health literacy (the knowledge and skills needed to understand and use health information). Health literacy can be an issue for many Tasmanians, particularly those with culturally and linguistically diverse backgrounds
- integrate health literacy strategies into practice and use plain English when communicating with clients. Always assess a young person's health literacy level before providing information and resources. For more information go to: www.dhhs.tas.gov.au/publichealth/health_literacy and www.ceh.org.au
- provide health information for young people in their own language where possible. The following websites contain excellent multilingual resources: www.healthtranslations.vic.gov.au and www.mhcs.health.nsw.gov.au. (61–63)



5.4 Out-of-home care

As at 30 June 2015 there were 1,062 young people in out-of-home care in Tasmania. (65) Out-of-home care is defined as:

> *"overnight care for children aged 0–17 years of age, where the State or Territory makes a financial payment or a financial payment has been offered but declined by the carer"* (66)

The experience of the young person in out-of-home care affects their ongoing care, and the clinician's ability to provide ongoing and transitional support for their chronic condition. This can lead to spasmodic, interventional care and treatment and may have negative effects on the young person's condition and decrease their ability to cope with the changes in their body, condition, care and treatment plans.

Transition team members need to consider:

- young people in out-of-home care often have compromised/fractured access to family and social support
- young people in out-of-home care are at higher risk of:
  - higher levels of mental illness
  - maltreatment and neglect
  - substance abuse
  - low socioeconomic status.

Transition team members are encouraged to:

- be aware of whether the young person is under Custody or Guardianship Orders or temporary out of home living arrangements (e.g. foster care)
- have an understanding of substitute decision-making and guardianship laws; who is able to give permission for the young person
- consider a comprehensive health, psychosocial circumstances and ongoing support assessment such as the HEADSS assessment
- try to maintain consistent clinicians where possible
- assess readiness for transition, which may be delayed or need to occur earlier
- good communication between all parties is essential, including the sharing of records
- complete an electronic health record, while considering privacy and consent.

Further reading

Children, Young Persons and their Families Act 1997
www.dhhs.tas.gov.au/children/child_protection_services/children_young_persons_and_their_families

Practice point:
young people in out-of-home care in southern Tasmania

Young people in out-of-home care in the south have the opportunity to attend the out-of-home care screening clinic at the Royal Hobart Hospital. Young people require a referral from a general practitioner and they will receive an initial comprehensive assessment including dental, behavioural and developmental. Follow up is on an annual basis or earlier if required and for as long as the young person continues under Custody and Guardianship Orders.

It is planned that such a service will soon be available throughout the state.

www.outpatients.tas.gov.au/clinics/paediatric_out_of_home_care_clinic

5.5 Homeless youth

Young people are over-represented in the homeless population but accurate numbers are difficult to determine. It is estimated that there are between 200 and 600 young Tasmanians who are homeless.(67) Young people become homeless for a number of reasons such as: family dysfunction, family violence, alcohol and drug misuse, adverse childhood experiences, family homelessness and mental health problems. These young people are probably also disengaged from health services.

Transition team members need to consider:

- accessing Centrelink schemes and learning about relevant entitlements such as allowances and benefits, health care subsidy systems, hostels
- young people who are homeless probably have compromised/fractured access to family and social support
- young people who are homeless are at higher risk of:
  - higher levels of mental illness
  - maltreatment and neglect
  - substance abuse
  - low socioeconomic status

Transition team members are encouraged to:

- link these young people with services that can assist them in finding housing and support
- link these young people with activities such as youth mental health services
- ensure there is an electronic health record completed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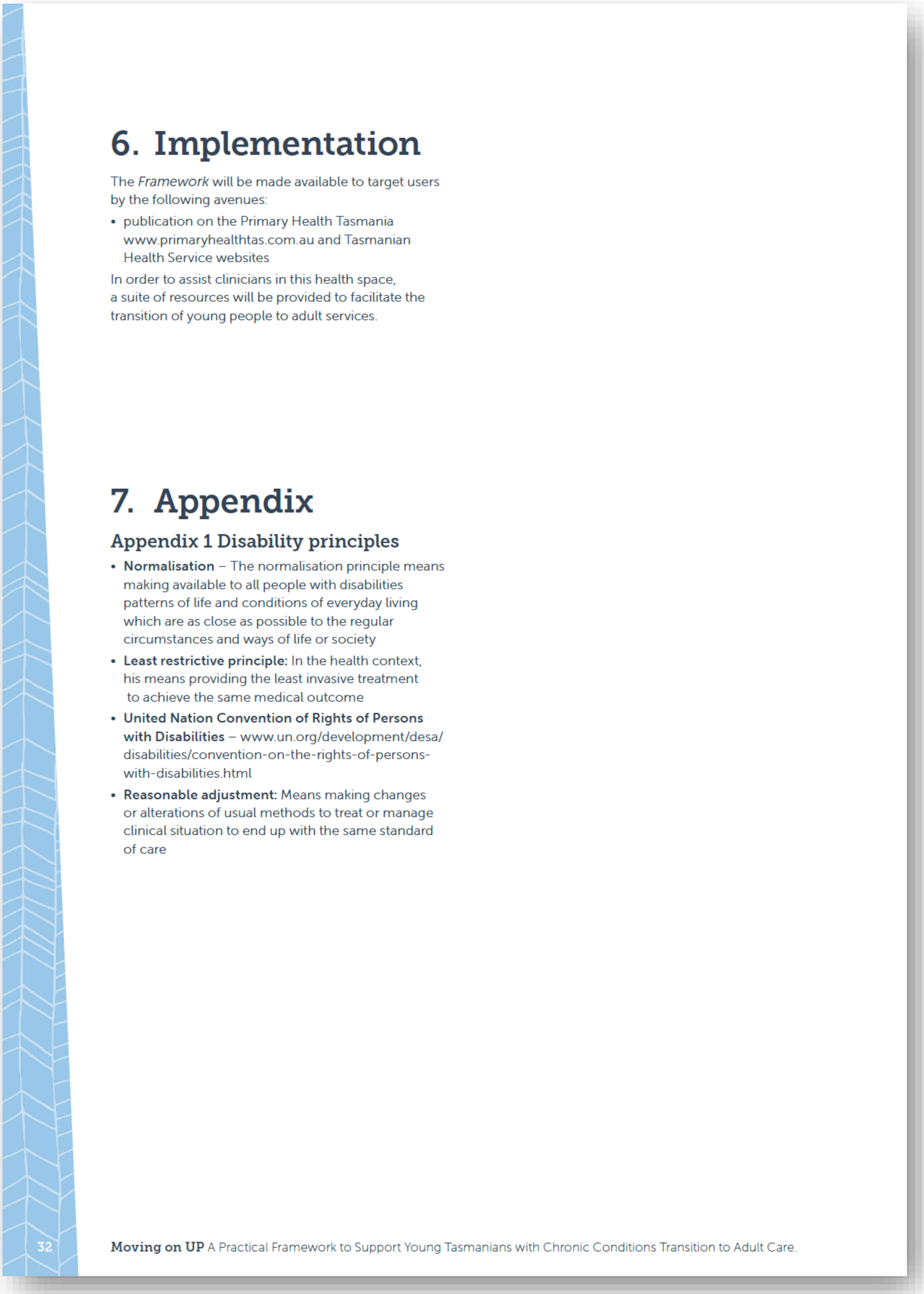

6. Implementation

The *Framework* will be made available to target users by the following avenues:

- publication on the Primary Health Tasmania www.primaryhealthtas.com.au and Tasmanian Health Service websites

In order to assist clinicians in this health space, a suite of resources will be provided to facilitate the transition of young people to adult services.

7. Appendix

Appendix 1 Disability principles

- **Normalisation** – The normalisation principle means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society
- **Least restrictive principle:** In the health context, his means providing the least invasive treatment to achieve the same medical outcome
- **United Nation Convention of Rights of Persons with Disabilities** – www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
- **Reasonable adjustment:** Means making changes or alterations of usual methods to treat or manage clinical situation to end up with the same standard of care

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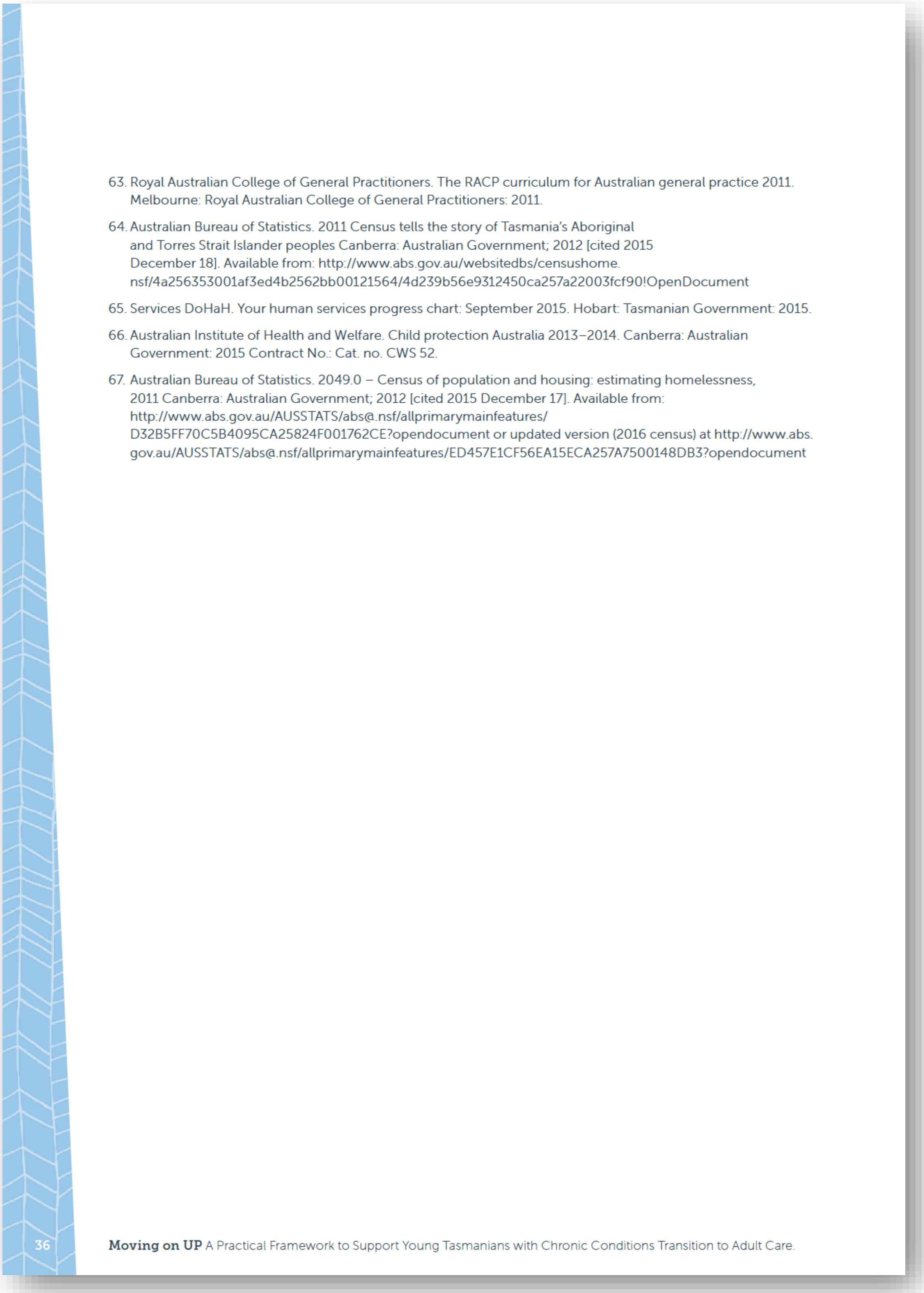

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The creation of the *Framework* does not bring with it additional funding for paediatric or adult healthcare services.

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Media release

28 March 2019

New framework to support young Tasmanians with chronic conditions

A new resource designed to ensure young Tasmanians living with chronic conditions experience a safe and supportive move from child to adult health services is now available for patients, carers and health professionals across the state.

The *Moving on Up* framework aims to provide health professionals, parents, carers and patients with easy-to-follow guidelines for a safe transition of care.

It recognises that transition isn't a one-off, administrative event – it's a complex process that must be tailored to meet each young person's unique needs.

It's designed to support young people with chronic conditions such as cystic fibrosis, congenital heart disease, diabetes, mental illness, as well as those with experience of childhood cancer or disability.

Research suggests chronic conditions affect the everyday lives of almost 64,000 young Tasmanians, Primary Health Tasmania spokesperson Sal Bucksey says.

"Often these young people will have become used to engaging with the health system in their childhood years. Because of that, the transition to adult services may be a challenge – one that coincides with an already transformative period of life," she says.

"This framework recognises that, and provides practical guidance to help the young person, their clinicians, and carers safely navigate the move up into the adult system."

Dr Graeme Bleach, a GP at the Eastern Shore Medical Centre in Hobart, says the framework acknowledges the crossover to adult services can also be an emotional turning point in a young person's life.

"A young person who has grown up with a chronic condition may not fully grasp its impact until they begin the transition into adulthood, and adult care," he says.

"A well-handled transition with the support of a trusted health professional like a GP is an invaluable part of making sure they don't feel like their adult life is starting with them being defined by their condition."

Additional guidance for supporting young people with mental health conditions, developmental disability, experience with homelessness or unique cultural backgrounds is included in the framework, he says.

The framework and its accompanying resources were developed by Primary Health Tasmania (Tasmania PHN) in partnership with key clinical advisors, and are evidence-based, in line with national and international best practice, and endorsed by the Tasmanian Department of Health.

Hard copies of the *Moving on Up* framework have been sent to general practices across Tasmania, and the resource is free to download on Primary Health Tasmania's website.

The new *Moving on Up* framework builds on the excellent contributions of a range of local clinicians to a 2016 children's transition resource.

www.primaryhealthtas.com.au

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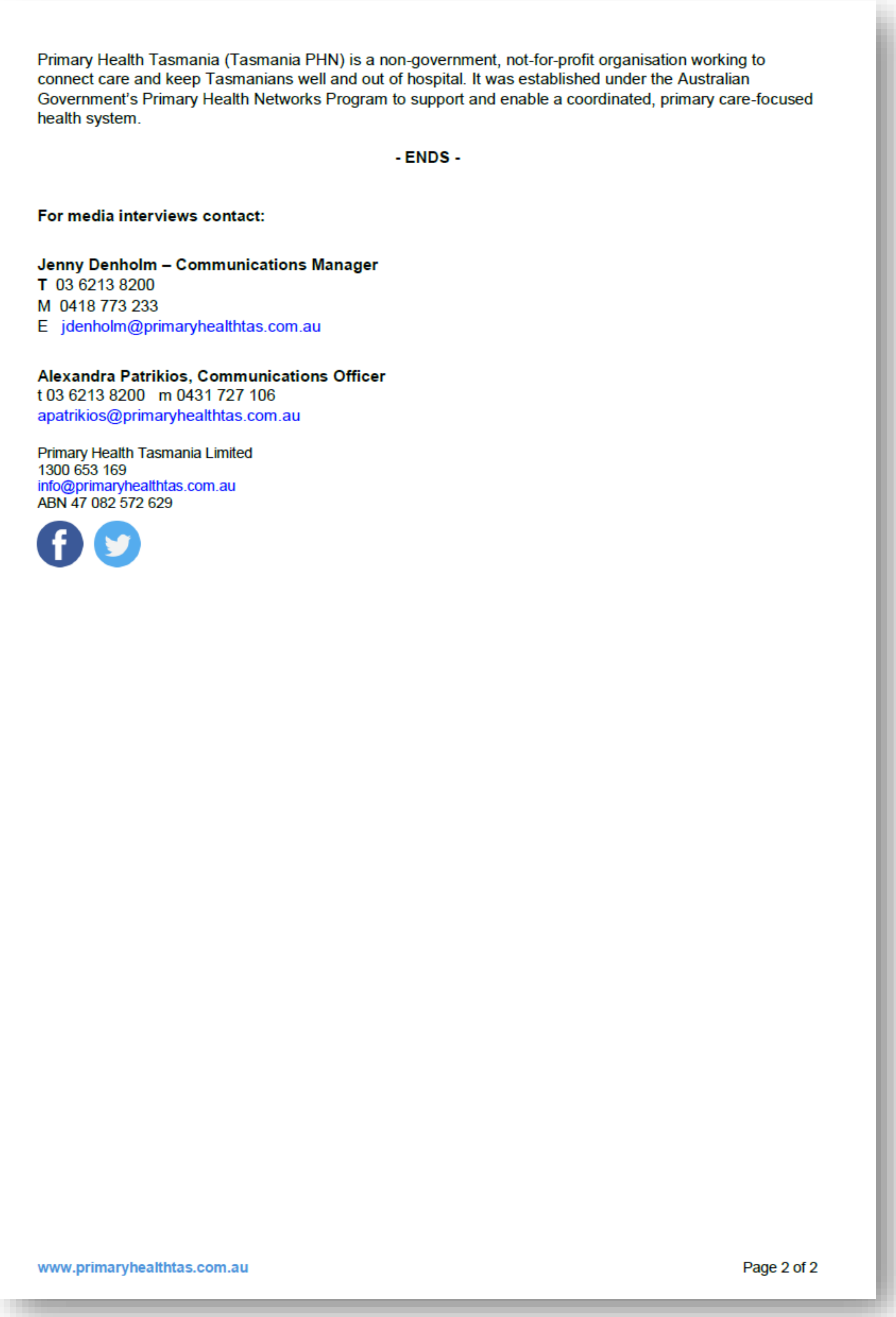

Primary Health Tasmania (Tasmania PHN) is a non-government, not-for-profit organisation working to connect care and keep Tasmanians well and out of hospital. It was established under the Australian Government's Primary Health Networks Program to support and enable a coordinated, primary care-focused health system.

- ENDS -

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YOUTH HEALTH

Jack Dyson

Ensuring continuous care with the Moving on Up framework

'THAT guy with CF.' It's a label Jack Dyson actively avoided when he was a teenager, in and out of hospital for cystic fibrosis treatment at a time when his schoolmates didn't have to worry about managing a chronic health condition.

"For a long time, I didn't really give a damn about my health, and put it on the backburner," the now 22-year-old says.

"I never really, for lack of a better term, gave a shit."

The attitude took a toll. When he was about 15, Jack was just 55 kilos, with 70 per cent lung function and, in his words, a terrible body mass index.

Something had to change: Jack was getting closer to the point where he'd have to leave the Royal Hobart Hospital's paediatric cystic fibrosis service and transition over to adult care.

"It was a long process to figure out what was going on," he remembers.

Eventually, Jack stepped up. He started to take his health seriously and, when the time came, felt ready for the transfer from child to adult services.

It's a critical moment for people who grow up with a chronic condition and one that, if not managed well, can pose significant risks to their ongoing treatment and care.

That's why Primary Health Tasmania, alongside the Tasmanian Government and Tasmanian Health Service, produced

14 ISSUE 11 | NOVEMBER 2019 **PRIMARY HEALTH MATTERS**

Moving on Up — a practical framework to support the transition of young Tasmanians with chronic conditions to adult care.

Updated in 2019, the framework aims to provide health professionals, parents, carers, and patients with easy-to-follow guidelines for a safe transition of care, from birth to young adulthood.

It recognises that transition isn't a one-off, administrative event — it's a complex process that must be tailored to meet each young person's unique needs.

> **"It's really about a shifting of responsibility."**
>
> **Nicole Saxby**

The framework is designed to support young people with chronic conditions such as cystic fibrosis, congenital heart disease, diabetes, mental illness, as well as those with experience of childhood cancer or disability.

Research suggests chronic conditions affect the everyday lives of almost 64,000 young Tasmanians, Primary Health Tasmania's Sal Bucksey says.

"For some, the transition to adult services can be a challenge — one that coincides with an already transformative period of life," she says.

"We hope the framework, as much as it can, may help clinicians, carers, and young people navigate that process in a safe and supported way."

Dietitian Nicole Saxby was instrumental in the development of the first incarnation of the framework and is completing a PhD broadly based on its principles.

In her work as the Tasmanian Health Service's statewide paediatric cystic fibrosis coordinator, she says roughly 10 per cent of her patients are approaching the point where they need to transfer to adult services.

That's 'transfer', as distinct from 'transition'.

So, what's the difference?

"There's the transfer that happens between paediatrics and adult, then there's transition, which can start at a much younger age, by getting kids involved and learning about their condition," she says.

"It's really about a shifting of responsibility."

That might sound aspirational or complementary when compared to the strictly medical aspects of a young person's care.

But, as Nicole explains, supporting a well-developed transition years before the transfer to adult services can have significant, tangible benefits.

"We have proven in the cystic fibrosis service that it can improve a patient's quality of life, their social and emotional wellbeing, their relationship to school, their body image," she says.

"And if we don't manage it well, then we lose them, and they're not on the radar."

That said, Nicole says it's quite normal for adolescents with chronic conditions to go through a period where they engage less because they "just want to be normal" — something Jack, naturally enough, understands.

"Nothing really helped me get through (that stage) but in my head, I sort of just realised that I was going to get older, and people were going to realise you have CF sooner or later," he says.

"My headspace was basically to batten down the hatches.

"I still get people whenever I'm coughing asking if I have a cold, though. It still does my head in, to this day, but it's just one of those things."

Paediatric cystic fibrosis nurse Jennifer Summers says adolescence is a trying time for anyone, let alone a child with a chronic condition, and it can be real challenge for clinicians to find ways to keep teenagers engaged with their health and wellbeing.

"But with Jack, we didn't have the luxury of giving up," she says.

"We had to keep coming up with new ways to try to engage him — the thing that possibly helped with Jack was going to the gym."

So much so, Jack now works at a gym and has carved out an Instagram profile that mixes weight training and progress shots with unflinching insights into the reality of his condition (including selfies in hospital bathroom mirrors).

Jennifer says she even refers some of her current young patients to Jack's posts — which are often accompanied with frank hashtags like #f***CF — to give them an idea of what's possible.

It's a small act, but just one of the tactics she employs to try to get young people to start taking responsibility for their condition.

Other techniques may sound innocuous — things like encouraging young patients to make their own appointments at the front desk or starting to manage their own scripts — but can form the behavioural bedrocks of good self-care.

"It just becomes their normal — chronic health care is their normal," Jennifer explains.

"So we just try to set them up with small, achievable goals."

According to Jack, the habit of setting and attaining his own health-related goals persists beyond those developmental years, and into fully fledged adulthood.

"I'm still learning to this day — it's not a process that ends," he says.

"It keeps going." ■

Want to know more? Go to bit.ly/2yYwYJ8

Primary Health Tasmania's Moving on Up resources

- ■ **Moving on Up framework** — including methodology, transition stages, care components and consideration for specific groups.
- ■ **Moving on Up framework summary** — an A3 chart outlining the key aspects of the Moving on Up framework.
- ■ **Moving on Up key transition stages** — an A4 chart outlining the key transition stages of the Moving on Up framework.
- ■ **Moving on Up checklists and care plan** — a series of practical checklists for clinicians, parents, carers, and patients.

Appendix D

Supplementary files presented with the work in Chapter 4

Publication [9]

1D) Search results – Guidelines considered for inclusion and corresponding professional organisations

2D) N. Saxby, S. Beggs, N. Kariyawasam, M. Battersby, S. Lawn, Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate supported chronic condition self-management? A systematic review. Chronic Ill. (2020) https://doi.org/10.1177/1742395318799844

1D) Search results – guidelines considered for inclusion

Guideline considered			
Name	**Organisation Produced by**	**Primarily located through**	**Included**
NACA Australian Asthma Handbook	36	guideline search	YES
SIGN and BTS British Guideline on the Management of Asthma	37 & 38	guideline search	YES
MSCBC Asthma in Children - diagnosis and management	39	guideline search	YES
Department of Veterans Clinical practice guideline for the management of asthma in children and adults	40	guideline search	YES
RNAO Promoting asthma control in children	41	guideline search	YES
AAAAI Asthma diagnosis	1	professional organisation website	NO
AAAAI Environmental diagnosis and management	1	professional organisation website	NO
AAAAI Asthma treatment: immunotherapy	1	professional organisation website	NO
AAAAI Asthma treatment: Prevention of mortality	1	professional organisation website	NO
AAAAI Asthma treatment: Adherence	1	professional organisation website	NO
AAAAI Occupational asthma	1	professional organisation website	NO
CDC Strategies for addressing asthma within a coordinator school health program	34	professional organisation website	NO
NHLBI Asthma care quick reference	31	professional organisation website	NO
Global Initiative for Asthma	5	professional organisation, and clinicians	YES
NICE guideline (NG80) Asthma: diagnosis, monitoring and chronic asthma management	35	professional organisation website	NO
Definition, evaluation and treatment of sever asthma ERS/ATS guideline 2014	32	professional organisation website	NO

NHLBI 2007 National Asthma Education and Prevention - Expert Panel Report 3, guidelines diagnosis and management of asthma	31	Professional organisation website	NO
Type 1 diabetes in children, adolescents and adults		guideline search	YES
National evidence based guidelines for type 1 diabetes…(NHRMC endorsed)	42	guideline search	YES
2014 Global IDF/ISPAD guidelines for diabetes in childhood and adolescents	14	professional org and clinicians	YES
2017 National standards for diabetes self-management education and support		guideline search	YES
Management of diabetes: a national clinical guideline		guideline search	YES
Diabetes (type 1 and type 2) in children and young people		guideline search	YES
ADA Children and Adolescents: Standards of Medical Care in Diabetes 2017	12	guideline search	YES
ASCE/ACE Clinical Practice Guidelines for Developing a Diabetes Comprehensive Care plan	18	professional organisation website	YES
Diabetes UK Evidence based nutrition guidelines	19	professional association	NO
CFF Enteral tube feeding clinical guidelines	24	professional organisation website	NO
CFF Consensus report on nutrition for paediatric patients with CF 2002 (Borowitz)	24	professional organisation website	NO
CFF Nutrition in children and adults clinical care guidelines 2008 (Stallings)	24	professional organisation website	NO
CFF Chronic medications to maintain lung health clinical care guidelines 2013 (Mogayzel)	24	professional organisation website	NO
CFF Pulmonary exacerbations clinical care guidelines 2009 (Mogayzel)	24	professional organisation website	NO
CFF CF airway clearance therapies clinical care guidelines 2009 (Flume)	24	professional organisation website	NO
CFF Preschool-aged care clinical care guidelines 2016 (Lahiri)	24	professional organisation website	NO
CFF Clinical Care Guidelines for Cystic Fibrosis Related Diabetes 2010 (CFF)	24	professional organisation website	NO
CFF Liver disease clinical care guidelines 1999 (Sokol)	24	professional organisation website	NO

CFF bone disease in CF clinical care guidelines 2005 (Airs)	24	professional organisation website	NO
CFF Screening & treating depression and anxiety guidelines 2016 (Quittner)	24	professional organisation website	NO
CFF CFTR Modulator Therapy Care Guidelines published 2018 (Ren)	24	professional organisation website	
ECFS Guideline principles on how to manage relevant psychological aspects within a CF team: interdisciplinary approaches 2011 (Nobili)	23	professional organisation website	NO
ESPEN-ESPGHAN-ECFS guidelines for nutrition care for infants, children and adults with CF 2016 (Turck)	23	guideline search	NO
European Cystic Fibrosis Society Standards of Care 2014	23	professional organisation website	NO
Cystic fibrosis Standards of care, Australia	25	professional organisation website	NO
Cystic Fibrosis Trust standards of care 2011	43	professional organisation website	NO
CFA Infection control guidelines 2012	25	professional organisation website	NO
CFA infection control policy 2015	25	professional organisation website	NO
Nutrition guidelines for cystic fibrosis in Australia and New Zealand 2017 (saxby)	25	professional organisation website	NO
Physiotherapy for cystic fibrosis in Australia and Enw Zealand (Button)	30	professional organisation website	NO

Corresponding numbers representing professional organisations

1	* National Institute of Allergy and Infectious Diseases NIH (USA)
2	* American Academy of Allergy Asthma & Immunology
3	* Asthma and Allergy Foundation of America
4	* American College of Allergy, Asthma and Immunology
5	* Global Initiative for Asthma
6	* Asthma Canada
7	* Allergy UK

8 * Asthma UK
9 * World Allergy Organization
10 * Australian Society of Clinical Immunology and Allergy (ASCIA)
11 * American Association for Respiratory Care
12 * American Diabetes Association
13 * JDRF
14 * International Diabetes Federation
15 * Joslin Diabetes Centre
16 * Diabetes Canada
17 * Diabetes Australia
18 * American Association of Clinical Endocrinologists
19 * Diabetes UK
20 * National Institute of Diabetes and Digestive and Kidney Diseases (NIH)
21 * ISPAD International Society for Pediatric and Adolescent Diabetes
22 * Endocrine Society (US)
23 * European Cystic Fibrosis Society
24 * Cystic Fibrosis Federation (USA)
25 * Cystic Fibrosis Australia
26 * Cystic Fibrosis New Zealand
27 * Cystic Fibrosis Canada
28 * Cystic Fibrosis Worldwide
29 * American Lung Association
30 * Thoracic Society of Australia and New Zealand
31 * National Heart, Lung and Blood Institute
32 * American Thoracic Society
34 Centres for Disease Control and Prevention
35 National Institute for Health and Care Excellence
36 National Asthma Council of Australia
37 Scottish Intercollegiate Guideline Network (SIGN)
38 British Thoracic Society (BTS)
39 Medical Commission of British Columbia
40 Department of Veteran Affairs USA
41 Royal Nurses' Association of Ontario
42 Australian Diabetes Society
43 Cystic Fibrosis Trust

2D) Publication

Review

chronic illness

Chronic Illness
0(0) 1–14

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Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review

Nicole Saxby[1,2], Sean Beggs[2], Nadish Kariyawasam[3], Malcolm Battersby[1] and Sharon Lawn[1]

Abstract

Objectives: To determine whether evidence-based practice guidelines promote developmentally appropriate chronic condition self-management for children with asthma, type I diabetes mellitus, and cystic fibrosis.

Methods: Systematic review of clinical guidelines current as at 22 September 2017, including assessment of quality of each guideline using the iCAHE 'Guideline Quality Checklist', and mapping of the supporting evidence.

Results: Fifteen guidelines were identified: asthma (*n*=7) and type I diabetes mellitus (*n*=7), CF (*n*=1). Guideline quality was variable, and 11 different grading systems were used. In total, there were 28 recommendations promoting age/developmental considerations. Recommendations focused on: collaboration (*n*=15), chronic condition self-management education (*n*= 17), clinicians' skills (*n*= 4); personalized action plans (*n*=3), problem-solving (*n*=2); and the assessment of children's chronic condition self-management needs (*n*=3). Developmental transitions are highlighted as important time points in some guidelines: preschool (*n*=2), and adolescence (*n*=3). All guidelines encouraged triadic partnerships between children, adult caregivers and clinicians. Evidence supporting the developmental aspects

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of the guidelines' recommendations was poor; only 14 out of 57 journals listed as evidence were concordant.

Discussion: Current guidelines articulate that developmentally appropriate chronic condition self-management is important; however, more work needs to be done to translate the concept into practical clinical tools.

Keywords

Asthma, chronic condition self-management, cystic fibrosis, diabetes, paediatrics

Received 30 January 2018; accepted 7 August 2018

Introduction

More than 1 in 10 Australian children lives with a chronic medical condition.[1] To maximise health and allow participation in 'normal' childhood activities, children with chronic conditions and their families need to complete daily treatments and monitoring activities, referred to as chronic condition self-management (CCSM).[2,3] Unfortunately, many children (particularly adolescents) do not effectively engage in CCSM.[4,5] Poor CCSM is linked to worse health outcomes, decreased quality of life, increased interactions with the acute health system and amplified financial burden.[5–7]

As children grow, they become more confident and autonomous in managing their own affairs, relating to other people, and being involved in decisions impacting on them.[8] For children with chronic conditions, this process also includes learning how to look after their own healthcare needs and the establishment of lifelong views towards healthcare.[9] Children's developmental stage will affect their capacity to understand, cope with and manage their chronic condition,[8,9] and the type of health education strategies that are likely to be most effective.[10,11] It is important to recognise that developmental stage is not necessarily defined by children's age.[8] Children with chronic conditions can, and do, develop self-management skills at varying rates and intervals.[12,13]

Self-management support is what clinicians, families and health care systems do to assist children develop the skills, knowledge, and behaviours they need to manage their chronic conditions.[3,14] Children with chronic conditions are likely to interact with clinicians regularly,[3] learning the skills they need to manage their health over a long period.[12,13] This frequent contact offers clinicians opportunities to provide CCSM support in a ways that help children to build the complexity of their skills on top of skills they have previously aquired.[3] The term 'clinician' encompasses a variety of disciplines including medicine, nursing and allied health. In paediatric settings, clinicians work together as an interdisciplinary team towards common CCSM goals with children and their families.[3]

Developmentally appropriate CCSM is a re-emerging concept. The term 'self-management' was originally proposed in the mid-1960s by Creer and Christian[15] and Creer et al.[16] to describe children being active participants in their own asthma care. This early work by Creer's team was based on the developmental theory of Bandura.[15,16] Over time, however, CCSM research has shifted away from children and increasingly focused on adults.[17] Thus, the majority of the literature in this area is adult-based.

In the first framework to support paediatric CCSM, Modi et al.[3] (p.e474) concluded,

"developmental transitions [. . ..] are critical windows of opportunities to instigate family and health care system-based interventions to sustain adaptive self-management." As described in this framework, childhood development has a dynamic, heterogeneous nature. It changes over time with age and is influenced by a child's experiences.[3] Young children cannot be expected to assume full responsibility for their conditions management. However, over time, they can be encouraged to become cooperative self-managers, together with their adult caregivers and clinicians. The manner in which clinicians are implementing CCSM in a developmentally appropriate way is currently unknown.

Three chronic conditions of childhood particularly relevant to Australian and international practice are asthma, type 1 diabetes mellitus (T1DM) and cystic fibrosis (CF). Asthma is the most common chronic condition affecting Australian children (affects one in 10 children), and is among the most frequent reasons for emergency department presentations.[1,18] While the numbers of children with T1DM are smaller (affects one in 100 children), incidence is on the rise amongst Australian children.[1] CF is the most common life-threatening recessive inherited condition that affects Caucasians.[19] Asthma, T1DM and CF were selected due to their differing natures (i.e. etiologies, symptoms and prognosis) and differing complexities of treatment regimens. There are also similarities between these conditions, including the need for daily management and monitoring. Studying these conditions allows identification of commonalities, and differences, in guidelines recommending CCSM support for children.

Self-management support is an important guideline component in the care of chronic conditions. In Australia, the National Health and Medical Research Council (NHMRC) recommends the use of clinical practice guidelines to improve quality of care through the application of consistent evidence-based practice.[20] The aim of this systematic review was to examine if evidenced-based guidelines promote developmentally appropriate self-management support for children diagnosed with asthma, T1DM and CF.

Methods

Data sources

A comprehensive literature search, supported by a medical librarian, was conducted. Seven international guideline databases were searched: National Guideline Clearinghouse (United States of America (USA)), Canadian Medical Association Infobase (Canada), National Health Service Evidence and The National Institute for Health and Care Excellence (NICE) (United Kingdom), Scottish intercollegiate Guidelines Network (SIGN) (Scotland), New Zealand Guidelines Group, and the NHMRC.

To ensure that no guidelines of international significance to CCSM were missed, 15 clinicians from across Australasia ($n = 6$), Europe ($n = 3$) and North America including Canada ($n = 6$), each with more than five years' experience in the care of children with asthma, T1DM and CF, were consulted. Furthermore, the websites of 32 professional asthma, T1DM and CF organisations were searched for current guidelines (e.g. American Academy of Allergy Asthma and Immunology, International Society for Pediatric and Adolescent Diabetes, Cystic Fibrosis Foundation, European Cystic Fibrosis Society).

Eligibility

Inclusion criteria. Guidelines were included if they were current as of the 22 September 2017 and if they were created by a professional organisation to assist a single discipline or an interdisciplinary team in managing asthma, T1DM, or CF. To meet inclusion criteria, guidelines also needed to have a section dedicated to CCSM and within that section contain the words "development*" or "age" or "age-appropriate" or "throughout life*."

Exclusion criteria. Guidelines were excluded if they focused on other childhood chronic conditions or were hospital-based guidelines.

Data extraction

A two-staged screening process was completed by the first author (NS) to confirm that guidelines met inclusion criteria – In stage 1, guidelines were screened for relevance through title and abstracts (i.e. they covered children and may include CCSM), and duplicates were removed. Stage 2 excluded guidelines that did not promote developmentally appropriate CCSM and guidelines that were rescinded. Reasons that guidelines were excluded were recorded on an Excel database.

For guidelines meeting inclusion criteria, the following data were extracted by the first author (NS) and confirmed by a second person (NK): general guideline characteristics, methodological development process, clinicians/patient groups targeted, settings and circumstances in which to use developmental CCSM, and practice recommendations for age/developmental CCSM inclusive of evidence hierarchy ranking. Recommendations were then classified into six research defined groups reflecting the components of effective CCSM.

- Collaboration (*i.e. promotion of an active health care triad, i.e. children, families and clinicians working together*);
- Education (*i.e. the provision of information, and the teaching of skills and techniques to children in a developmentally appropriate way to improve CCSM*);
- Clinicians' CCSM support skills (*i.e. clinicians who are adequately trained and who will support children's ability to learn CCSM skills at differing ages and developmental stages*);
- Personalised action plans (*i.e. the provision of a written instructions to help children and their adult caregivers manage the chronic condition and respond proactively to changes in signs and symptoms*);
- Problem-solving and decision-making (*i.e. the developmentally appropriate teaching of strategies for problem resolution, and the ability to select an appropriate education strategy*); and
- Assessment and monitoring of CCSM needs (*i.e. measuring the CCSM capacity of children over time*).[3]

The above groupings were based broadly on CCSM components outlined in Modi et al.[3] It is worth noting that there may be some overlap between groupings (e.g. collaboration would be required for effective education and also for problem-solving and decision making).

Data synthesis

Descriptive analysis was undertaken by NS to present each guideline's general characteristics, including the grading system used to assess evidence quality and strength of recommendations. Full-text journal articles listed as evidence for recommendations were then assessed for concordance with developmentally based CCSM considerations.

Two independent assessors (NS and NK) appraised guideline quality using the International Centre for Allied Health (iCAHE) 'Guideline Quality Checklist', which measures quality across six domains: availability (i.e. available in full text, complete reference list, summary of recommendations provided); dates (i.e. date of completion and planned review stated); underlying evidence (i.e. strategy to assess evidence and quality stated); guideline developers (i.e. developers qualified to develop the guideline); guideline purpose and users (i.e. purpose and uses clearly articulated); and ease of use (i.e. readable and easy to navigate).'[21] This checklist is validated for construct validity, inter-tester reliability and clinical utility against the research-focused AGREE-II instrument.[21] The research team chose to use the iCAHE Checklist because it is time-efficient to administer and Australian-based. Quality rankings were expressed as average % total iCAHE scores with standard deviations to represent agreement between the two appraisers (total agreement SD = 0, moderate agreement SD <15, poor agreement SD >15).

This review was an analysis of published work. Thus, it did not require ethical approval.

Results

Seven guideline databases yielded 1636 results. Additional guidelines were identified through reviewing professional organisation websites (n = 79) and by asking clinicials (n = 13). After removing duplicates and screening (stage 1), 46 guidelines met the inclusion criteria and full texts were obtained. Further screening (stage 2) resulted in the inclusion of 15 guidelines (see Figure 1).

General guideline characteristics

In relation to country of origin, guidelines originated from the USA ($n = 5$), Canada ($n = 4$), United Kingdom ($n = 3$), Australia ($n = 2$), and Belgium ($n = 1$). They included guidelines for T1DM ($n = 7$), asthma ($n = 6$), and CF ($n = 1$) (see Table 1 for summary characteristics of included guidelines).

Guidelines by quality

The best quality guidelines overall were the Australian 'National Asthma Handbook',[18] the 'British Guideline on the Management of Asthma',[22] the Australian 'National evidence-based guidelines for type 1 diabetes in children, adolescents and adults',[27] and the Scottish 'Management of diabetes: a national clinical guideline'.[31] These four guidelines ranked first in each of the iCAHE domains. See Table 1 for all rankings.

Two guidelines did not grade the strength of the evidence and/or recommendations.[23,29] The other 12 guidelines used 12 different systems to do so: $n = 2$ NHMRC,[20] $n = 1$ Global Initiative for Asthma,[34] $n = 1$ SIGN and NICE,[35] $n = 1$ Oxford,[36] $n = 1$ Department of Veteran Affairs and Department of Defence,[37] $n = 1$ Registered Nurses Association of Ontario (RNAO),[9] $n = 1$ Canadian Diabetes Association,[26] $n = 1$ American Diabetes Association,[38] $n = 1$ National Collaborating Centre for Women's and Children's Health (UK),[33] $n = 1$ Cystic Fibrosis Foundation,[19] and $n = 1$ the American Association of Clinical Endocrinologists.[32] Grading of the strength of recommendations, depending on scale used, was heterogeneous. Levels given to similar recommendations ranged from the highest level of evidence available down to consensus opinion.

Guideline recommendations

Together, the 15 guidelines provide 29 specific developmentally based recommendations for CCSM. One guidelines mentioned these considerations in the narrative text only.[34] Some guidelines included multiple recommendations in the same grouping (e.g. two or three different recommendations for CCSM education). Practice recommendations centered on developmentally appropriate:

- Collaboration ($n = 15$ recommendations).[9,18,19,22,24–30,32,33]
- All guidelines stated that CCSM support was the responsibility of the entire interdisciplinary team, with triadic collaboration

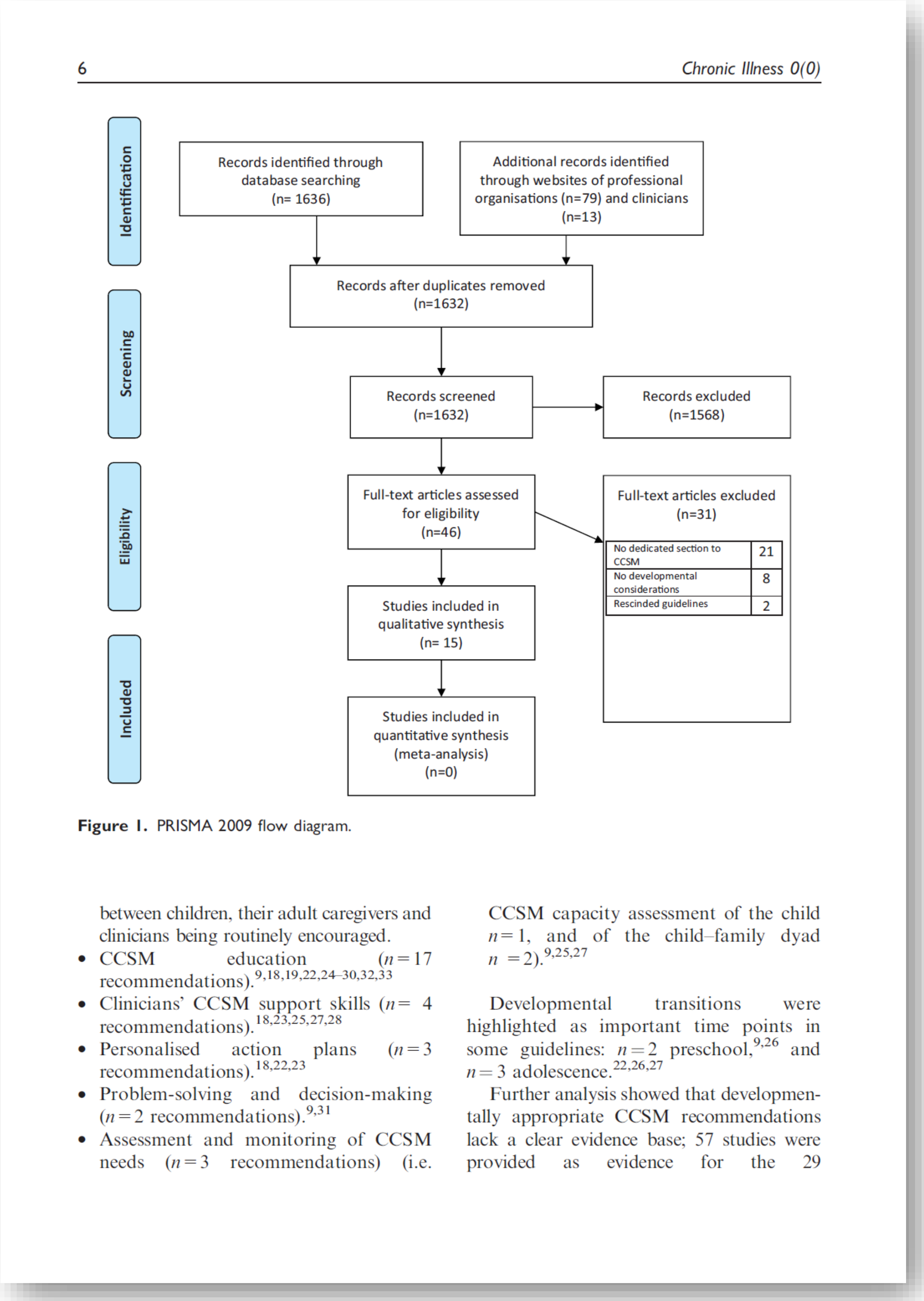


Figure 1. PRISMA 2009 flow diagram.

between children, their adult caregivers and clinicians being routinely encouraged.

- CCSM education ($n = 17$ recommendations).[9,18,19,22,24–30,32,33]
- Clinicians' CCSM support skills ($n = 4$ recommendations).[18,23,25,27,28]
- Personalised action plans ($n = 3$ recommendations).[18,22,23]
- Problem-solving and decision-making ($n = 2$ recommendations).[9,31]
- Assessment and monitoring of CCSM needs ($n = 3$ recommendations) (i.e. CCSM capacity assessment of the child $n = 1$, and of the child–family dyad $n = 2$).[9,25,27]

Developmental transitions were highlighted as important time points in some guidelines: $n = 2$ preschool,[9,26] and $n = 3$ adolescence.[22,26,27]

Further analysis showed that developmentally appropriate CCSM recommendations lack a clear evidence base; 57 studies were provided as evidence for the 29

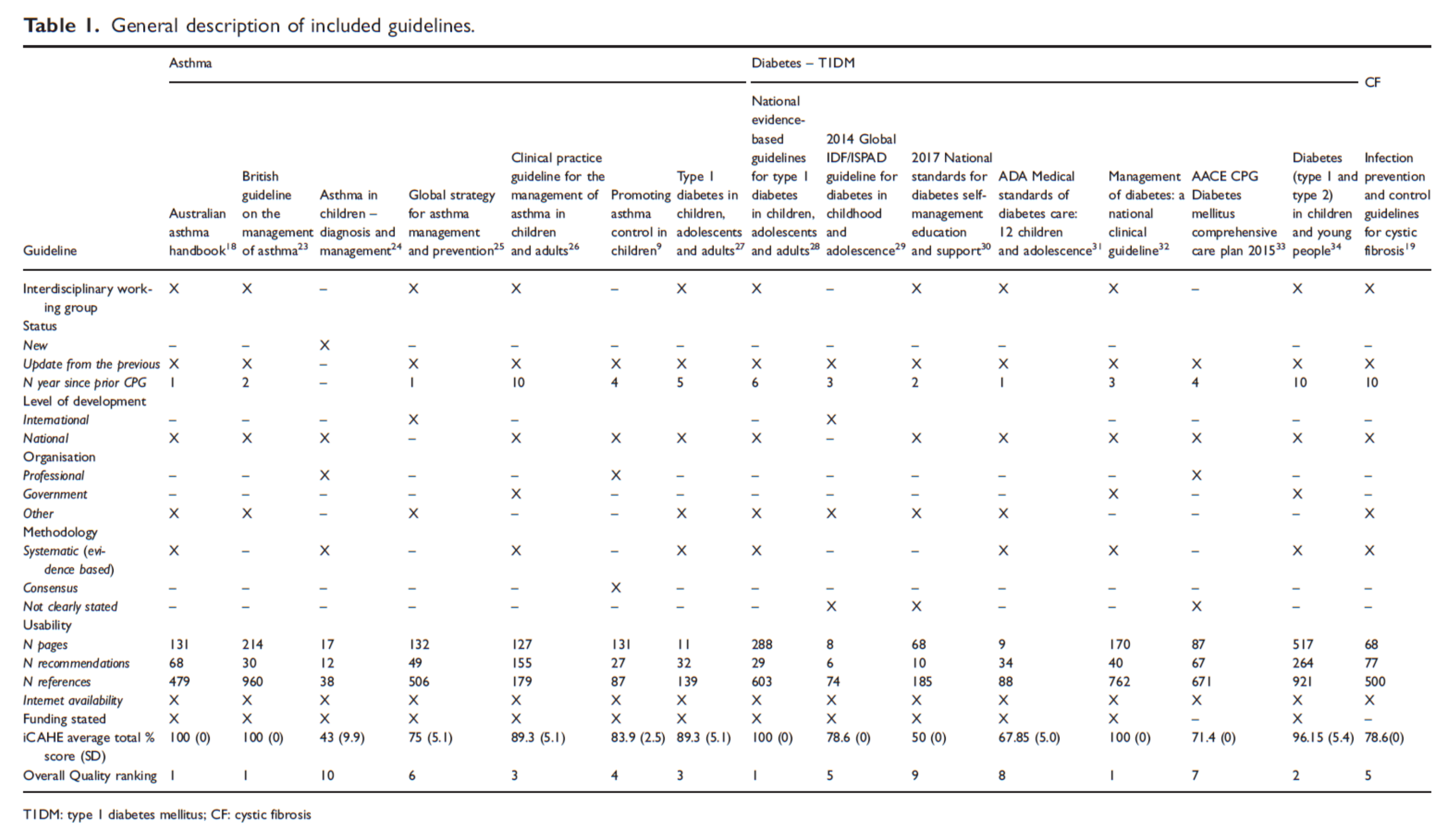


Table 1. General description of included guidelines.

	Asthma							Diabetes – T1DM							CF
Guideline	Australian asthma handbook[18]	British guideline on the management of asthma[23]	Asthma in children – diagnosis and management[24]	Global strategy for asthma management and prevention[25]	Clinical practice guideline for the management of asthma in children and adults[26]	Promoting asthma control in children[9]	Type 1 diabetes in children, adolescents and adults[27]	National evidence-based guidelines for type 1 diabetes in children, adolescents and adults[28]	2014 Global IDF/ISPAD guideline for diabetes in childhood and adolescence[29]	2017 National standards for diabetes self-management education and support[30]	ADA Medical standards of diabetes care: 12 children and adolescence[31]	Management of diabetes: a national clinical guideline[32]	AACE CPG Diabetes mellitus comprehensive care plan 2015[33]	Diabetes (type 1 and type 2) in children and young people[34]	Infection prevention and control guidelines for cystic fibrosis[19]
Interdisciplinary working group	X	X	–	X	X	–	X	X	–	X	X	X	–	X	X
Status															
New	–	–	X	–	–	–	–	–	–	–	–	–		–	–
Update from the previous	X	X	–	X	X	X	X	X	X	X	X	X	X	X	X
N year since prior CPG	1	2	–	1	10	4	5	6	3	2	1	3	4	10	10
Level of development															
International	–	–	–	X	–			–	X			–	–	–	–
National	X	X	X	–	X	X	X	X	–	X	X	X	X	X	X
Organisation															
Professional	–	–	X	–	–	X	–	–	–	–	–	–	X	–	–
Government	–	–	–	–	X	–	–	–	–	–	–	X	–	X	–
Other	X	X	–	X	–	–	X	X	X	X	X	–	–	–	X
Methodology															
Systematic (evidence based)	X	–	X	–	X	–	X	X	–	–	X	X	–	X	X
Consensus	–	–	–	–	–	X	–	–	–	–	–	–	–	–	–
Not clearly stated	–	–	–	–	–	–	–	–	X	X	–	–	X	–	–
Usability															
N pages	131	214	17	132	127	131	11	288	8	68	9	170	87	517	68
N recommendations	68	30	12	49	155	27	32	29	6	10	34	40	67	264	77
N references	479	960	38	506	179	87	139	603	74	185	88	762	671	921	500
Internet availability	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Funding stated	X	X	X	X	X	X	X	X	X	X	X	X	–	X	–
iCAHE average total % score (SD)	100 (0)	100 (0)	43 (9.9)	75 (5.1)	89.3 (5.1)	83.9 (2.5)	89.3 (5.1)	100 (0)	78.6 (0)	50 (0)	67.85 (5.0)	100 (0)	71.4 (0)	96.15 (5.4)	78.6(0)
Overall Quality ranking	1	1	10	6	3	4	3	1	5	9	8	1	7	2	5

T1DM: type 1 diabetes mellitus; CF: cystic fibrosis developmentally based CCSM recommendations and in-text comments. Only 14 (24.6%) of these studies, written in English, were found to be direct evidence for developmental considerations. Evidence was stronger for education ($n = 6$ concordant studies)[10,39–43] and less so for all other areas for which each had less than two supporting studies (i.e. collaboration, clinicians CCSM support skills, action plans, and problem solving and decision making). In all guidelines, developmental considerations were only one part of multi-component recommendations.

Support tools available for clinicians. Two guidelines provided clinicians with practical tools to increase children's participation in their healthcare.[9,23] The RNAO asthma guideline included two tools: a summary of developmental theories and issues concerning health and illness; and a practical guide of what are developmentally appropriate asthma CCSM behaviours, based on Piagetian concepts of cognitive development and Erikson's theory of psychosocial development.[9] A developmental psychologist was involved in the creation of the RNAO tools.[9] The Medical Services Commission of British Columbia asthma guideline provided asthma action plans in two age groupings – i.e. less than 6 years old, and 6 to 18 years old.[23]

Conversely, none of the three guidelines that recommended clinicians assessed CCSM and developmental capacity of the child and/or child–parent dyad provided any measures to do so.[9,25,27]

Discussion

The most prominent finding of this review was that guidelines promoting developmentally appropriate CCSM lack a clearly articulated evidence base. Only 14 (24.6%) out of the 57 studies listed as evidence were concordant with the recommendations made, with the strongest evidence provided by guideline authors being for CCSM education.

Overall, 15 guidelines of various quality recommended that CCSM support be provided in a developmentally appropriate way. This finding was applicable and generalisable across a wide variety of conditions – asthma, T1DM and CF. The 29 clinical care recommendations within these guidelines centered on developmentally appropriate: collaboration, CCSM education; clinicians' CCSM support skills; personalised action plans; problem-solving and decision-making; and assessment of children's and/or families' knowledge about the condition and its treatment. Nonetheless, all 29 of these guideline recommendations were too vague to be of any practical relevance to clinicians.

Collaboration

The 15 included guidelines promoted the use of triadic partnerships without providing any supportive evidence. Children over the age of five years should be presumed competent to be involved in their own healthcare, in partnership with their adult caregivers and clinicians.[44] Unfortunately, according to a good quality systematic review completed in 2007, children tend to have little meaningful healthcare involvement.[44] Children are least likely to be active participants in the treatment planning and discussion parts of consultations when CCSM is often raised.[44]

For clinicians, three-way consultations are more complex than didactic consultations due to the need to contextualise health information in a way that both children and adults can understand, and the need to listen to children and adults equally and to consider any differences of opinions before planning ongoing healthcare.[45,46] Ways that clinicians can involve children more in consultations are to ensure that all adults in the room are supportive of their participation, and to engage children within the first half of a consultation.[44]

Education

All but one of the included guidelines ($n = 14/15$) promoted the delivery of developmentally appropriate CCSM education to transfer knowledge, skills, and abilities necessary for children to look after their own healthcare needs. In these guidelines, six studies were quoted as evidence for providing developmentally appropriately CCSM education.[10,39–43] A further literature search by our research group (submitted for publication elsewhere),[47] however, revealed that there are several additional randomised controlled trials in children with asthma, T1DM and CF (with statistically significant results) which were not referenced by the guideline authors.[11,48–59] Common themes for delivering developmentally appropriate education to children are:

- Age-appropriate stages of developmental psychology must be followed, with children being directly involved in CCSM from infancy through to adulthood.
- Educational programs should be tailored specifically for infants, school-aged children, younger adolescents, older adolescents and adult caregivers.
- CCSM should be facilitated in conjunction with self-efficacy.
- Structured written curriculum is beneficial, with modular components building on CCSM skills that have been previously learnt by children.
- Curriculum topics should include – knowledge of condition, impact of condition, symptom monitoring, responding to symptoms, actively participating in their own clinical care, being able to use a written action plan, lifestyle, and accessing support services.
- Problem-solving and decision-making should be emphasised and
- Using play, role playing and arts-based activities may facilitate the learning of infants and school aged children.

These themes are consistent with proven adult self-management education programs.[17]

Clinicians' CCSM support skills

The need for clinicians to have appropriate skills to support children to develop CCSM skills was articulated in four guidelines. Nonetheless, what these clinical skills would look like was not clearly articulated. Published in 2009, Flinders University CCSM capabilities resource outlines the skills that the healthcare workforce needs to deliver effective CCSM support across the lifespan.[14,60] Paediatric clinicians keen to improve their CCSM support skills should consider completing professional development in areas such as: communication, assessment of self-management capacity (understanding strengths and barriers), collaborative care planning, use of peer supports, psychosocial assessment and support, understanding of models of health behaviour change, motivational interviewing, and how to work better in an interprofessional environment.[14]

Tools, such as the developmentally based CCSM skill guide seen in RNAO 2008,[9] may help with translation to practice.

Action plans

Three guidelines recommended that children and their families be provided with written instructions to manage the chronic condition/s in everyday life.[18,22,23] Written instructions for CCSM in the home environment are commonly referred to as "action plans," and their purpose is to help guide prevention, management of symptoms and when to seek medical help.

Only one out of three guidelines promoting action plans provided versions targeted at children of different ages – i.e. an asthma action plan for children aged <6 years, and a separate action plan for children aged 6 to 18 years.[23] As mentioned in the Australian Asthma Handbook,[18] the reason behind a lack of developmentally appropriate action plans for children may be related to there being no established guidance regarding the ideal format and the critical instructions that need to be included. However, research has shown that individuals with low health literacy can comprehend pictorial action plans.[61]

Problem-solving and decision-making

Two guidelines recognised the importance of children being taught developmentally appropriate strategies for problem resolution. Structured problem-solving for children with chronic conditions appears to be significant gap in the current literature base. Further research in this area is required before useful guideline recommendations can be made.

Assessment and monitoring of CCSM needs

While three guidelines recommended that clinicians measure the CCSM capacity of children over time, neither of these guidelines cross-referenced any appropriate tools to do so. To date, no systematic reviews have been completed looking at the validity of tools to assess children's CCSM skills and thus this remains a gap in the knowledge base. Clinicians would benefit from having a clear go to research that articulates appropriate CCSM capacity tools for children.

Translating guideline recommendations into practice

Mere presence of high quality evidence in clinical guidelines does not necessarily result in translation to practice.[62,63] As was highlighted in this review, despite most guidelines having been developed systematically, their recommendations supporting "developmentally appropriate CCSM" are vague and do not provide clinicians with practical advice.

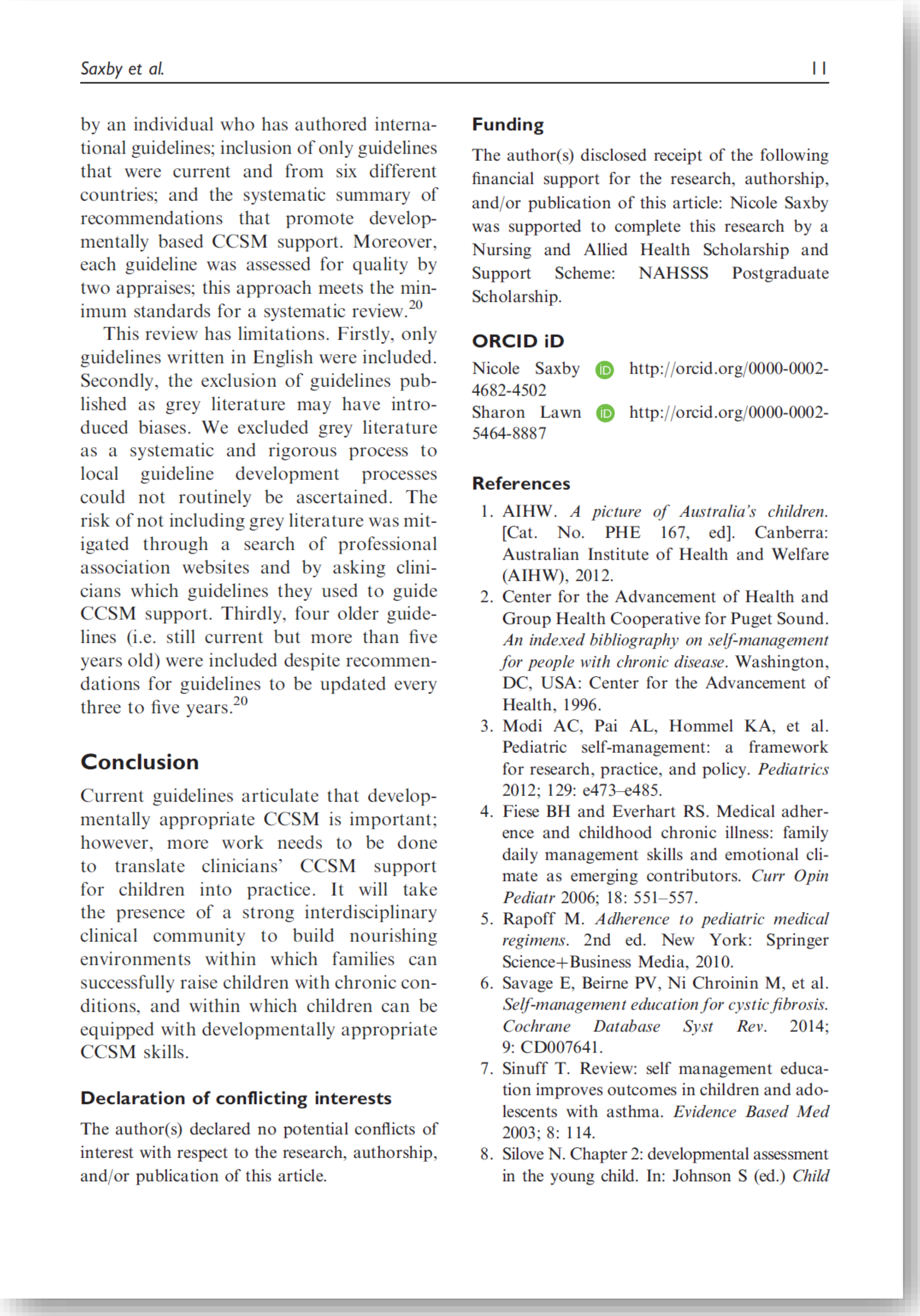
An example of a difficult to implement recommendation is to "Assess patient and/or family for educational needs as well as for preferences and/or barriers to learning." This recommendation requires clinicians to consider literacy, physical, developmental, emotional or psychological challenges as well as specific cultural and/or spiritual beliefs. Despite a level-A evidence ranking being assigned to this recommendation (i.e. there is strong evidence for this recommendation and clinicians should be applying this intervention to all eligible patients), none of the references included in this review support the assessment of a child's developmental stage. Clinicians may have difficulty interpreting the unclear evidence base of recommendations such as this.

A co-incidental finding, resulting from different methodologies used by the guideline development groups, was that multiple systems for grading evidence and recommendations were included in the guidelines. For clinicians, this creates unnecessary confusion. One guideline development group reported having previously trialed (twice) the international GRADE system in 2009; however, they ultimately decided to not adopt this methodology because of the major resource challenges it would present.[24]

Evidence-based recommendations need to be presented in a way that is both assessable and relevant, and integrated into strategies that are feasible for clinicians to use in their busy clinical practice.

Strengths and limitations

The strengths of our review include: a comprehensive guideline search which was supported by a medical librarian and conducted



by an individual who has authored international guidelines; inclusion of only guidelines that were current and from six different countries; and the systematic summary of recommendations that promote developmentally based CCSM support. Moreover, each guideline was assessed for quality by two appraises; this approach meets the minimum standards for a systematic review.[20]

This review has limitations. Firstly, only guidelines written in English were included. Secondly, the exclusion of guidelines published as grey literature may have introduced biases. We excluded grey literature as a systematic and rigorous process to local guideline development processes could not routinely be ascertained. The risk of not including grey literature was mitigated through a search of professional association websites and by asking clinicians which guidelines they used to guide CCSM support. Thirdly, four older guidelines (i.e. still current but more than five years old) were included despite recommendations for guidelines to be updated every three to five years.[20]

Conclusion

Current guidelines articulate that developmentally appropriate CCSM is important; however, more work needs to be done to translate clinicians' CCSM support for children into practice. It will take the presence of a strong interdisciplinary clinical community to build nourishing environments within which families can successfully raise children with chronic conditions, and within which children can be equipped with developmentally appropriate CCSM skills.

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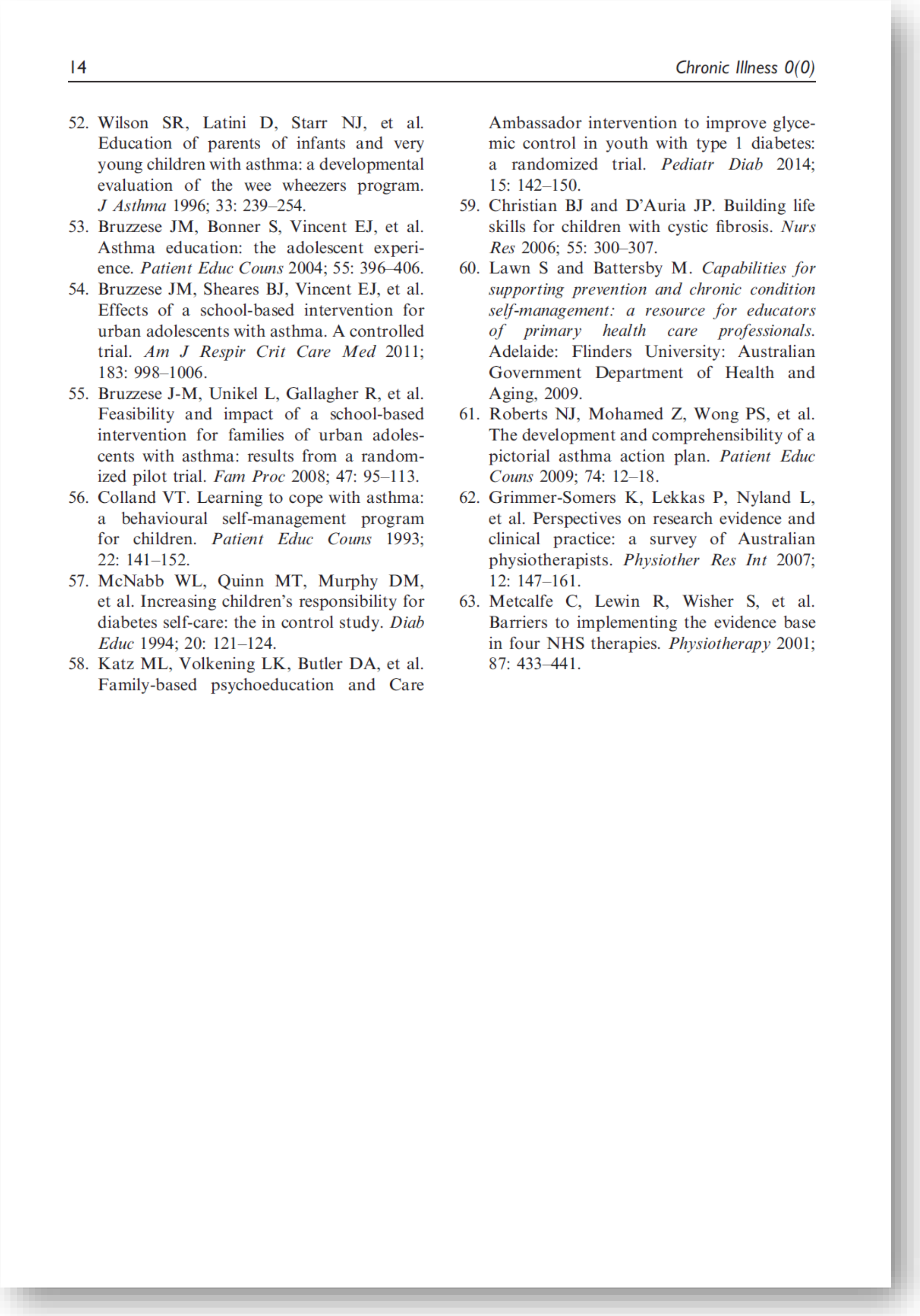

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Appendix E

Supplementary files presented with the work in Chapter 6

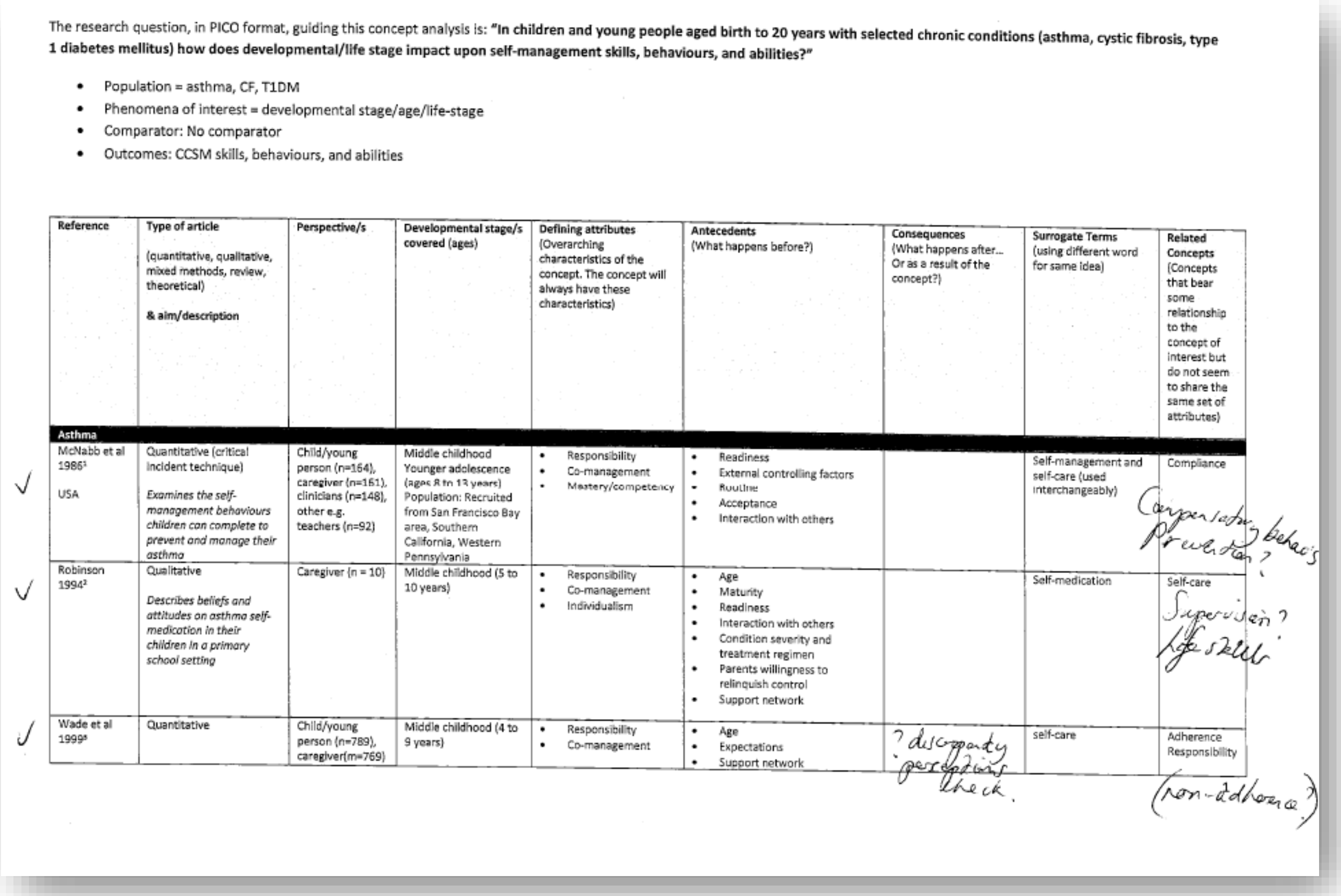
Research related documents

1E) Example of concept analysis theming for each included study (attributes, antecedents, consequences, surrogate terms, related concepts)

2E) CER-Qual evidence tables

1E) Example of concept analysis theming for each included study (attributes, antecedents, consequences, surrogate terms, related concepts)

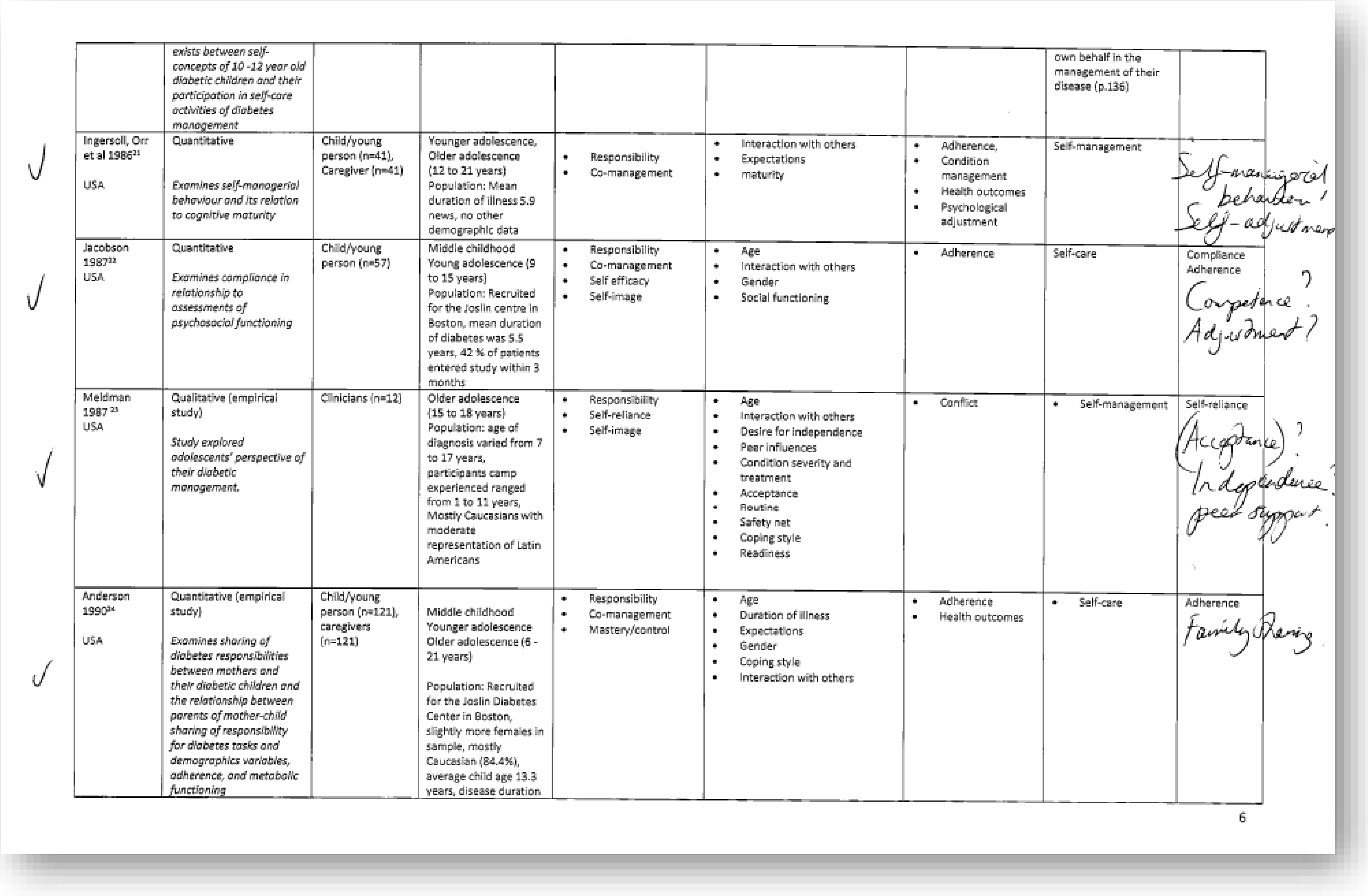
For brevity of this appendix, two pages of raw themeing for the concept analysis provided as an example only.



The research question, in PICO format, guiding this concept analysis is: **"In children and young people aged birth to 20 years with selected chronic conditions (asthma, cystic fibrosis, type 1 diabetes mellitus) how does developmental/life stage impact upon self-management skills, behaviours, and abilities?"**

- Population = asthma, CF, T1DM
- Phenomena of interest = developmental stage/age/life-stage
- Comparator: No comparator
- Outcomes: CCSM skills, behaviours, and abilities

	Reference	**Type of article** (quantitative, qualitative, mixed methods, review, theoretical) **& aim/description**	**Perspective/s**	**Developmental stage/s covered (ages)**	**Defining attributes** (Overarching characteristics of the concept. The concept will always have these characteristics)	**Antecedents** (What happens before?)	**Consequences** (What happens after… Or as a result of the concept?)	**Surrogate Terms** (using different word for same idea)	**Related Concepts** (Concepts that bear some relationship to the concept of interest but do not seem to share the same set of attributes)
	Asthma								
✓	McNabb et al 1986[1] USA	Quantitative (critical incident technique) *Examines the self-management behaviours children can complete to prevent and manage their asthma*	Child/young person (n=164), caregiver (n=161), clinicians (n=148), other e.g. teachers (n=92)	Middle childhood Younger adolescence (ages 8 to 13 years) Population: Recruited from San Francisco Bay area, Southern California, Western Pennsylvania	• Responsibility • Co-management • Mastery/competency	• Readiness • External controlling factors • Routine • Acceptance • Interaction with others		Self-management and self-care (used interchangeably)	Compliance Compensatory behav's Prevention?
✓	Robinson 1994[2]	Qualitative *Describes beliefs and attitudes on asthma self-medication in their children in a primary school setting*	Caregiver (n = 10)	Middle childhood (5 to 10 years)	• Responsibility • Co-management • Individualism	• Age • Maturity • Readiness • Interaction with others • Condition severity and treatment regimen • Parents willingness to relinquish control • Support network		Self-medication	Self-care Supervision? Life skills
✓	Wade et al 1999[3]	Quantitative	Child/young person (n=789), caregiver(m=769)	Middle childhood (4 to 9 years)	• Responsibility • Co-management	• Age • Expectations • Support network	? discrepancy perceptions check.	self-care	Adherence Responsibility (non-adherence?)



		exists between self-concepts of 10 -12 year old diabetic children and their participation in self-care activities of diabetes management						own behalf in the management of their disease (p.136)	
✓	Ingersoll, Orr et al 1986[21] USA	Quantitative *Examines self-managerial behaviour and its relation to cognitive maturity*	Child/young person (n=41), Caregiver (n=41)	Younger adolescence, Older adolescence (12 to 21 years) Population: Mean duration of illness 5.9 news, no other demographic data	- Responsibility - Co-management	- Interaction with others - Expectations - maturity	- Adherence, - Condition management - Health outcomes - Psychological adjustment	Self-management	Self-managerial behaviour / Self-adjustment
✓	Jacobson 1987[22] USA	Quantitative *Examines compliance in relationship to assessments of psychosocial functioning*	Child/young person (n=57)	Middle childhood Young adolescence (9 to 15 years) Population: Recruited for the Joslin centre in Boston, mean duration of diabetes was 5.5 years, 42 % of patients entered study within 3 months	- Responsibility - Co-management - Self efficacy - Self-image	- Age - Interaction with others - Gender - Social functioning	- Adherence	Self-care	Compliance Adherence Competence? Adjustment?
✓	Meldman 1987 [23] USA	Qualitative (empirical study) *Study explored adolescents' perspective of their diabetic management.*	Clinicians (n=12)	Older adolescence (15 to 18 years) Population: age of diagnosis varied from 7 to 17 years, participants camp experienced ranged from 1 to 11 years, Mostly Caucasians with moderate representation of Latin Americans	- Responsibility - Self-reliance - Self-image	- Age - Interaction with others - Desire for independence - Peer influences - Condition severity and treatment - Acceptance - Routine - Safety net - Coping style - Readiness	- Conflict	- Self-management	Self-reliance (Acceptance)? Independence? peer support.
✓	Anderson 1990[24] USA	Quantitative (empirical study) *Examines sharing of diabetes responsibilities between mothers and their diabetic children and the relationship between parents of mother-child sharing of responsibility for diabetes tasks and demographics variables, adherence, and metabolic functioning*	Child/young person (n=121), caregivers (n=121)	Middle childhood Younger adolescence Older adolescence (6 - 21 years) Population: Recruited for the Joslin Diabetes Center in Boston, slightly more females in sample, mostly Caucasian (84.4%), average child age 13.3 years, disease duration	- Responsibility - Co-management - Mastery/control	- Age - Duration of illness - Expectations - Gender - Coping style - Interaction with others	- Adherence - Health outcomes	- Self-care	Adherence Family Sharing

6

2E) CER-Qual evidence tables

This table presents on the following CER-Qual component as adapted for use in concept analysis.

- Themes and sub-themes:
    - Themes have been classified according to attributes (essential and desirable), antecedents and consequences
    - Where applicable, sub-themes relating to each theme are also listed
- List of the studies contributing to the review findings (i.e. the supporting references)
- Evidence list:
    - Presents evidence for the four CER-Qual components for each theme/sub-theme (i.e. methodological limitations, coherence, adequacy, and relevance) and rates level of concern (i.e. no or very minor concerns, minor concerns that may reduce confidence in the findings, moderate concerns that will probably reduce confidence in the findings, serious concerns that are likely to reduce confidence)
    - The following levels of concerns
- Overarching confidence ratings:
    - Each sub-theme has been assigned an overarching confidence rating reflecting the evidence (i.e. high – it is highly likely that theme/sub-theme is a reasonable representation of the phenomenon of interest; moderate – it is likely that the theme/sub-theme is a reasonable representation of the phenomenon of interest; low – it is possible that the theme/sub-theme is a reasonable representation of the phenomenon of interest; very low – it is not clear whether the review findings is a reasonable representation of the phenomenon of interest)
- Summary of evidence statement for each sub-theme

Theme name and category	CER-Qual summaries of the findings' statements	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	CER-Qual assessment of confidence in the evidence	Explanation of CER-Qual assessment
Co-management ESSENTIAL ATTRIBUTE n=44/58 Overarching confidence = High	Shared supported self-management between the child/young person and their caregivers	[9, 250, 253-273, 275, 276, 280-285, 288-290, 292-298, 300, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Responsibility, ESSENTIAL ATTRIBUTE n=44/58 Overarching confidence = High	Transfer of responsibility for supported self-management tasks is a shifting and shared process between the child/young person and their caregivers	[9, 250, 252, 253, 255, 257-259, 261-275, 278, 281-285, 287-290, 292-295, 297-301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Levels of obtaining responsibility for supported self-management tasks are not necessarily consistent and may relapse	[9, 255-257, 262, 267, 271-274, 280, 289, 294, 299-301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Responsibility for preventative management tasks is the area where caregiver supervision/support may be needed the longest	[252, 253, 274, 300, 301]	Minor methodological limitations	No or very minor concerns about coherence	Minor concerns that may reduce the confidence in findings	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

	In younger and older adolescence, transfer of responsibility for supported self-management tasks are not necessarily balanced by the adolescent assuming the required responsibility	[263, 273]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns that may reduce the confidence in findings	No or very minor concerns about relevance	Moderate	No or very minor concerns regarding methodological limitations coherence, and relevance. Moderate concerns about adequacy.
Mastery/competence, ESSENTIAL ATTRIBUTE n=18/58 Overarching confidence = High	Comprehensive skill, ability or healthcare behaviour related to a particular supported self-management task	[250, 252, 254, 257, 259, 260, 263-265, 269, 287, 293, 296, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Attaining supported self-management skills and healthcare behaviours is transitional (i.e., gradual over time)	[9, 22, 253, 254, 260, 262-264, 266, 268, 270, 274, 275, 278, 282, 289, 290, 296, 298, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Patterns of development for supported self-management skills and healthcare behaviours are generally orderly and predictable	[9, 22, 253, 254, 260, 262-264, 268, 270, 274, 275, 278, 281, 290, 296, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Caregiver supported self-management knowledge and skills precede those of children/young people	[269, 270, 288]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy that may reduce the confidence in findings	No or very minor concerns about relevance	Moderate	No or very minor concerns regarding methodological limitations coherence, and relevance.

								Moderate concerns about adequacy.
	New supported self-management skills and healthcare behaviours tend to build on those already learnt	[281, 287, 302]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy that may reduce the confidence in findings n=3	No or very minor concerns about relevance	Moderate	No or very minor concerns regarding methodological limitations coherence, and relevance. Moderate concerns about adequacy.
Individualism, ESSENTIAL ATTRIBUTE n=14/58 Overarching confidence = Moderate	Children and young people develop supported self-management skills and healthcare behaviours at different rates (inter-personal)	[9, 21, 253, 254, 263, 270, 271, 281, 282, 288, 298, 302]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Development of supported self-management skills and healthcare behaviours can experience peaks and periods of limited progress	[298]	Minor methodological limitations	N/A	Serious concerns about adequacy as n=1	No or very minor concerns about relevance	Low	No or very minor concerns regarding methodological limitations coherence, and relevance. Serious concerns coherence and adequacy.
	A balance between encouraged supported self-management autonomy and prolonged dependence needs to be achieved on an individual basis	[282, 286, 297]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy that may reduce the confidence in findings	No or very minor concerns about relevance	Moderate	No or very minor concerns regarding methodological limitations coherence, and relevance. Moderate

								concerns about adequacy.
Self-efficacy, DESIRABLE ATTRIBUTE n=10/58 Overarching confidence = Moderate	Child/young person's belief in themselves and their abilities in relation to supported self-management	[251, 256, 261, 265, 272, 274, 282, 284, 287, 294]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy that may reduce the confidence in findings	No or very minor concerns about relevance	Moderate	No or very minor concerns regarding methodological limitations coherence, and relevance. Moderate concerns about adequacy.
Self-image, DESIRABLE ATTRIBUTE n=4/58 Overarching confidence = Low	Children and young people with positive self-image are more likely to participate in supported self-management	[251, 256, 261, 275]	Minor methodological limitations	No or very minor concerns about coherence	Serious concerns about adequacy as n=4	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence and relevance. Serious concerns about adequacy.
Self-reliance, DESIRABLE ATTRIBUTE n=2/55 Overarching confidence = Low	Reliance on one's own powers and resources to complete supported self-management tasks, rather than reliance on caregivers	[274, 303]	Minor methodological limitations	No or very minor concerns about coherence	Serious concerns about adequacy as n=2	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence and relevance. Serious concerns about adequacy.
Interactions with others, ENABLING ANTECEDENT n=42/58 Overarching confidence = High	Relates to shifting responsibility (essential attribute) and amount of support needed from others to participate in supported self-management (e.g. caregivers, families, clinicians, and peers)	[9, 250, 252, 253, 255, 257-259, 261, 264-266, 268-275, 278, 280-282, 284-292, 294, 295, 297-299, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

Age, ENABLING ANTECEDENT n=33/58 Overarching confidence = High	Supported self-management skills and healthcare behaviours increase with age	[9, 21, 22, 251, 254, 256-259, 262, 264, 266-268, 270, 271, 274, 278, 279, 281, 283, 285, 288, 290, 292, 294-298, 303]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
	Children and young people can participate in supported self-management from an early age	[9, 254, 259, 262, 270, 271, 281, 283, 288, 302]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Support network, ENABLING ANTECEDENT n=19/58 Overarching confidence = High	Relates to having people there supporting children/young people to participate in supported self-management e.g. teachers, peers, health professionals, caregivers, community	[9, 21, 253, 255, 259, 266, 271, 274, 275, 280, 282, 283, 288, 289, 291, 293, 295, 298, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Maturity, ENABLING ANTECEDENT n=15/58 Overarching confidence = High	Relates to a child's/young person's ability to respond to a given environment in an appropriate way. There are four types of maturity underpinning supported self-management – physical, cognitive, language and communication, social and emotional.	[21, 255, 259, 263, 264, 266, 273, 275, 277, 282, 287-289, 294, 302]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

Duration of chronic condition/s, ENABLING ANTECEDENT n=12/58 Overarching confidence = Moderate	Lived experience = increased chronic condition self-management skills and healthcare behaviours	[21, 257, 261, 263, 270, 272, 281, 283] References inconsistent with theme/sub-theme: [22, 278, 287, 300]	Minor methodological limitations	Moderate concerns about coherence (n=8 support, n=4 inconsistent)	Moderate concerns about adequacy as n=8	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, and relevance. Moderate concerns about coherence and adequacy.
Desire for independence, ENABLING ANTECEDENT n=8/58 Overarching confidence = Moderate	Independence appears to be important at all developmental stages, with adolescents in particular being motivated by independence in managing their chronic condition/s	[21, 263, 266, 274, 285, 289, 293, 301]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy as n=8	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence and relevance. Moderate concerns about adequacy.
Self-acceptance, ENABLING ANTECEDENT n=7/55 Overarching confidence = Moderate	Degree of self-acceptance of chronic condition (partial or full) and/or desire to be normal may impact upon a child's/young person's capacity to participate in supported self-management	[250, 261, 266, 274, 281, 289, 293]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy as n=7	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence and relevance. Moderate concerns about adequacy.
Routines, ENABLING ANTECEDENT n=6/58 Overarching confidence = Moderate	There is a need for supported self-management activities to be incorporated into daily life. This is particularly relevant to children in the early and middle years of childhood. In younger and	[9, 250, 253, 270, 271, 274]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy as n=6	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence and relevance. Moderate

	older adolescence, influences outside of the family (including peer influences) play a larger role in structuring healthcare behaviour practices.							concerns about adequacy.
Empowerment, ENABLING ANTECEDENT n=3/58 Overarching confidence = Low	Caregivers who realise that children and young people need to manage their own chronic condition/s and they empower them to do so are more likely to achieve positive outcomes	[9, 255, 270]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy as n=3	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence and relevance. Moderate concerns about adequacy.
Safety net, ENABLING ANTECEDENT n=3/58 Overarching confidence = Low	A safeguard against possible adverse outcomes from children taking on supported self-management tasks	[274, 275, 280]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy as n=3	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence and relevance. Moderate concerns about adequacy.
Goals, ENABLING ANTECEDENT n=1/55 Overarching confidence = Very low	Discussing goal setting is a way to actively engage young people in older adolescence in their healthcare and learning what is important to them.	[301]	Minor methodological limitations	N/A as n=1	Serious concerns about adequacy as n=1	Moderate concerns about relevance [Relevant to older adolescents only]	Very low	No or very minor concerns about methodological limitations. Moderate concerns about relevance. Serious concerns about coherence and adequacy.
Self-advocacy, ENABLING ANTECEDENT n=1/58	The action of a young person in older adolescence representing themselves about their best interests in relation to	[301]	Minor methodological limitations	N/A as n=1	Serious concerns about adequacy as n=2	Moderate concerns about relevance	Very low	No or very minor concerns about methodological limitations. Moderate

Overarching confidence = Very low	supported self-management					[Relevant to older adolescents only]		concerns about relevance. Serious concerns about coherence and adequacy.
Condition severity and treatment regimen, BARRIER ANTECEDENT n=14/58 Overarching confidence = Moderate confidence	More severe condition = more ability child has to participate in supported self-management (note: seems particularly relevant for asthma)	[253, 269, 288, 290] References inconsistent with theme/sub-theme: [279]	Minor methodological limitations	Moderate concerns about coherence n=4 references supporting sub-theme, and n=1 not supporting sub-theme	Moderate concerns about adequacy	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, and relevance. Moderate concerns about coherence and adequacy.
	Caregiver parenting styles can be affected with severity of chronic condition	[255, 272]	Minor methodological limitations	No or very minor concerns about coherence	Serious concerns about adequacy as n=2	No or very minor concerns about relevance	Moderate	Noor very minor concerns about methodological limitations, adherence and relevance. Serious concerns about adequacy
	Demands of chronic condition may influence children's/young people's ability to assume responsibility for supported self-management	[21, 253, 264-266, 269, 274, 278, 279, 285, 288, 290]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Caregivers reluctance to relinquish control, BARRIER ANTECEDENT n=9/58 Overarching confidence = High confidence	Caregivers may feel tension between giving children/young people opportunities to complete supported self-management tasks and the fear of negative consequences	[253, 255, 263, 270, 276, 282, 288, 290, 294]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

Gender, ENABLING AND BARRIER ANTECEDENT n=13/58 Overarching confidence = Moderate	There may be differences between boys and girls in being able to complete supported self-management tasks and healthcare behaviours and tasks, and in taking responsibility – with girls often displaying more ability than boys, or achieving skill mastery at earlier ages.	[21, 22, 257, 261-263, 275, 294, 300] References inconsistent with theme/sub-theme: [256, 267, 285, 289].	Minor methodological limitations	Moderate concerns about coherence	No or very minor concerns about adequacy	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, adequacy and relevance. Moderate concerns about coherence.
Peer influences, ENABLING AND BARRIER ANTECEDENT n=8/58 Overarching confidence = Moderate	Social issues with peers are likely to have a profound influence on the chronic condition experience of children and young people. Peers are influential at all stages but become increasingly influential during adolescence.	[263, 266, 271, 272, 274, 283, 289, 293]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=8	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.
Coping styles, ENABLING AND BARRIER ANTECEDENT n=6/58 Overarching confidence = Moderate	Coping style of the child/young person and/or the caregivers e.g. humour, spiritual, avoidance	[21, 257, 261, 266, 272, 274]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=6	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.
Environmental factors, ENABLING AND BARRIER ANTECEDENT n=5/58 Overarching confidence = Moderate	Supported self-management behaviours can be influenced by environmental factors e.g. home, school, wider socio-economic influences	[9, 255, 262, 268, 272]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=5	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.

Expectations, ENABLING AND BARRIER ANTECEDENT n=4/58 Overarching confidence = Moderate	Children/young people complete supported self-management tasks according to their perceived expectations of significant others	[260, 275, 281, 293]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=4	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.
	Caregivers and clinicians may have low expectations and unwillingly suppress children's and young people's motivation to start taking supported self-management responsibility, which may foster resistance and reduce motivation	[260, 281, 293]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=3	No or very minor concerns about relevance	Low	No or minor concerns about methodological limitations, coherence and relevance. Serious concern about adequacy.
Willingness to participate, ENABLING AND BARRIER ANTECEDENT n=4/58 Overarching confidence = Moderate	Child/young person's willingness to participate in supported self-management (either with support or autonomously) – can be positive or negative	[263, 275, 289, 308]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=4	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.
Opportunities to practise, ENABLING AND BARRIER ANTECEDENT n=4/58 Overarching confidence = Moderate	Relates to the provision of specific opportunities to practise chronic condition self-management skills, decision making and problem solving Actions of adults that are beyond the child's/ young person's control that impinge on the ability of the child/young person to self-manage (e.g. limited	[9, 250, 253, 289]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=4	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, coherence and relevance. Moderate concern about adequacy.

	opportunities to practise skills)							
Participation in outside of family activities, ENABLING AND BARRIER ANTECEDENT n=3/58 Overarching confidence = Low	Supported self-management behaviours can be influenced by participation in outside of family activities e.g. camps hobbies	[251, 262, 297]	Minor methodological limitations	No or very minor concerns about coherence	Serious concerns about adequacy n=3	No or very minor concerns about relevance	Low	No or minor concerns about methodological limitations, coherence and relevance. Serious concern about adequacy.
Social functioning, ENABLING AND BARRIER ANTECEDENT n=1/58 Overarching confidence = Very low	Children's/young people's interaction with their environment and subsequent ability to participate in supported self-management	[256]	Minor methodological limitations	N/A as n=1	Serious concerns about adequacy as n=1	Moderate concerns about relevance [Relevant to older adolescents only]	Very low	No or minor concerns about methodological limitations. Moderate concern about relevance. Serious concerns about coherence and adequacy.
Discordance, CONSEQUENCE n=18/58 Overarching confidence = Moderate	Discrepancy of perceptions (potential or actual) between caregivers, child/young person and or health professional reports of supported self-management skills and healthcare behaviours, and/or the allocation of responsibility	[252, 254, 257, 260, 273, 280, 283, 290, 292, 294-298, 300, 301] <u>References inconsistent with theme/sub-theme:</u> [21, 264]	Minor methodological limitations	Moderate concerns about coherence – n=16/18 references support	No or very minor concerns about adequacy	No or very minor concerns about relevance	Moderate	No or minor concerns about methodological limitations, adequacy and relevance. Moderate concerns about coherence.
Adherence/compliance, CONSEQUENCE n=14/58	Higher levels of non-adherence observed when caregivers overestimated the level of adolescent involvement in supported self-management	[252]	Minor methodological limitations	N/A as n=1	Serious concerns about adequacy as n=1	Moderate concerns about relevance [Relevant to older	Low	No or minor concerns about methodological limitations. Moderate concerns about

Overarching confidence = Moderate						adolescents only]		relevance. Serious concerns about coherence and adequacy.
	Although older children/young people know more about the management of their chronic condition and assume more responsibility, their adherence is lower than that of younger children	[21, 256, 258, 279, 298]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=5	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence, and relevance. Moderate concerns about coherence.
	General adherence (unspecified pattern)	[252, 257, 266, 279, 284, 292, 299, 301]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy (could also add in references from other sub-themes in this area)	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Health outcomes, CONSEQUENCE n=10/58 Overarching confidence = High	Potential for health outcomes to worsen with increasing age	[257, 258, 261, 265, 266, 273, 277, 294, 297, 299]	Minor methodological limitations	No or very minor concerns about coherence	No or very minor concerns about adequacy (could also add in references from other sub-themes in this area)	No or very minor concerns about relevance	High	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Condition management, CONSEQUENCE n=6/58 Overarching confidence = Moderate	Potential for condition management worsen with increasing ag	[252, 261, 266, 286, 292, 301]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=6	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence, and relevance. Moderate concerns about coherence.

Conflict, CONSEQUENCE n=6/58 Overarching confidence = Moderate	Conflicts between children/young people and caregivers are more likely when children become more independent in the management of their chronic condition/s	[21, 270, 274, 282, 298]	Minor methodological limitations	No or very minor concerns about coherence	Moderate concerns about adequacy n=5	No or very minor concerns about relevance	Moderate	No or very minor concerns about methodological limitations, coherence, and relevance. Moderate concerns about adequacy.
	Diet management/modification can be a particular source of parent-child conflict (as self-management dietary aspects involve family unit to greater extent than others)	[21, 262, 298]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=3	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Serious concerns about adequacy.
Psychological, CONSEQUENCE n=3/58 Overarching confidence = Low	Psychological adjustment and coping ability changes over time and affects children/young people's ability to self-manage	[256, 266, 273]	Minor methodological limitations	Moderate concern about coherence as some studies suggest improve with age and some studies suggest worsen with age (inconsistency between studies - Ingersoll 1986 suggests potential to worsen with age, Jacobson 1987 and Kelo 2011 to improve with age)	Severe concerns about adequacy n=3	No or very minor concerns about relevance	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.

Autonomy, CONSEQUENCE n=2/58 Overarching confidence = Low	Children/young people having the capacity and taking responsibility for developmentally appropriate self-management tasks	[9, 272]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=3	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.
Interdependence, CONSEQUENCE n=2/58 Overarching confidence = Low	Children/young people having a close relationship re self-management – each of them provides the other with support and helps the other complete self-management tasks	[274, 301]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=3	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.
Transfer to adult care, CONSEQUENCE n=3/58 Overarching confidence = Low	The final transfer process of shifting of management from paediatric healthcare settings to adult healthcare settings	[9, 301]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=3	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.
Accountability, CONSEQUENCE n=2/58 Overarching confidence = Low	The ability of children/young people to be accountable to complete the necessary daily self-management tasks and healthcare behaviours	[9, 261]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=2	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.
Accuracy (of completing supported self-management tasks)/task performance, CONSEQUENCE n=2/58	How a child/young person does on a given self-management task.	[262, 266]	Minor methodological limitations	No or very minor concerns about coherence	Severe concerns about adequacy n=2	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.

Overarching confidence = Low								
Personal growth/maturity, CONSEQUENCE n=2/58 Overarching confidence = Low	The process of ongoing and understanding oneself (children/young people) and developing self-management capacity in order to achieve their fullest potential.	[281, 293]	Minor methodological limitations		Severe concerns about adequacy n=2	No or very minor concerns about relevance.	Low	No or very minor concerns about methodological limitations, coherence, and relevance. Severe concerns about adequacy.
Goals, CONSEQUENCE n=1/58 Overarching confidence = Very low	Setting of goals that relate to the child's/young persons ability to engage in self-management behaviours which fit in their own life patterns.	[278]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Motivation to adhere, CONSEQUENCE n=1/58 Overarching confidence = Very low	Internal motivation of the child/young person to participate in self-management tasks and positive healthcare behaviours.	[263]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Fatalism, CONSEQUENCE n=1/58 Overarching confidence = Very low	The belief that events are predetermined and negative - relates to caregivers concerns about children/young people taking on responsibility of self-management.	[252]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Normalicy, CONSEQUENCE n=1/58	Nearly all school-age children find it difficult and embarrassing to be unlike their friends and to fit the demands of the chronic	[266]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe

Overarching confidence = Very low	condition/s and its care into their lives.							concerns about coherence and adequacy.
Acceptance, CONSEQUENCE n=1/58 Overarching confidence = Very low	Children/young people accepting they have a chronic condition and that they need to participate in daily self-management tasks.	[256]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Confidence, CONSEQUENCE n=1/58 Overarching confidence = Very low	Children and young people having a belief that they can complete specific self-management tasks and healthcare behaviours to the required level.	[297]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Quality of life, CONSEQUENCE n=1/58 Overarching confidence = Very low	The standard of health, comfort and happiness experienced by the individual with the chronic condition and/or their caregivers and families	[265]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Partnership, CONSEQUENCE n=1/58 Overarching confidence = Very low	Children/young people and their caregivers achieving positive partnerships in relation to self-management.	[281]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.
Child agency, CONSEQUENCE n=1/58	Children and young people being able to make choices and decisions in relation to their own self-management participation.	[272]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe

Overarching confidence = Very low								concerns about coherence and adequacy.
Knowledge, CONSEQUENCE n=1/58 Overarching confidence = Very low	Improved self-management knowledge of children/young people and/or their caregivers acquired through self-management education or personal experience of living with a chronic condition.	[258]	Minor methodological limitations	N/A as n=1	Severe concerns about adequacy n=1	No or very minor concerns about relevance.	Very low	No or very minor concerns about methodological limitations and relevance. Severe concerns about coherence and adequacy.

Appendix F

Supplementary files presented with the work in Chapter 7

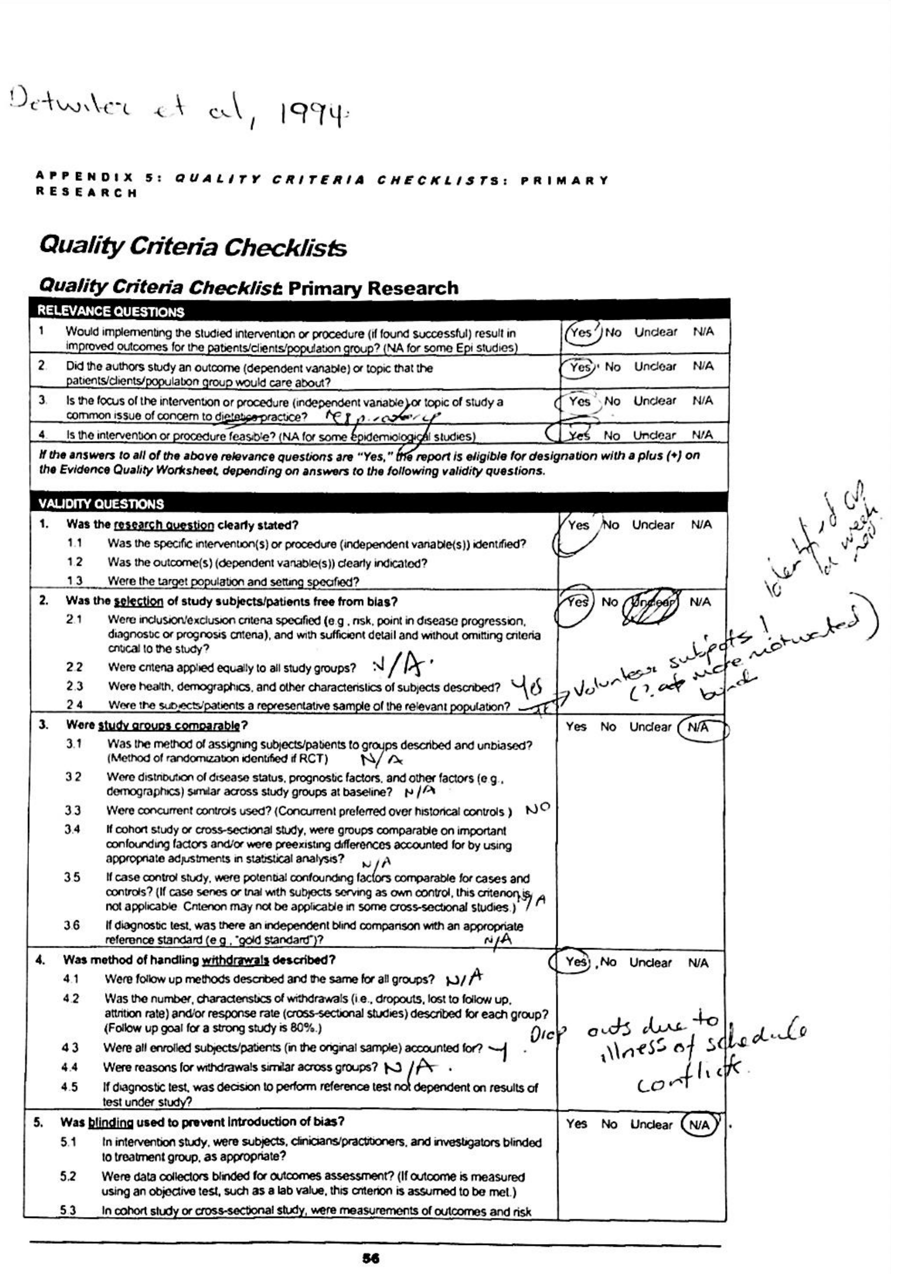
Research related documents

1F) Quality criteria checklist for primary research – completed example

Publication [8]

2F) N. Saxby, S. Beggs, M. Battersby, S. Lawn, What are the components of effective chronic condition self-management educational interventions for children and adolescents? A systematic review. Patient Educ. Couns. 102 (2019) 606–622. https://doi.org/10.1016/j.pec.2018.11.001

1F) Example of completed primary research checklist



Detwiler et al, 1994.

APPENDIX 5: *QUALITY CRITERIA CHECKLISTS:* PRIMARY RESEARCH

Quality Criteria Checklists

Quality Criteria Checklist: Primary Research

RELEVANCE QUESTIONS	
1 Would implementing the studied intervention or procedure (if found successful) result in improved outcomes for the patients/clients/population group? (NA for some Epi studies)	[✓ Yes] No Unclear N/A
2 Did the authors study an outcome (dependent variable) or topic that the patients/clients/population group would care about?	[✓ Yes] No Unclear N/A
3 Is the focus of the intervention or procedure (independent variable) or topic of study a common issue of concern to ~~dietetics~~ practice? respiratory	[✓ Yes] No Unclear N/A
4 Is the intervention or procedure feasible? (NA for some epidemiological studies)	[✓ Yes] No Unclear N/A

If the answers to all of the above relevance questions are "Yes," the report is eligible for designation with a plus (+) on the Evidence Quality Worksheet, depending on answers to the following validity questions.

VALIDITY QUESTIONS	
1. Was the research question clearly stated? 1.1 Was the specific intervention(s) or procedure (independent variable(s)) identified? 1.2 Was the outcome(s) (dependent variable(s)) clearly indicated? 1.3 Were the target population and setting specified?	[✓ Yes] No Unclear N/A
2. Was the selection of study subjects/patients free from bias? 2.1 Were inclusion/exclusion criteria specified (e.g., risk, point in disease progression, diagnostic or prognosis criteria), and with sufficient detail and without omitting criteria critical to the study? 2.2 Were criteria applied equally to all study groups? N/A. 2.3 Were health, demographics, and other characteristics of subjects described? Yes 2.4 Were the subjects/patients a representative sample of the relevant population? → Volunteer subjects! (? are more motivated bunch)	[✓ Yes] No ~~Unclear~~ N/A
3. Were study groups comparable? 3.1 Was the method of assigning subjects/patients to groups described and unbiased? (Method of randomization identified if RCT) N/A 3.2 Were distribution of disease status, prognostic factors, and other factors (e.g., demographics) similar across study groups at baseline? N/A 3.3 Were concurrent controls used? (Concurrent preferred over historical controls.) NO 3.4 If cohort study or cross-sectional study, were groups comparable on important confounding factors and/or were preexisting differences accounted for by using appropriate adjustments in statistical analysis? N/A 3.5 If case control study, were potential confounding factors comparable for cases and controls? (If case series or trial with subjects serving as own control, this criterion is not applicable. Criterion may not be applicable in some cross-sectional studies.) N/A 3.6 If diagnostic test, was there an independent blind comparison with an appropriate reference standard (e.g., "gold standard")? N/A	Yes No Unclear [✓ N/A]
4. Was method of handling withdrawals described? 4.1 Were follow up methods described and the same for all groups? N/A 4.2 Was the number, characteristics of withdrawals (i.e., dropouts, lost to follow up, attrition rate) and/or response rate (cross-sectional studies) described for each group? (Follow up goal for a strong study is 80%.) 4.3 Were all enrolled subjects/patients (in the original sample) accounted for? Y. 4.4 Were reasons for withdrawals similar across groups? N/A. 4.5 If diagnostic test, was decision to perform reference test not dependent on results of test under study?	[✓ Yes] No Unclear N/A Drop outs due to illness of schedule conflict.
5. Was blinding used to prevent introduction of bias? 5.1 In intervention study, were subjects, clinicians/practitioners, and investigators blinded to treatment group, as appropriate? 5.2 Were data collectors blinded for outcomes assessment? (If outcome is measured using an objective test, such as a lab value, this criterion is assumed to be met.) 5.3 In cohort study or cross-sectional study, were measurements of outcomes and risk	Yes No Unclear [✓ N/A]

Identified as [illegible] week [illegible]

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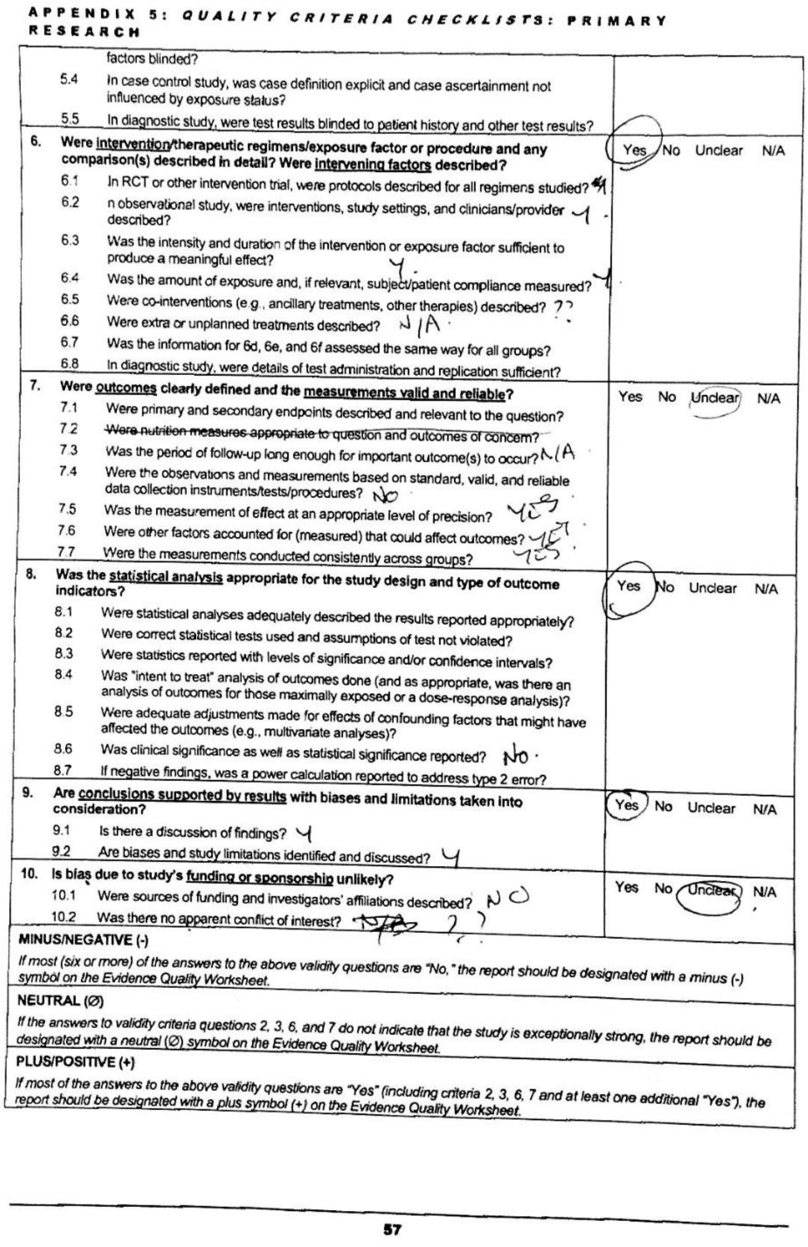


	factors blinded?	
5.4	In case control study, was case definition explicit and case ascertainment not influenced by exposure status?	
5.5	In diagnostic study, were test results blinded to patient history and other test results?	
6.	**Were intervention/therapeutic regimens/exposure factor or procedure and any comparison(s) described in detail? Were intervening factors described?**	[✓ Yes] No Unclear N/A
6.1	In RCT or other intervention trial, were protocols described for all regimens studied? Y	
6.2	n observational study, were interventions, study settings, and clinicians/provider described? Y	
6.3	Was the intensity and duration of the intervention or exposure factor sufficient to produce a meaningful effect? Y	
6.4	Was the amount of exposure and, if relevant, subject/patient compliance measured? Y	
6.5	Were co-interventions (e.g., ancillary treatments, other therapies) described? ??	
6.6	Were extra or unplanned treatments described? N/A	
6.7	Was the information for 6d, 6e, and 6f assessed the same way for all groups?	
6.8	In diagnostic study, were details of test administration and replication sufficient?	
7.	**Were outcomes clearly defined and the measurements valid and reliable?**	Yes No [✓ Unclear] N/A
7.1	Were primary and secondary endpoints described and relevant to the question?	
7.2	~~Were nutrition measures appropriate to question and outcomes of concern?~~	
7.3	Was the period of follow-up long enough for important outcome(s) to occur? N/A	
7.4	Were the observations and measurements based on standard, valid, and reliable data collection instruments/tests/procedures? No	
7.5	Was the measurement of effect at an appropriate level of precision? Yes	
7.6	Were other factors accounted for (measured) that could affect outcomes? Yes	
7.7	Were the measurements conducted consistently across groups? Yes	
8.	**Was the statistical analysis appropriate for the study design and type of outcome indicators?**	[✓ Yes] No Unclear N/A
8.1	Were statistical analyses adequately described the results reported appropriately?	
8.2	Were correct statistical tests used and assumptions of test not violated?	
8.3	Were statistics reported with levels of significance and/or confidence intervals?	
8.4	Was "intent to treat" analysis of outcomes done (and as appropriate, was there an analysis of outcomes for those maximally exposed or a dose-response analysis)?	
8.5	Were adequate adjustments made for effects of confounding factors that might have affected the outcomes (e.g., multivariate analyses)?	
8.6	Was clinical significance as well as statistical significance reported? No	
8.7	If negative findings, was a power calculation reported to address type 2 error?	
9.	**Are conclusions supported by results with biases and limitations taken into consideration?**	[✓ Yes] No Unclear N/A
9.1	Is there a discussion of findings? Y	
9.2	Are biases and study limitations identified and discussed? Y	
10.	**Is bias due to study's funding or sponsorship unlikely?**	Yes No [✓ Unclear] N/A
10.1	Were sources of funding and investigators' affiliations described? NO	
10.2	Was there no apparent conflict of interest? ??	

MINUS/NEGATIVE (-)

If most (six or more) of the answers to the above validity questions are "No," the report should be designated with a minus (-) symbol on the Evidence Quality Worksheet.

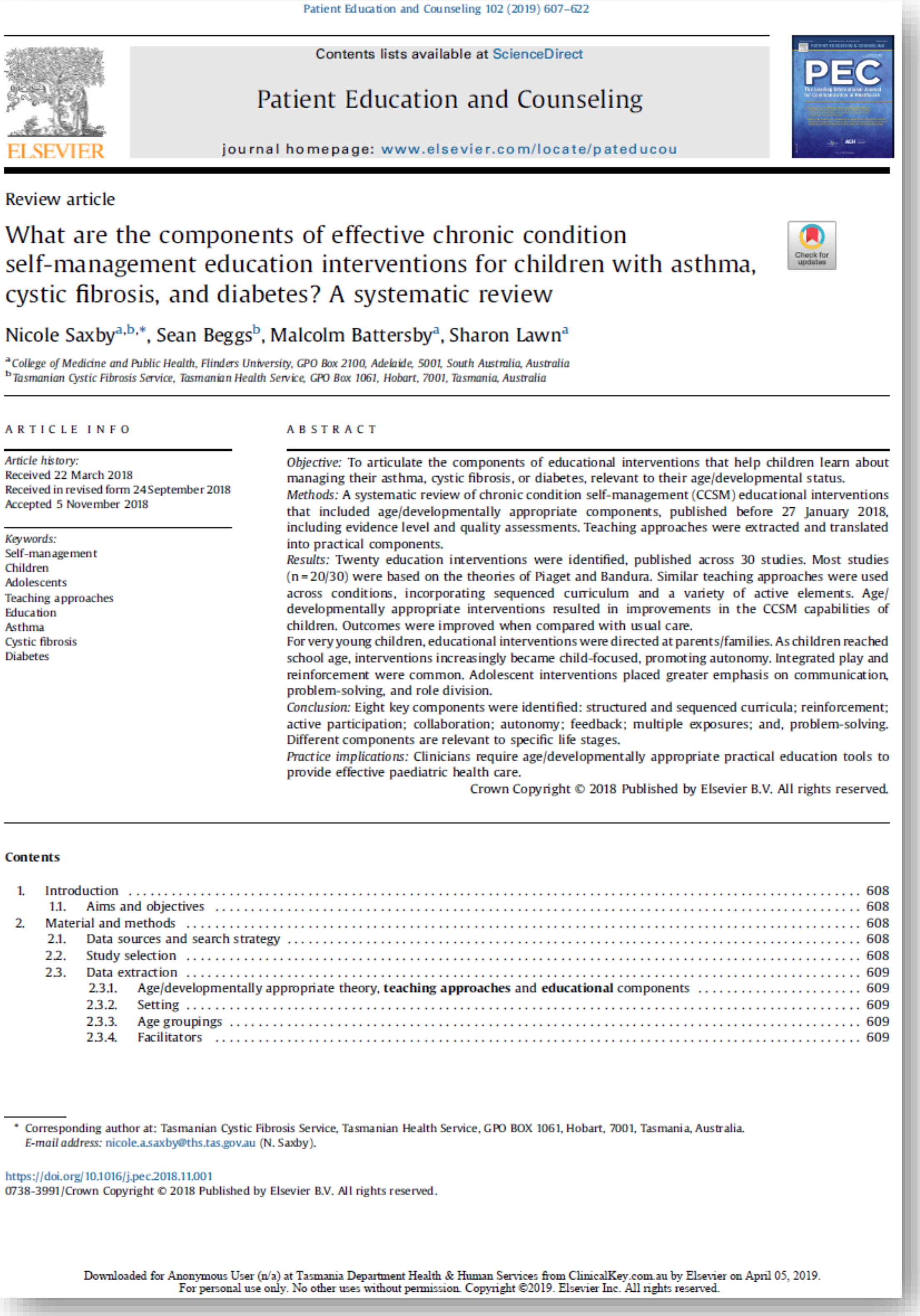
NEUTRAL (∅)

If the answers to validity criteria questions 2, 3, 6, and 7 do not indicate that the study is exceptionally strong, the report should be designated with a neutral (∅) symbol on the Evidence Quality Worksheet.

PLUS/POSITIVE (+)

If most of the answers to the above validity questions are "Yes" (including criteria 2, 3, 6, 7 and at least one additional "Yes"), the report should be designated with a plus symbol (+) on the Evidence Quality Worksheet.

2F) Publication



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Review article

What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review

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ABSTRACT

Objective: To articulate the components of educational interventions that help children learn about managing their asthma, cystic fibrosis, or diabetes, relevant to their age/developmental status.
Methods: A systematic review of chronic condition self-management (CCSM) educational interventions that included age/developmentally appropriate components, published before 27 January 2018, including evidence level and quality assessments. Teaching approaches were extracted and translated into practical components.
Results: Twenty education interventions were identified, published across 30 studies. Most studies (n = 20/30) were based on the theories of Piaget and Bandura. Similar teaching approaches were used across conditions, incorporating sequenced curriculum and a variety of active elements. Age/developmentally appropriate interventions resulted in improvements in the CCSM capabilities of children. Outcomes were improved when compared with usual care.
For very young children, educational interventions were directed at parents/families. As children reached school age, interventions increasingly became child-focused, promoting autonomy. Integrated play and reinforcement were common. Adolescent interventions placed greater emphasis on communication, problem-solving, and role division.
Conclusion: Eight key components were identified: structured and sequenced curricula; reinforcement; active participation; collaboration; autonomy; feedback; multiple exposures; and, problem-solving. Different components are relevant to specific life stages.
Practice implications: Clinicians require age/developmentally appropriate practical education tools to provide effective paediatric health care.

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Contents

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1. Introduction

Chronic conditions of childhood are common [1]. In Australia, asthma affects one in every 10 children, type one diabetes mellitus (T1DM) affects one in every 100 children, and cystic fibrosis (CF) affects 1 in every 2500 children [1,2]. Together, these three conditions impact the Australian population more than any other childhood chronic conditions (i.e., high social, health service resource and financial costs) [1,3]. With such high prevalence rates, it is almost inevitable that, over the course of a clinician's career, they will need to provide chronic condition self-management (CCSM) support to children.

Children's learning of self-management strategies, related to the management of their chronic condition, is associated with many positive outcomes. More specifically, childhood CCSM educational interventions have resulted in improvements in health outcomes, knowledge, quality of life, attendance at school, participation in social activities, and a decrease in health service interactions [4,5]. CCSM educational interventions aim to empower children to be involved in their health care through the provision of information, teaching of skills and techniques, and reinforcing positive behaviours over time [6].

In their 2003 landmark article, Lorig and Holman [6] suggested that the effectiveness of CCSM educational interventions is maximised when they are designed to assist children and their families in setting goals, solving problems, and planning for positive health behaviours. Others have stated that educational interventions should be motivational, equipping the family unit (i.e., the child, their parents and siblings) with the knowledge, skills, and confidence they need to manage the daily demands imposed by the chronic condition [5]. Despite the inclusion of these components, some interventions have failed to achieve their potential (i.e. demonstrate positive health outcomes) due to fact that children require different educational emphases as they develop self-management capacities over time [7]. Clark et al. [7] advocate for the use of developmentally appropriate program of educational content and tasks; a view that is supported by older systematic reviews and meta-analyses, which show that asthma self-management educational interventions are most effective when they are guided by evidence-based strategies, and a cognitively appropriate theoretical framework [4,8].

While Australian and international clinical practice guidelines encourage age/developmentally appropriate CCSM education for children with asthma, T1DM, and CF, these guidelines lack a clear evidence base [9]. No published systematic reviews that look at age/developmentally appropriate CCSM educational strategies for children could be located. Unfortunately, paediatric clinicians may not be aware which teaching approaches represent good teaching practices for CCSM [9]. By allowing clinicians to access a CCSM educational toolbox that is designed to suit children's ages and developmental needs (e.g., similar to what school teachers use in the classroom setting), health outcomes may be further improved.

1.1. Aims and objectives

This systematic review aimed to articulate the components of effective educational interventions that help children learn about managing chronic conditions (i.e., asthma, diabetes and CF), relevant to their age/developmental status.

2. Material and methods

The protocol for this review follows guideline recommendations, as set out in the 2009 PRISMA statement for systematic reviews and meta-analyses [10]. Due to a large amount of heterogeneity between CCSM educational interventions, a meta-analysis could not be performed.

2.1. Data sources and search strategy

Studies were identified through an extensive search of medical databases: EBSCO (Medline, CINAHL, Biomedical Reference Collection, Nursing and Allied Health Collection, Psychological and Behavioural Sciences Collection, PsychInfo, SocINDEX), Elsevier (Embase) and Informit (Health sub-database). Search terms used were based on the National Library of Medical subject headings (i.e., MeSH terms) and included "asthma", "diabetes mellitus, type 1", "cystic fibrosis", "child", "adolescent", "self-care", "self-management" and "education" (https://meshb.nlm.nih.gov/search). To ensure that no studies of relevance were missed, the search strategy was supplemented with a review of citations listed for all included studies. Only studies published in English were eligible for inclusion.

2.2. Study selection

Studies were included if they were published before 27 January 2018, and if they focused on children and adolescents (aged $\leq$20

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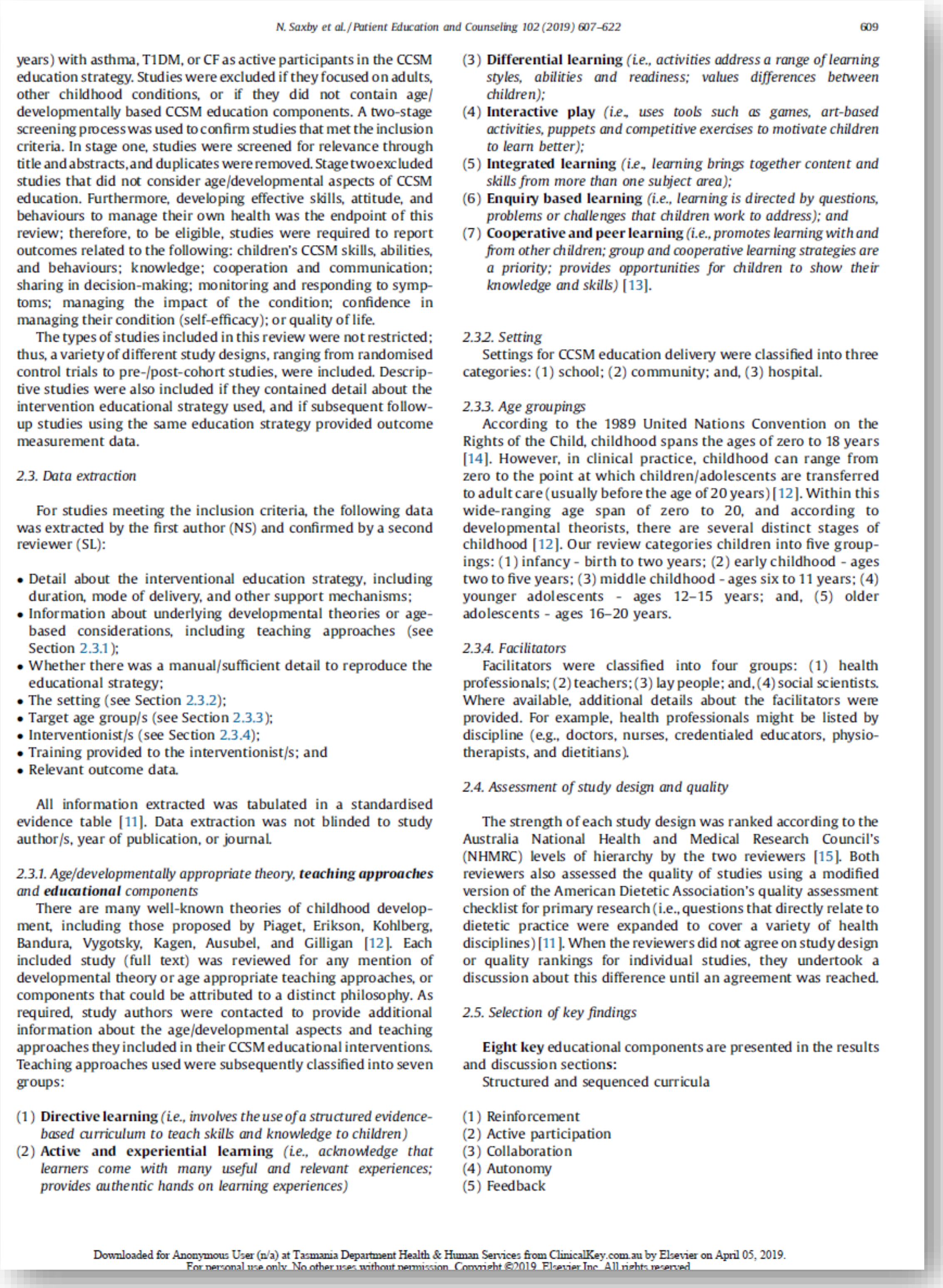

years) with asthma, T1DM, or CF as active participants in the CCSM education strategy. Studies were excluded if they focused on adults, other childhood conditions, or if they did not contain age/developmentally based CCSM education components. A two-stage screening process was used to confirm studies that met the inclusion criteria. In stage one, studies were screened for relevance through title and abstracts, and duplicates were removed. Stage two excluded studies that did not consider age/developmental aspects of CCSM education. Furthermore, developing effective skills, attitude, and behaviours to manage their own health was the endpoint of this review; therefore, to be eligible, studies were required to report outcomes related to the following: children's CCSM skills, abilities, and behaviours; knowledge; cooperation and communication; sharing in decision-making; monitoring and responding to symptoms; managing the impact of the condition; confidence in managing their condition (self-efficacy); or quality of life.

The types of studies included in this review were not restricted; thus, a variety of different study designs, ranging from randomised control trials to pre-/post-cohort studies, were included. Descriptive studies were also included if they contained detail about the intervention educational strategy used, and if subsequent follow-up studies using the same education strategy provided outcome measurement data.

2.3. Data extraction

For studies meeting the inclusion criteria, the following data was extracted by the first author (NS) and confirmed by a second reviewer (SL):

- Detail about the interventional education strategy, including duration, mode of delivery, and other support mechanisms;
- Information about underlying developmental theories or age-based considerations, including teaching approaches (see Section 2.3.1);
- Whether there was a manual/sufficient detail to reproduce the educational strategy;
- The setting (see Section 2.3.2);
- Target age group/s (see Section 2.3.3);
- Interventionist/s (see Section 2.3.4); and
- Training provided to the interventionist/s; and
- Relevant outcome data.

All information extracted was tabulated in a standardised evidence table [11]. Data extraction was not blinded to study author/s, year of publication, or journal.

2.3.1. Age/developmentally appropriate theory, **teaching approaches** and **educational** components

There are many well-known theories of childhood development, including those proposed by Piaget, Erikson, Kohlberg, Bandura, Vygotsky, Kagen, Ausubel, and Gilligan [12]. Each included study (full text) was reviewed for any mention of developmental theory or age appropriate teaching approaches, or components that could be attributed to a distinct philosophy. As required, study authors were contacted to provide additional information about the age/developmental aspects and teaching approaches they included in their CCSM educational interventions. Teaching approaches used were subsequently classified into seven groups:

(1) **Directive learning** *(i.e., involves the use of a structured evidence-based curriculum to teach skills and knowledge to children)*
(2) **Active and experiential learning** *(i.e., acknowledge that learners come with many useful and relevant experiences; provides authentic hands on learning experiences)*
(3) **Differential learning** *(i.e., activities address a range of learning styles, abilities and readiness; values differences between children);*
(4) **Interactive play** *(i.e., uses tools such as games, art-based activities, puppets and competitive exercises to motivate children to learn better);*
(5) **Integrated learning** *(i.e., learning brings together content and skills from more than one subject area);*
(6) **Enquiry based learning** *(i.e., learning is directed by questions, problems or challenges that children work to address); and*
(7) **Cooperative and peer learning** *(i.e., promotes learning with and from other children; group and cooperative learning strategies are a priority; provides opportunities for children to show their knowledge and skills)* [13].

2.3.2. Setting

Settings for CCSM education delivery were classified into three categories: (1) school; (2) community; and, (3) hospital.

2.3.3. Age groupings

According to the 1989 United Nations Convention on the Rights of the Child, childhood spans the ages of zero to 18 years [14]. However, in clinical practice, childhood can range from zero to the point at which children/adolescents are transferred to adult care (usually before the age of 20 years) [12]. Within this wide-ranging age span of zero to 20, and according to developmental theorists, there are several distinct stages of childhood [12]. Our review categories children into five groupings: (1) infancy - birth to two years; (2) early childhood - ages two to five years; (3) middle childhood - ages six to 11 years; (4) younger adolescents - ages 12–15 years; and, (5) older adolescents - ages 16–20 years.

2.3.4. Facilitators

Facilitators were classified into four groups: (1) health professionals; (2) teachers; (3) lay people; and, (4) social scientists. Where available, additional details about the facilitators were provided. For example, health professionals might be listed by discipline (e.g., doctors, nurses, credentialed educators, physiotherapists, and dietitians).

2.4. Assessment of study design and quality

The strength of each study design was ranked according to the Australia National Health and Medical Research Council's (NHMRC) levels of hierarchy by the two reviewers [15]. Both reviewers also assessed the quality of studies using a modified version of the American Dietetic Association's quality assessment checklist for primary research (i.e., questions that directly relate to dietetic practice were expanded to cover a variety of health disciplines) [11]. When the reviewers did not agree on study design or quality rankings for individual studies, they undertook a discussion about this difference until an agreement was reached.

2.5. Selection of key findings

Eight key educational components are presented in the results and discussion sections:

Structured and sequenced curricula

(1) Reinforcement
(2) Active participation
(3) Collaboration
(4) Autonomy
(5) Feedback

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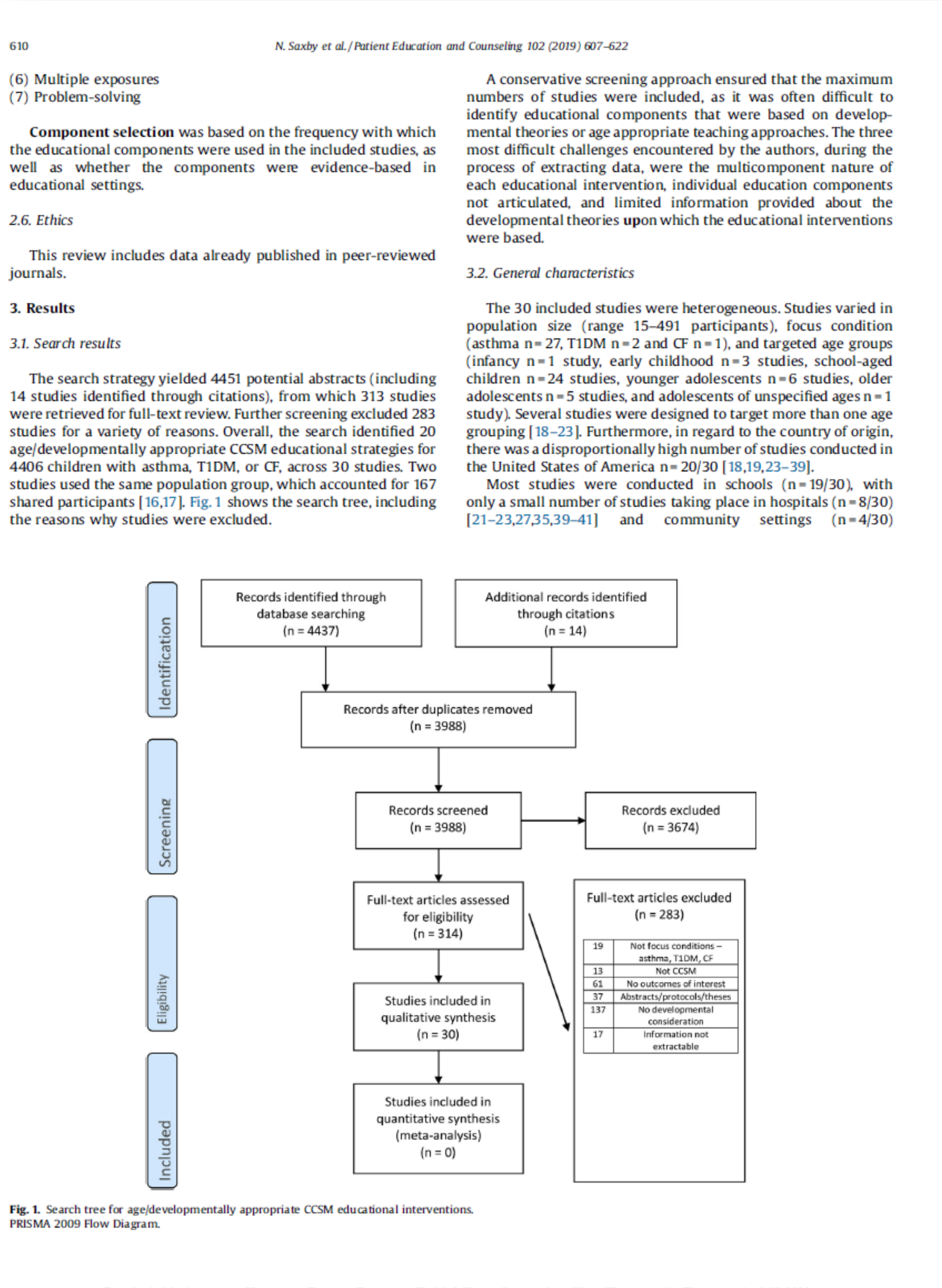

(6) Multiple exposures
(7) Problem-solving

Component selection was based on the frequency with which the educational components were used in the included studies, as well as whether the components were evidence-based in educational settings.

2.6. Ethics

This review includes data already published in peer-reviewed journals.

3. Results

3.1. Search results

The search strategy yielded 4451 potential abstracts (including 14 studies identified through citations), from which 313 studies were retrieved for full-text review. Further screening excluded 283 studies for a variety of reasons. Overall, the search identified 20 age/developmentally appropriate CCSM educational strategies for 4406 children with asthma, T1DM, or CF, across 30 studies. Two studies used the same population group, which accounted for 167 shared participants [16,17]. Fig. 1 shows the search tree, including the reasons why studies were excluded.

A conservative screening approach ensured that the maximum numbers of studies were included, as it was often difficult to identify educational components that were based on developmental theories or age appropriate teaching approaches. The three most difficult challenges encountered by the authors, during the process of extracting data, were the multicomponent nature of each educational intervention, individual education components not articulated, and limited information provided about the developmental theories upon which the educational interventions were based.

3.2. General characteristics

The 30 included studies were heterogeneous. Studies varied in population size (range 15–491 participants), focus condition (asthma n = 27, T1DM n = 2 and CF n = 1), and targeted age groups (infancy n = 1 study, early childhood n = 3 studies, school-aged children n = 24 studies, younger adolescents n = 6 studies, older adolescents n = 5 studies, and adolescents of unspecified ages n = 1 study). Several studies were designed to target more than one age grouping [18–23]. Furthermore, in regard to the country of origin, there was a disproportionally high number of studies conducted in the United States of America n = 20/30 [18,19,23–39].

Most studies were conducted in schools (n = 19/30), with only a small number of studies taking place in hospitals (n = 8/30) [21–23,27,35,39–41] and community settings (n = 4/30)

19	Not focus conditions – asthma, T1DM, CF
13	Not CCSM
61	No outcomes of interest
37	Abstracts/protocols/theses
137	No developmental consideration
17	Information not extractable

Fig. 1. Search tree for age/developmentally appropriate CCSM educational interventions.
PRISMA 2009 Flow Diagram.

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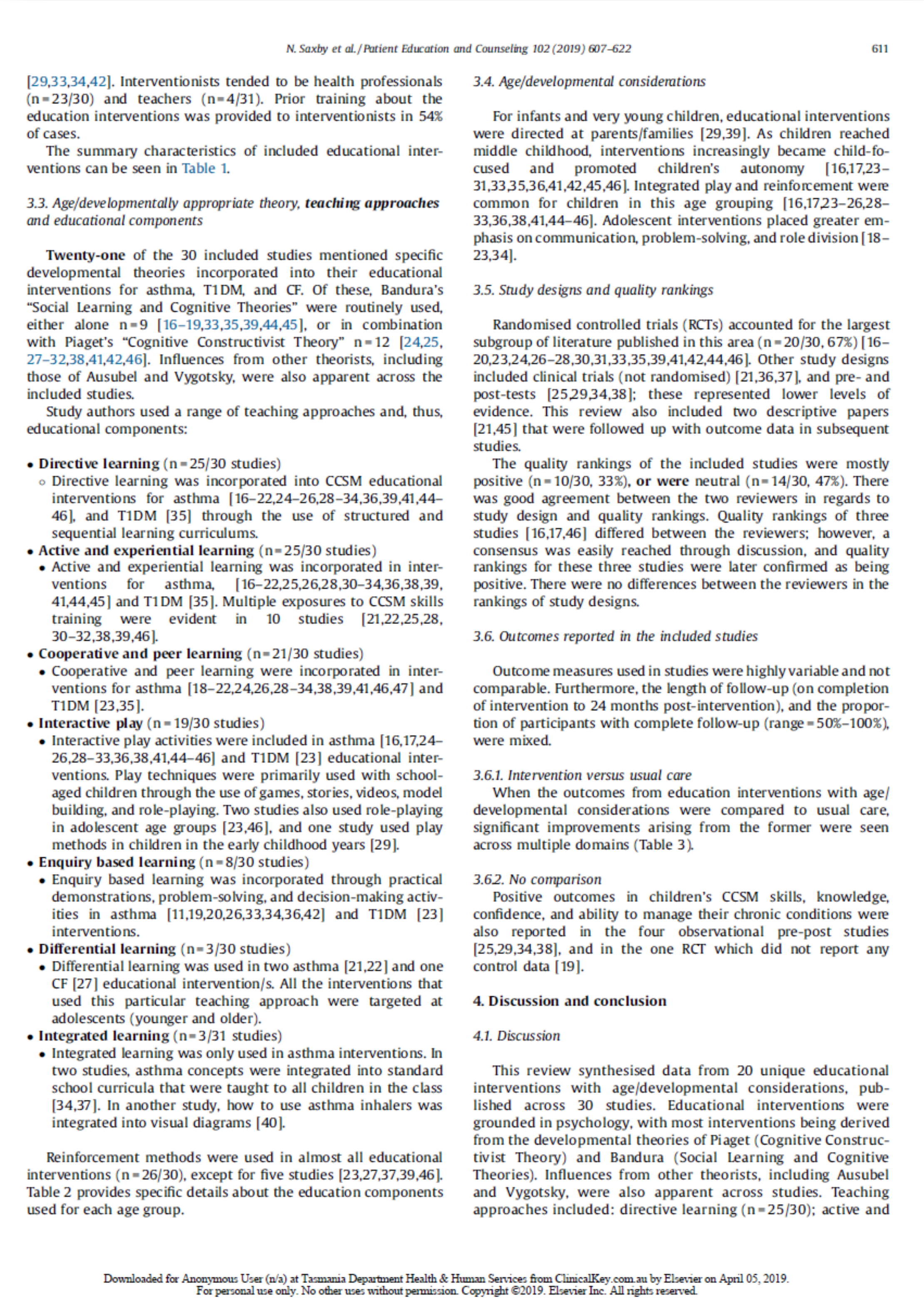

[29,33,34,42]. Interventionists tended to be health professionals (n = 23/30) and teachers (n = 4/31). Prior training about the education interventions was provided to interventionists in 54% of cases.

The summary characteristics of included educational interventions can be seen in Table 1.

3.3. Age/developmentally appropriate theory, ***teaching approaches*** *and educational components*

Twenty-one of the 30 included studies mentioned specific developmental theories incorporated into their educational interventions for asthma, T1DM, and CF. Of these, Bandura's "Social Learning and Cognitive Theories" were routinely used, either alone n = 9 [16–19,33,35,39,44,45], or in combination with Piaget's "Cognitive Constructivist Theory" n = 12 [24,25, 27–32,38,41,42,46]. Influences from other theorists, including those of Ausubel and Vygotsky, were also apparent across the included studies.

Study authors used a range of teaching approaches and, thus, educational components:

- **Directive learning** (n = 25/30 studies)
  - Directive learning was incorporated into CCSM educational interventions for asthma [16–22,24–26,28–34,36,39,41,44–46], and T1DM [35] through the use of structured and sequential learning curriculums.
- **Active and experiential learning** (n = 25/30 studies)
  - Active and experiential learning was incorporated in interventions for asthma, [16–22,25,26,28,30–34,36,38,39, 41,44,45] and T1DM [35]. Multiple exposures to CCSM skills training were evident in 10 studies [21,22,25,28, 30–32,38,39,46].
- **Cooperative and peer learning** (n = 21/30 studies)
  - Cooperative and peer learning were incorporated in interventions for asthma [18–22,24,26,28–34,38,39,41,46,47] and T1DM [23,35].
- **Interactive play** (n = 19/30 studies)
  - Interactive play activities were included in asthma [16,17,24–26,28–33,36,38,41,44–46] and T1DM [23] educational interventions. Play techniques were primarily used with school-aged children through the use of games, stories, videos, model building, and role-playing. Two studies also used role-playing in adolescent age groups [23,46], and one study used play methods in children in the early childhood years [29].
- **Enquiry based learning** (n = 8/30 studies)
  - Enquiry based learning was incorporated through practical demonstrations, problem-solving, and decision-making activities in asthma [11,19,20,26,33,34,36,42] and T1DM [23] interventions.
- **Differential learning** (n = 3/30 studies)
  - Differential learning was used in two asthma [21,22] and one CF [27] educational intervention/s. All the interventions that used this particular teaching approach were targeted at adolescents (younger and older).
- **Integrated learning** (n = 3/31 studies)
  - Integrated learning was only used in asthma interventions. In two studies, asthma concepts were integrated into standard school curricula that were taught to all children in the class [34,37]. In another study, how to use asthma inhalers was integrated into visual diagrams [40].

Reinforcement methods were used in almost all educational interventions (n = 26/30), except for five studies [23,27,37,39,46]. Table 2 provides specific details about the education components used for each age group.

3.4. Age/developmental considerations

For infants and very young children, educational interventions were directed at parents/families [29,39]. As children reached middle childhood, interventions increasingly became child-focused and promoted children's autonomy [16,17,23–31,33,35,36,41,42,45,46]. Integrated play and reinforcement were common for children in this age grouping [16,17,23–26,28–33,36,38,41,44–46]. Adolescent interventions placed greater emphasis on communication, problem-solving, and role division [18–23,34].

3.5. Study designs and quality rankings

Randomised controlled trials (RCTs) accounted for the largest subgroup of literature published in this area (n = 20/30, 67%) [16–20,23,24,26–28,30,31,33,35,39,41,42,44,46]. Other study designs included clinical trials (not randomised) [21,36,37], and pre- and post-tests [25,29,34,38]; these represented lower levels of evidence. This review also included two descriptive papers [21,45] that were followed up with outcome data in subsequent studies.

The quality rankings of the included studies were mostly positive (n = 10/30, 33%), **or were** neutral (n = 14/30, 47%). There was good agreement between the two reviewers in regards to study design and quality rankings. Quality rankings of three studies [16,17,46] differed between the reviewers; however, a consensus was easily reached through discussion, and quality rankings for these three studies were later confirmed as being positive. There were no differences between the reviewers in the rankings of study designs.

3.6. Outcomes reported in the included studies

Outcome measures used in studies were highly variable and not comparable. Furthermore, the length of follow-up (on completion of intervention to 24 months post-intervention), and the proportion of participants with complete follow-up (range = 50%–100%), were mixed.

3.6.1. Intervention versus usual care

When the outcomes from education interventions with age/developmental considerations were compared to usual care, significant improvements arising from the former were seen across multiple domains (Table 3).

3.6.2. No comparison

Positive outcomes in children's CCSM skills, knowledge, confidence, and ability to manage their chronic conditions were also reported in the four observational pre-post studies [25,29,34,38], and in the one RCT which did not report any control data [19].

4. Discussion and conclusion

4.1. Discussion

This review synthesised data from 20 unique educational interventions with age/developmental considerations, published across 30 studies. Educational interventions were grounded in psychology, with most interventions being derived from the developmental theories of Piaget (Cognitive Constructivist Theory) and Bandura (Social Learning and Cognitive Theories). Influences from other theorists, including Ausubel and Vygotsky, were also apparent across studies. Teaching approaches included: directive learning (n = 25/30); active and

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Table 1
Summary characteristics age/developmentally appropriate CCSM educational interventions for children with asthma, CF, and T1DM.

Intervention, Country	Study type, NHRMC ranking and quality (participants)	Underling developmental/ age-based theories	Description of CCSM intervention	Manual/ detail to reproduce	Setting	Age group	Interventionist	Training provided	Relevant outcomes
ASTHMA									
'Asthma education program' [36] United States of America (USA)	Parcel et al. 1980 Cross over cohort study III–3Ø (n = 104)	Unspecified	● Child- and family-centred ● 24 × 40-minute sessions for children ○ Children and parents come together at the end of each session ● Small groups (unspecified) ● Developmentally appropriate tool/s: ○ Children's book "Teaching my parents about asthma" and concept related stories Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Interactive play (stories) ○ Enquiry based learning	YES	School	Middle childhood	Teachers and health professionals (psychologists, nurses)	NO	1980 (Parcel et al.) Following the 24-week program compared to controls: ● ↑ knowledge of younger† and older school children† ● ↑ children's perception of having more control over their asthma† ● A trend towards ↓ in children's anxiety levels but NS
'Asthma Care Training – For Kids' [33] USA	Lewis et al. 1984 RCTII- (n = 76)	Bandura	● Child- and family-centred ● 5 × 60-minute sessions for children and parents ○ Children and parents taught in separate groups for first 45 minutes of each session ○ Children and parents come together at the end of each session ● Small groups (4 to 7 children) ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Interactive play (games) ○ Enquiry based learning ○ Cooperative and peer learning	YES	Community	Middle childhood	Teachers, and health professionals (asthma educators, nurses, doctors)	NO	1984 (Lewis et al.) At 12 months compared to controls (non-developmentally appropriate lectures): ● ↑ compliance with CCSM tasks (children's self-report)* ● ↓ impact of asthma symptoms (parent report)* ● ↑ communication between children and their parents* At 12 months for both intervention and control groups: ● ↑ children's positive beliefs about CCSM and asthma†
'Open Airways for Schools' [28,30,31,32,38, 43] USA	Evans et al. 1987 RCT II+ (n = 239) Horner 1998 Pre-post IV+ (n = 15) Spencer et al. 2000 Pre-post IV- (n = 364) Evans et.al 2001 RCT IIØ (n = 239) Bruzzese et al. 2001 Pre-post IVØ (n = 54) Clark et al. 2004 RCT IIØ (n = 291)	Piaget and Bandura	● Child-centred ● 6 × 40-minute group sessions for children ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Integrated play (stories, games) ○ Cooperative and peer learning	YES	School	Middle childhood	Social scientists and health professionals (unspecified)	YES	1987 (Evans et al.) At 12 months compared to controls (usual care): ● ↑ children's CCSM skills† ● ↑ children's self-efficacy† ● ↑ children's influence on parental decision making† ● ↑ children's number of actions taken by children in managing their asthma† 1998 (Horner) Following 6-week program intervention group (pre-post): ● ↑ children's knowledge† 2000 (Spencer et al.) Following 6-week program intervention group (pre-post): ● ↓ children's symptoms of asthma‡ 2001 (Evans et al.) At 12 months compared to controls (usual care): ● ↑ parents CCSM skills† ● ↑ communication between child and parents re: CCSM†, which was associated strongly with parental CCSM skills 2001 (Bruzzese et al.) At 12 months compared to controls (usual care): ● Children's communication was positively associated with parental self-management behaviours† 2004 (Clark et al. 2004) At 24 months (pre-post) intervention group: ● ↑ children's CCSM skills † At 24 months compared to controls (usual care): ● ↓ children's symptoms of asthma‡
'Modified Open Airways for Schools' [24] USA	Bowen 2012 RCTII- (n = 32)	Piaget and Bandura	As above for Open Airways for Schools, with the following changes: ● Program content synthesised into 3 × 60- minute sessions	NO	School	Middle childhood	Unspecified	Unspecified	2012 (Bowen) Following 3-week program compared to controls (usual care): ● ↑ children's asthma knowledge† ● A trend towards higher QOL but NS
'Huff and Puff' [29] USA	Detwiler et al. 1994 Pre-post IV+ (n = 148)	Piaget and Bandura	● Child- and family-centred ● 3 × 90-minute group sessions for children and parents ● 2 × 120-minute group sessions for parents ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Integrated play (games, children's imagination, sensory involvement) ○ Cooperative and peer learning	YES	Community	Early and middle childhood	Health professionals (nurses, doctors)	YES	1994 (Detwiler et al.) At 12 months (pre-post) intervention group: ● ↑ children's asthma knowledge‡ ● ↑ children's CCSM ability in 4/5 items‡ (stop and rest, breathe slowly, relax, drink fluids) ● ↑ children's confidence to manage their asthma‡
'The Roaring Adventures of Puff' [16,17,44,45] Canada	McGhan et al. 1998 Descriptive paper Cicutto et al. 2005 RCT IIØ (n = 256) McGhan et al. 2010 RCT II+ (n = 176) Mandhane et al. 2010 RCT II+ (n = 287)	Bandura	● Child-, family- and teacher-centred ● 6 × 60-minute group sessions for children ● 1x parent and teacher asthma awareness event ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Interactive play (games, model building) ○ Cooperative and peer learning	YES	School	Middle childhood	Health professionals (nurses, physios, health care students)	YES	1998 (McGhan et al.) – no outcome data 2005 (Cicutto et al.) At 2 months compared to controls (usual care): ● ↑ children's CCSM skills† ● ↑ children's self-efficacy† ● ↑ QOL† 2010 (McGhan et al.) At 6 months compared to controls (usual care): ● ↑ parent's knowledge† ● ↑ children's self-efficacy† ● ↑ QOL† 2010 (Mandane et al.) No significant results ● trends to improvement in QOL and parent assessment of child's symptoms
'Young Children Managing Asthma' & 'What's That Noise' [42] Australia	Holzheimer et al. 1998 RCT IIØ (n = 80)	Piaget and Bandura	● Child-centred ● Developmentally appropriate tool/s ○ Videotape 4 minutes long 'Young children managing asthma' ○ Picture book 'What's that noise?' ● Teaching approaches ○ Interactive play (stories) ○ Enquiry based learning	N/A	Community	Early childhood	Health professionals (unspecified)	NO	1998 (Holzhimer et al.) At 3 months compared to controls (usual care): ● asthma video and asthma book ↑ children's knowledge about condition‡ ● asthma video only ↑ children's knowledge about condition† ● asthma book only ↑ children's knowledge of condition†

Table 1 (*Continued*)

Intervention, Country	Study type, NHRMC ranking and quality (participants)	Underling developmental/ age-based theories	Description of CCSM intervention	Manual/ detail to reproduce	Setting	Age group	Interventionist	Training provided	Relevant outcomes
'Wee Wheezers' [39] USA	Wilson et al. 1996 RCT IIØ (n = 76)	Bandura	● Family-centred ● 4 × 120-minute group for parents ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Cooperative and peer learning	YES	Hospital (outpatient clinics)	Infancy, early childhood	Health professionals (nurses)	NO	1996 (Wilson et al.) At 1 month compared to controls (usual care): Reduction in child health morbidity†
'Asthma Self-Management for Adolescents Program (ASMA)' [19,20] USA	Bruzzese et al. 2004 RCT IIØ (feasibility) (n = 45) Bruzzese et al. 2011 RCT II+ (n = 345)	Bandura	● Adolescent-centred ● 5- to 8-week group sessions PLUS individual coaching sessions for adolescents ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Enquiry based learning ○ Cooperative and peer learning	NO	School	Younger and older adolescents	Health professionals (psychologists)	NO	2004 (Bruzzese et al.) Following completion of 8-week program (pre-post): ● ↑ understanding of the chronic nature of asthma (86%) ● ↑ knowledge of asthma medications and controlling symptoms (100%) ● ↑ knowledge of medication side effects and triggers (100%) No control data reported 2011 (Bruzzese et al.) At 6 months relative to controls (usual care): ● ↑ adolescent self-efficacy‡ ● ↑CCSM behaviours taking more steps to prevent symptoms at 6 months† ● ↑ use of a written action plan‡ At 12 months relative to controls (usual care): ● ↑ adolescent self-efficacy† ● ↑ use of a written action plan‡
'It's a Family Affair Program' [18] USA	Bruzzese et al. 2008 RCT IIØ (n = 24)	Bandura	● Child- and family-centred ● 6 × 75-minute adolescent group CCSM education sessions ● 5 × 90-minute parental group sessions ○ Parental sessions focused on child rearing skills to support children's growing autonomy ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Cooperative and peer learning	NO	School	Adolescents (unspecified)	Health professionals (psychologists)	NO	2008 (Bruzzese et al.) At 2 months compared to controls (usual care): ● ↑ adolescents knowledge of asthma† ● ↑ CSSM beliefs (self-efficacy)† ● ↑ positive CCSM attitudes and behaviours†
'Asthma 411 Initiative' [37] USA	Pike et al. 2011 Clinical trial III–2- (n = 236)	Grade appropriate school curriculum	● Child-centred ● 15 standard school lessons ● Teaching approaches ○ Integrated learning – asthma concepts included in 3 primary education subjects ■ Math ■ Science ■ Communication arts	NO	School	Middle childhood	Teachers	YES	2011 (Pike et al.) At the completion of program (pre-post) intervention group: ● ↑ knowledge - individual‡, combined students‡ Intervention vs. comparator group = differences were NS
'Coping with Asthma at Home and at School' [41] The Kingdom of the Netherlands	Colland 1993 RCT IIIØ (n = 195)	Bandura and Piaget	● Child-centred ● 10 × 60-minute group sessions ○ Combination of CCSM training, cognitive behaviour therapy and developmentally based education ○ Parents invited for short periods each session ● Developmentally appropriate tool/s ○ Games designed to match developmental level of concrete operational thinking (asthma quarter, asthma quiz, asthma floor puzzle) ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Interactive play ○ Cooperative and peer learning	YES	Hospital (outpatient clinics)	Middle childhood	Health professionals	NO	1993 (Colland et al.) At 6 months and 12 months follow-up compared to placebo and control groups: ● ↑ children's CCSM coping skills‡ ● ↑ children's CCSM knowledge‡
'Let's talk about asthma' [34] USA	Mammen et al. 2017 Pre-post IV+ (n = 42)	Grade appropriate school curriculum	● Adolescent-centred ● 12-hour program, 4 sessions (delivered over 2 to 3 days) ● Teaching approaches ○ Directive learning ○ Active and experiential learning ○ Integrated learning ○ Enquiry based learning ○ Cooperative and peer learning	YES	Community	Older adolescents	Health professionals	NO	2017 (Mammen et al.) Following 4 sessions (pre-post) intervention group: ● ↑ self-efficacy† ● ↑ adolescent CCSM knowledge and problem solving skills‡ Most significant effects were seen in: the awareness of long-term consequences of uncontrolled asthma, ability to recognise symptoms, correctly monitor symptoms and identify if asthma was uncontrolled
'Rural Children with Asthma – Interactive Educational Intervention' [26] USA	Butz et al. 2005 [26] II RCT+ (n = 221)	Unspecified	● Child-centred ● 2 × 120-minute sessions for children PLUS ● 1 parental education workshop ● Teaching approaches ○ Direct learning ○ Active and experiential learning ○ Interactive play ○ Enquiry based learning ○ Cooperative and peer learning	N/A	School	Middle childhood	Health professionals (asthma educator)	NO	2005 (Mammen et al.) At 10 months or a full school year compared to controls (usual care): ● ↑ knowledge – parents ‡, children‡ ● ↑ child self-efficacy† (NS parents) ● No significant differences seen in QOL measures
'Asthma Visual Mapping' [40] Iran	Bozorgrad et al. 2013 III-1- (n = 80)	Unspecified	CCSM education to use asthma inhaler devices via the visual concept mapping (i.e., use of diagrams which are understandable to children without them needing the ability to read or write) ● Use of pictures showing how to use spray 3 to 7 links ● Prepared in 2 versions (boys and girls) Teaching approaches ● Integrated learning	N/A	Hospital (outpatients)	Middle childhood	Unspecified	NO	2013 (Bozorgrad et al.) Immediately post-program relative to controls: ● ↑ QOL† In the intervention group before and after the program: ● ↑ activity‡ ● ↑ symptom awareness‡ ● ↑ emotional management‡
'Modular Education Program for Chronically Ill Children and Their Families (ModuS)' [21,22] This intervention can be altered to suit a variety of	Ernst 2016 Descriptive study Ernst 2017 Clinical trial III–1+ (n = 491)	Unspecified	● Child- and family-centred ● 30 × 45-minute sessions ○ Separate curricular and didactic approach for children and parents ○ 6 joint sessions for parents and children, ○ 12 age appropriate sessions for children ○ 12 sessions for parents ● Separate groups for different age	YES	Hospital	Middle childhood, younger adolescents, older adolescents	Health professionals (paediatricians, psychologists plus other disciplines as required)	YES	2016 (Ernst 2016) N/A 2017 (Ernst 2017) Assessed in children with asthma. at 6 weeks both in the modular and conventional care programs delivered: ● ↑ knowledge of families ● ↑ QOL of children ● ↑ life satisfaction ● ↓ disease burden of families

Table 1 (*Continued*)

Intervention, Country	Study type, NHRMC ranking and quality (participants)	Underling developmental/ age-based theories	Description of CCSM intervention	Manual/ detail to reproduce	Setting	Age group	Interventionist	Training provided	Relevant outcomes
chronic conditions Germany			groups ◦ 6 to 12 years, ◦ 13 to 17 years ● Small groups (4 to 8 families) ● Teaching approaches ◦ Directive learning ◦ Active and experiential learning ◦ Differential learning ◦ Cooperative and peer learning						When intervention group outcomes at 6 weeks were compared to controls, only children's reported asthma knowledge was significantly different.
'Children with Chronic Illnesses' [46] Asthma and epilepsy intervention Argentina	Tieffenberg et al. 2000 RCT IIØ (n = 188)	Piaget and Bandura	● Child- and family-centred ● 5 × 120-minute sessions ● Family reinforcement sessions at 2 and 6 months post-intervention ● Teaching approaches ◦ Directive learning ◦ Active and experiential learning ◦ Interactive play ◦ Cooperative and peer learning	YES	School	Middle childhood, younger and older adolescents	Teachers	YES	2000 (Tieffenberg et al.) Asthma results only - At six months compared to controls (usual care): ● ↑ knowledge† ● ↑beliefs (self-efficacy) † ● ↑ positive attitudes and behaviours †
CYSTIC FIBROSIS **'Building life skills with cystic fibrosis'** [27] USA	Christian et al. 2006 RCT IIØ (n = 116)	Bandura and Piaget	● Child-centred ● Individual home-based session (assessing children's current knowledge and how they manage in home environment) PLUS ● Group program ● Teaching approaches ◦ Differential learning (content individualised to each child's experience of CF using their own life experiences)	YES	Hospital	Middle childhood	Health professionals (unspecified)	YES	2006 (Christian et al.) At nine months compared to controls (usual care): ● ↓perceived impact ‡ ● ↓perceived loneliness ‡
DIABETES **'In Control'** [35] USA	McNabb et al. 1994 RCT IIØ (n = 24)	Bandura	● Child-and family-centred ● 6x group education sessions ◦ Separate children and parent groups ◦ Parents also taught parenting skills ● Teaching approaches ◦ Directive learning ◦ Active and experiential learning ◦ Cooperative and peer learning	NO	Hospital	Middle childhood	Health professionals (unspecified)	YES	1994 (McNabb et al.) At three months compared to controls (usual care), children: ● ↑ responsibility (insulin)† ● ↑ response to symptoms† ● ↑ maintaining records‡ ● ↑ communicating with others †
'Care Ambassador and family-based psychoeducation' [23] USA	Katz 2014 RCT IIIØ (n = 153)	Unspecified	● Child- and family-centred ● Family-focused teamwork intervention (split into two age groups 8 to 12 years, 13+ years) ● 30-minute session with child and their parent//guardian on the day of their quarterly clinic visit ● Teaching approaches ◦ Active and experiential learning ◦ Enquiry based learning ◦ Cooperative and peer learning	No	Hospital	Middle childhood, young adolescents	Lay people	YES	2014 (Katz) There were no significant differences at 12 months in CCSM skills and behaviours, QOL or family conflict At 2 years, compared to the control group, the intervention group: ● Greater parental involvement in CCSM†

Denotes study quality: + = high quality, Ø = neutral and - = low quality. Denotes significance †p ≤ 0.05 and ‡ p ≤ 0.01, * clinical p ≥ 0.05, NS = not significantDenotes: ↑ increase, ↓decrease.

Table 2
Education components broken down by age grouping and specific methods used.

Educational component	Age grouping	Skill/ method/ topic	Selected practice example
1 **Structured and sequenced curriculum** [16,17,18,19,20,21,22,24,25,26,28,29,30,-31, 32,33,34,35,36,36,39,41,44,45,46] n = 26/30	Infancy	Parent-focused curricula covering all aspects of CCSM, plus stress management.	Detail of an individual curriculum was too long to include in this table – see Ernst et al. [22] p.1154 for an excellent example
	Early childhood	Parent-focused curricula covering all aspects of CCSM, plus stress management, young children from ages 4 years up included in some sessions.	
	Middle childhood	Curricula were generally targeted at increasing children's basic knowledge of their chronic condition and coping strategies. Topics covered: ● basic information about the chronic condition and children's feelings ● recognising and responding to symptoms ● treatments and when to seek help ● living a healthy lifestyle (e.g. being physically active, eating well, hand-hygiene) ● handling problems related to the chronic condition at school	
	Younger adolescence	Adolescent curricula were aimed at increasing CCSM autonomy and independence. Topics are similar to those covered in the middle childhood age grouping, with increased emphasis placed on problem solving, decision making, and coping with negative impacts of having a chronic condition.	
	Older adolescence	As per information listed for younger adolescence, with additional importance placed on reaching independence prior to transition to adult healthcare services.	
6 **Reinforcement strategies** [16,17,18,19,20,21,22,24,25,26,28,29,30,-31, 32,33,34,35,36,36,40,41,42,44,45] n = 26/30	Infancy	–	**Middle childhood example:** Colland et al. [41] used reward systems as a way of motivating children towards positive health behaviours. Individuals or small groups were able to "earn rewards". Each time a child completed their CCSM homework activities then he/she was able to colour in a line on a big poster (sowing a giant thermometer), on which 100 lines were drawn. Lines were also able to be coloured in when group work was completed to a satisfactory level. When 25 lines had been coloured in, then the entire group received a reward, in the form of a small game. **Younger and older adolescence example:** In the 2008 intervention by Bruzzese et al. [28], homework activities were given to both the adolescent and caregiver groups. Adolescent homework activities focused on CCSM skills to build self-efficacy, and caregiver homework activities focused on childrearing and positive support approaches. Homework activities were structured to allow caregivers and children/adolescents to interact in positive ways, and to practice relevant skills together.
	Early childhood	Take home CCSM action plans (for caregivers)	
	Middle childhood	Homework activities for children and caregivers, written support material for caregivers, children's demonstrations of skills learned, debriefing for both children and caregivers at the end of education sessions, take home CCSM action plans (for caregivers), earning of reward, promotion of /internal incentives, goal setting for children	
	Younger and older adolescence	Homework activities for adolescents and caregivers, teach-back methodology, take home CCSM action plans, and summaries of education sessions (for adolescents), earning of rewards, promotion of internal incentives, goal setting for adolescence	
10 **Active participation** [16,17,18,19,20,21,22,25,26,28,30,31,32,-33,34, 35,36,38,39,41,44,45] n = 25/30	Infancy	No direct engagement of children	**Early and middle childhood example:** Detwiler et al. [29] used puppets to actively engage children in CCSM. The use of puppets draws on children's imaginations. Children were asked to identify with the puppet "Huff", who ignores early symptoms, forgets what to do to manage his asthma, and wheezes. Children observe the negative consequences of what happens to Huff because of his poor CCSM behaviours. But, the children are also given a positive role model to observe called "Puff" who is very good at managing his asthma. After learning about asthma management through the use of these puppets, children then get the opportunity to practice their newly learnt CCSM skills.
	Early childhood	Skills training, hands on participation, use of stories and characters to teach skills (books/videos), observation, modelling (puppets, actors, cartoons), opportunities to practice CCSM skills	
	Middle childhood	Skill training, hands on participation, case- based learning, observation, role playing, children's demonstration of skills learned at the end of each education session, interactive game playing to practice decision making, use of stories to initiate discussions around the chronic condition, arts based activities and model building, behaviour modelling (caregivers, facilitators, book characters, puppets), goal setting ● Interventions involving active participation for children in the middle years of childhood tended to have a particular focus on preventing, identifying and controlling symptoms	
	Younger and older adolescence	Skill training, hands on participation, modelling (facilitators), case-based learning, home visits to identify triggers (asthma), role playing, goal setting	

Table 2 (*Continued*)

Educational component	Age grouping	Skill/ method/ topic	Selected practice example
14 **Collaboration** [18,19,20,21,22,1,2,3,4,5,6,7,8,9,10,11,12,-13,14,15,16,17,18,19,20,21,22,23,24,26,28,29,30,31,32,-33,34,35,38,39,41,46,47] n= 21/30	Infancy	–	**Middle childhood example:** The 1987 study by Evans et al. [30] promoted child to caregiver communication. This intervention (i.e. the "Open Airways for Schools" program) was provided directly to children; parents did not attend. Children's autonomy and independent actions as self-managers were encouraged, with children being given the responsibility to recognise and respond to their own symptoms (whether or not their caregiver was present). The program also encouraged children to provide information to their caregivers to help caregivers make informed asthma management decisions.
	Early childhood	–	
	Middle childhood	Collaboration between children, their caregivers, and clinicians are encouraged, communication strategies promoted, children given opportunities to directly ask health professionals questions, caregivers encouraged to support and supervise children's CCSM activities, teamwork activities, group processing, sharing of perceptions and experiences, peer group learning	
	Younger and older adolescence	Collaboration between adolescents, their caregivers, and clinicians are encouraged, communication strategies promoted, teamwork activities, group processing, increased focus on peer group learning and sharing of experiences	
18 **Autonomy** [16,17,18,19,20,21,22,23,28,29,30,31,32,33,34,36,38,41,43,44,45,46] n= 20/30	Infancy	Infants are completely dependent on adult caregivers for all CCSM activities	**Younger and older adolescence example:** The intervention described by Bruzzese et al. [28] strongly promotes adolescent CCSM autonomy. Autonomy is promoted using two complementary but separate strategies: ● Adolescent sessions focused on prevention and management of asthma – behavioural based program; ● Parental sessions focused on child rearing skills to support the adolescent's growing autonomy. Co-joint sessions were not offered, as the focus was on increasing the autonomy of adolescent participants.
	Early childhood	Young children are completely dependent on adults for CCSM activities; however, some education interventions encouraged children's involvement in simple CCSM tasks (e.g. using an asthma puffer).	
	Middle childhood	Interventions become child centred in this age group. Most interventions acknowledged that children could begin to be autonomous for some CCSM activities. Some interventions specifically mentioned that children and caregivers should be treated as equals and partners in the CCSM learning and caring process.	
	Younger and older adolescence	Strong encouragement of adolescents to be autonomous in their own CCSM, where possible. Caregivers encouraged to take on an advocacy and support role (separate caregiver only training provided to teach this role). The need for negotiation and clear CCSM role delineation between adolescents and caregivers was mentioned in some interventions. As above for younger adolescence	
22 **Feedback** [16,17,18,19,20,28,29,30,31,32,38,39,43,44,45,46] n= 16/30	Infancy	–	**Older adolescence example:** Mammen et al [34] integrate feedback mechanisms into their intervention. After CCSM activities were modelled by facilitators (e.g. inhaler techniques, use of peak flow meters and spaces, decision making during asthma attaches), adolescents practiced CCSM skills with feedback being provided on the spot until fluency was attained.
	Early childhood	Encouragement given when good CCSM behaviours or knowledge are demonstrated (positive approach), timely feedback	
	Middle childhood	Symptom diary interpretation, encouragement given when good CCSM behaviours or knowledge are demonstrated (positive approach), timely feedback	
	Younger and older adolescence	Opportunities to practice CCSM skills and get feedback during education sessions, caregiver praise, timely feedback	
26 **Multiple exposures** [21,22,25,28,30,31,32,38,39,46]. n= 10/30	Infancy	–	**Middle childhood example:** The papers by Ernst et al. [21] and Ernst et al. [22] describe the MoDuS program (**Modu**lares **S**chulungsprogramm). This program exposes children to CCSM related information and skills multiple times to help them internalise the information. Multiple exposures were coupled with giving children adequate time to practice doing the CCSM skills they had learned to do. In this program, feedback was also given during practice rehearsals to ensure that children retained the correct information. The MoDuS program is a generic CCSM program that can be used across a variety of conditions due to similarities in the need to monitor symptoms and manage treatments [22].
	Early childhood	–	
	Middle childhood	Repeated demonstrations and multiple opportunities to practice newly learnt CCSM skills	
	Younger and older adolescence	Repeated demonstrations and multiple opportunities to practice newly learnt CCSM skills	
30 **Problem solving** [11,19,20,23,26,33,34,36,42] n= 8/30	Infancy	–	**Middle childhood example** Lewis et al. [33] put children in the "driver's seat", emphasising that asthmatic children could take control of their condition (this represents a simple paradigm). An analogy was drawn between maintaining health and safely driving a car. Obeying traffic light signals was a key message, I.e. green for go, yellow for caution, and red for stop. Children controlled their asthma by using the colour system: ● Green coloured medications indicated keep going and prevent symptoms ● As mild symptoms develop, it is time for children to slow down and take a more cautious approach using medications coloured yellow ● If/when severe symptoms occur it is time to take red medications to stop the asthma episode
	Early childhood	–	
	Middle childhood	Use of simple paradigms to communicate messages, colour coding of key concepts, practical demonstrations, collaborative discussions between children and caregivers	
	Younger and older adolescence	Practical demonstrations, collaborative discussions, individualisation where possible (e.g. through use of CCSM assessments and one-on-one sessions were individual problems and challenges could be discussed)	

Table 3
CCSM outcomes for children's educational interventions with age/developmental considerations compared to usual care.

Children's	Number of studies reporting significant improvements when compared to usual care	Associated references
CCSM skills, abilities and behaviours	11	[18,20,23,30,31,33,35,40,41,44,46]
Knowledge	10	[16,18,22,24,29,34,36,37,41,42,46]
Cooperation/ communication	5	[23,30,31,33,35]
Sharing in decision making	3	[30,31,35]
Monitoring and responding to symptoms	5	[20,28,33,35,39]
Managing the impact of the condition	4	[27,33,36,41]
Self-efficacy	8	[16,18,20,26,30,34,44,46]
Quality of life	2	[16,44]

experiential learning (n = 26/30); cooperative and peer learning (n = 26/30); integrated play (n = 19/30); enquiry based learning (n = 8/30); differential learning (n = 3/30); and, integrated learning (n = 3/30). Unfortunately, all of the reviewed interventions included multiple teaching approaches. Thus, it was not possible to attribute causality or effectiveness to any particular educational component. Nevertheless, identification of educational components was still achievable.

Positive study outcomes indicate that the children who took part in CCSM educational interventions that were tailored to be developmentally/age appropriate were more able to deal with everyday life. In the case of asthma, T1DM and CF, children and adolescents who participated in these tailored interventions knew more about their condition, and what they could do themselves to minimise the effects their condition had on them. This was demonstrated by significant improvements in knowledge [16,18,22,24,29,34,36,37,41,42,46], CCSM skills and abilities [18,20,23,30,31,33,35,40,41,44,46], and symptom monitoring and control [20,28,33,35,39], when compared to children receiving usual care in the included RCT studies. Some studies also showed significant improvements in children's ability to communicate openly about their condition with their peers, parents, and health professionals [23,30,31,33,35].

4.1.1. Overarching concept – age/developmentally appropriate learning

The matching of teaching approaches to children's age/ developmental stage was identified as an overarching concept in CCSM educational interventions. It is important that knowledge and skills are taught to the right level of complexity. Younger children appear to benefit from the use of interactive play and cooperative and peer learning in both the studies included in this review, and educational literature [48]. Teaching approaches that support deeper learning (and, thus, are more appropriate for adolescents) included collaborative learning and enquiry-based learning. The educational literature suggests that older adolescent learners are more likely to respond to teaching approaches that have genuine relevance to their own experiences [49,50]. Clinicians should tailor educational interventions to the needs of infants, children in the early and middle years of childhood, younger adolescents, and older adolescents.

4.1.2. Key findings – educational components

Children's CCSM education was found to be more than just imparting knowledge. Clinicians can best support children to develop CCSM skills, and mastery, by utilising multiple educational components.

The first key component that clinicians should include in children's CCSM educational interventions is **'structured and sequenced curricula'** (promoted in n = 26/10 studies) [16–22,24–26,28–36,36,39,41,44–46]. Lessons should be sequential, to build on skills previously mastered by children. Moreover, the structure of lessons should enforce daily CCSM routines. In his theoretical work on childhood development, David Ausubel stressed the importance of acknowledging and using the previous learnings of children [12]. Ausubel also advocated for learning to take place in meaningful ways, through disciplined organising and connecting of concepts [12]. The effectiveness of structured sequenced curricula is well proven in the educational literature, as demonstrated by large scale meta-analyses [49,50].

Similar to proven adult models [51,52], children's CCSM educational interventions need a varied curriculum. Topics to cover are: Knowledge of condition; children's active **I**nvolvement in their CCSM; Care plan; Monitoring and Responding to symptoms; **managing** Impacts of the chronic condition (e.g., physical, emotional and social impacts); **L**ifestyle aspects (e.g., diet and exercise); and **S**upport Services (e.g., parents, clinicians, teachers and community). An easy way for clinicians and children to remember these topic areas is through the use of the acronym **KIC-MR-ILS** [51,52].

'Reinforcement' is the second most important key educational component (promoted in n = 26/30 studies). People facilitating children's CCSM educational interventions need to reinforce children's curiosity, problem identification (e.g., symptom monitoring), and problem-solving skills [53]. Methods such as children's demonstration of skills learned, debriefing at the end of sessions (children and parents), written support materials, take home CCSM action plans, and homework activities were regularly included in the educational interventions. Homework activities seem to have been designed to provide children with the opportunity to develop further the CCSM skills they had just learned [53]. Evidence suggests that reinforcement strategies are important components of effective education [53,54]. Research is sparse with regard to the importance of debriefing [53,54].

'Active participation' was identified as the third key component (promoted in n = 21/30 studies which used active, experiential, and interactive play teaching approaches) [16–22,25,26,28,30–36,38,39,41,44,45]. Children need to be active participants rather than spectators in the CCSM learning process. Active learning aims to provide authentic, experiential, and hands-on learning experiences [55]. The included studies acknowledged that learners needed time to interact with their peers and facilitators, as well as time to practice and adapt their newly learned CCSM skills. Active participation is a well-known evidence-based strategy for educating children and adolescents, and is promoted to teachers by government agencies [49,50,55].

The fourth key educational component was found to be **'collaboration'**, and is inclusive of participation (promoted in n = 21/30 studies) [18–22,1–24,26,28–35,38,39,41,46,47]. Developmental theorist Lev Vygotsky was an advocate for the use of collaborative group activities to assist learning [56]. Ways that clinicians can promote collaboration include using teamwork activities (strategically choosing children that will work well together), and encouraging everyone to participate in the same learning task. According to the education literature, collaborative learning takes place when children actively participate in negotiating roles, responsibilities, and outcomes [49,50]. In the educational setting, collaborative learning approaches are

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generally viewed as being effective, although effect sizes vary across studies [49,50].

The fifth key educational component was learner **'autonomy'** (promoted in n = 20/30 studies) [16–23,28–34,36,38,41,43–46]. Jean Piaget's belief that children are independent, and that development is guided by self-centred activities [12,56], strongly influenced the design of most of the studies included in this review, as evidenced by almost all included studies being child or adolescent focused. Placing the child at the centre of the CCSM educational intervention acknowledges their growing autonomy, and allows them to be trained to assume a leading role in their condition management. It is also essential that clinicians support self-efficacy, as recommended by developmental theorist Albert Bandura, when promoting the autonomy of children and adolescents [12,56].

'Feedback' was identified as the sixth key educational component needed to deliver children's CCSM programs [16–20,28–32,38,39,43–46]. A high level of facilitator-student interaction is required to teach children to be involved in CCSM, and feedback is critical. Feedback is important to both children with chronic conditions and facilitators, because it informs how progressing towards anticipated educational goals is going [55]. Timely feedback provides opportunities for immediate correction and improvement. Feedback can be provided by a variety of people, including parents, educational facilitators, and peers. Methods of providing feedback can be oral or written, as long as the feedback includes specific advice that children can use to improve their CCSM skills. Appropriate feedback is a well-proven educational component for children and their teachers [49,50].

Unexpectedly, **'multiple exposures'** was identified as the seventh key educational component (promoted in n = 10/30 studies) [21,22,25,28,30–32,38,39,46]. A well-cited educational article (> 70 citations) states that it takes, "three or four experiences involving interaction with relevant information for a new knowledge construct to be created in working memory and then translated to long-term memory" [57]. Multiple exposures are more than simple repetition or drill work [55]. They provide children with many opportunities to learn and practice CCSM skills, over time, through repeated learning opportunities [55]. Educational research demonstrates that multiple exposures have significant positive impacts on children being able to retain newly learned knowledge [49,50].

The eighth key educational component was **'problem-solving'** (promoted in n = 8/30 studies) [11,19,20,23,26,33,34,36,42]. Children with chronic conditions often face an uncertain, complex, and challenging future. Learning how to make well-informed decisions and solve problems can help children and adolescents better prepare for their futures [12,56]. Collaborative discussion is a complementary strategy to problem-based learning. Research on problem-based learning has found that positive gains in knowledge are equal to, or better than, gains that employ a traditional lecture style instruction [58].

4.1.3. Strengths and limitations of this review

This review addresses gaps in knowledge about children's CCSM educational interventions. While other paediatric research groups have identified and acknowledged the importance of CCSM educational components for children [59–61], this review marks the first time that components have been systematically classified. A well-recognised and structured process for conducting systematic reviews was followed [10]. Moreover, each of the included studies was assessed for evidence hierarchy level and quality by two reviewers.

Several limitations are also apparent. Firstly, only studies published in English were included. Secondly, most of the included studies focused on asthma, which limits the generalisability of the findings of this review. Thirdly, due to large heterogeneity between study parameters and outcomes measured, a meta-analysis could not be conducted. Researches wishing to conduct future research in this area may wish to use the 2015 framework of CCSM outcomes by Sattoe et al. [62]. Fourthly, some studies might have not been included due to the reviewers experiencing difficulty when trying to identify studies that included age/developmental aspects of CCSM education (see Section 3.1 for more information). Lastly, it was impossible to attribute causality to individual education components because each of the included CCSM educational interventions used multiple teaching approaches.

4.2. Conclusions and next steps

Self-management education interventions that are tailored to a child's age/developmental stage help children with asthma, T1DM, and CF to develop effective skills, attitudes, and behaviours to manage their health. The effectiveness of these interventions was secured by including the following educational components: structured and sequenced curricula; reinforcement; active participation; collaboration; autonomy; feedback; multiple exposures; and, problem-solving. Different components are relevant to specific life stages. Further research is needed to be able to attribute causality and effectiveness to individual educational components. For example, research teams could consider conducting RCTs where the intervention group receives **'structured and sequenced curricula'** or **'reinforcement methods'**, and the control group does not.

4.3. Practice implications

Health professionals should educate children with a variety of chronic conditions using age/developmentally appropriate teaching approaches. An additional contribution of this review was that it provides clinicians with the range of educational components that they can use to assist their young patients with learning CCSM. However, practical tools **still** need to be developed to guide clinicians in how to do this.

Conflicts of interest

The authorship group has no conflicts of interest to declare.

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Downloaded for Anonymous User (n/a) at Tasmania Department Health & Human Services from ClinicalKey.com.au by Elsevier on April 05, 2019.

Appendix G

Supplementary files presented with the work in Chapter 8

Research related documents

1G) Ethics approval (Flinders University Social and Behavioural Research Ethics Committee – Project identification 7205)

2G) Ethics approval (Tasmanian Health and Medical Human Research Ethics Committee – Project identification H0017044)

3G) Delphi participant information sheet

4G) Example of analysis and theming completed Delphi round 1

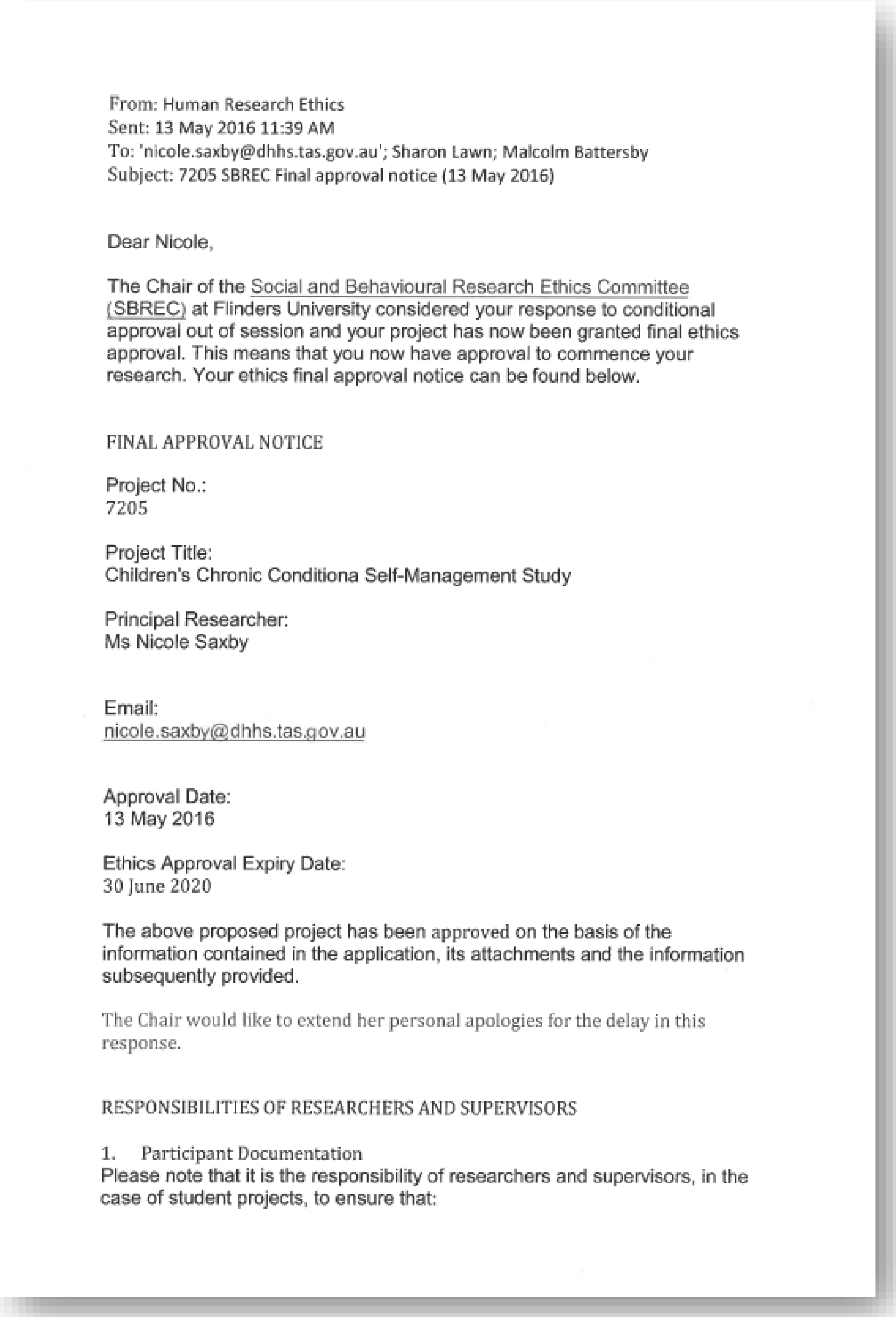
Publication [10]

5G) N. Saxby, K. Ford, S. Beggs, M. Battersby, S. Lawn, Developmentally Appropriate Supported Self-Management for Children and Young People with Chronic Conditions: A Consensus. Patient Educ. Couns. (2019) [Epub ahead of print]. https://doi.org/10.1016/j.pec.2019.09.029

Clinical tool

6G) Clinical tool produced for paediatric clinicians working across Tasmania– Partners in Health: Self-management Consensus List for Children and Young People

1G) Ethics approval (Flinders University Social and Behavioural Research Ethics Committee)



From: Human Research Ethics
Sent: 13 May 2016 11:39 AM
To: 'nicole.saxby@dhhs.tas.gov.au'; Sharon Lawn; Malcolm Battersby
Subject: 7205 SBREC Final approval notice (13 May 2016)

Dear Nicole,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:
7205

Project Title:
Children's Chronic Conditiona Self-Management Study

Principal Researcher:
Ms Nicole Saxby

Email:
nicole.saxby@dhhs.tas.gov.au

Approval Date:
13 May 2016

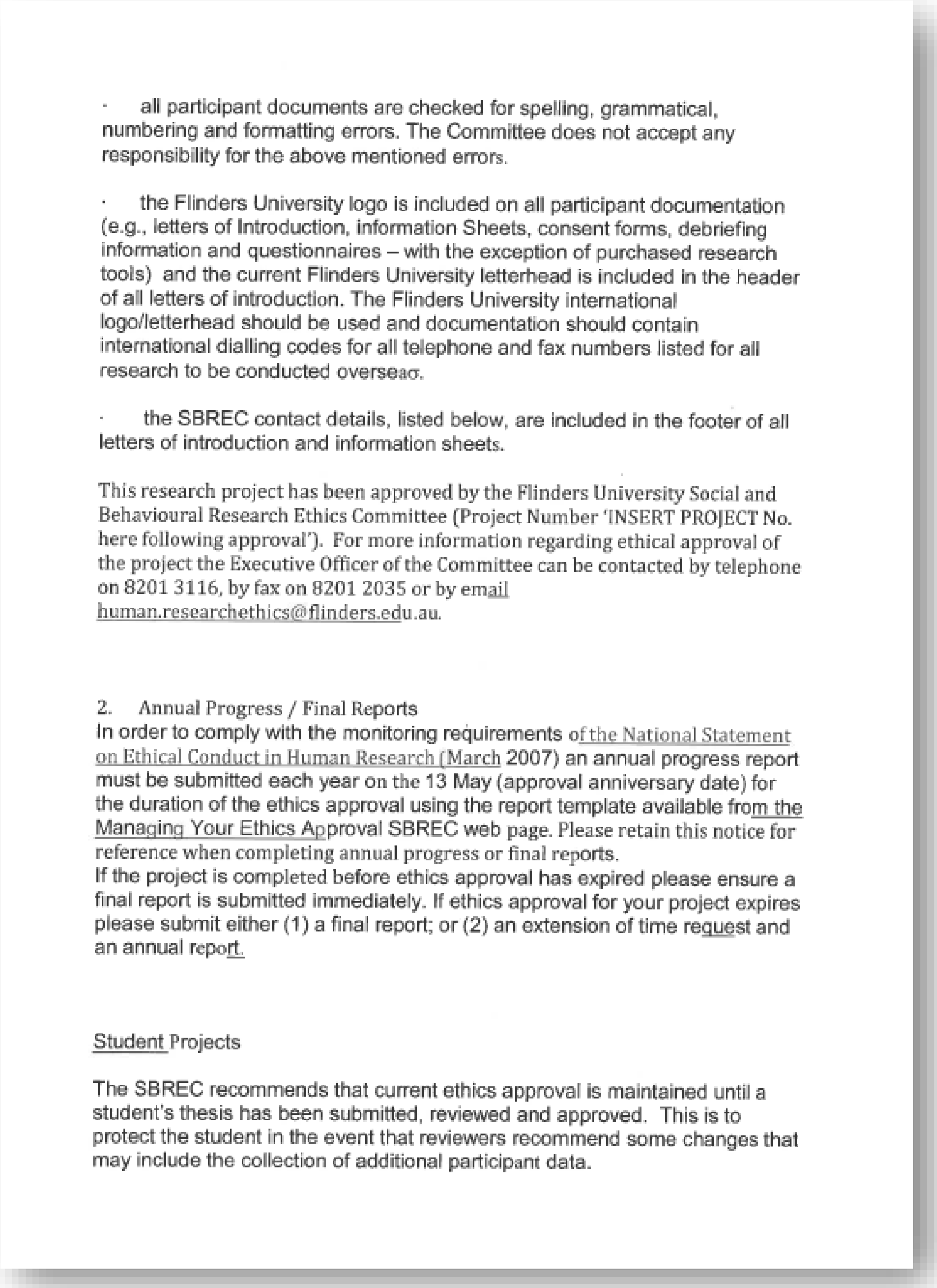
Ethics Approval Expiry Date:
30 June 2020

The above proposed project has been approved on the basis of the information contained in the application, its attachments and the information subsequently provided.

The Chair would like to extend her personal apologies for the delay in this response.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation
Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:



- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

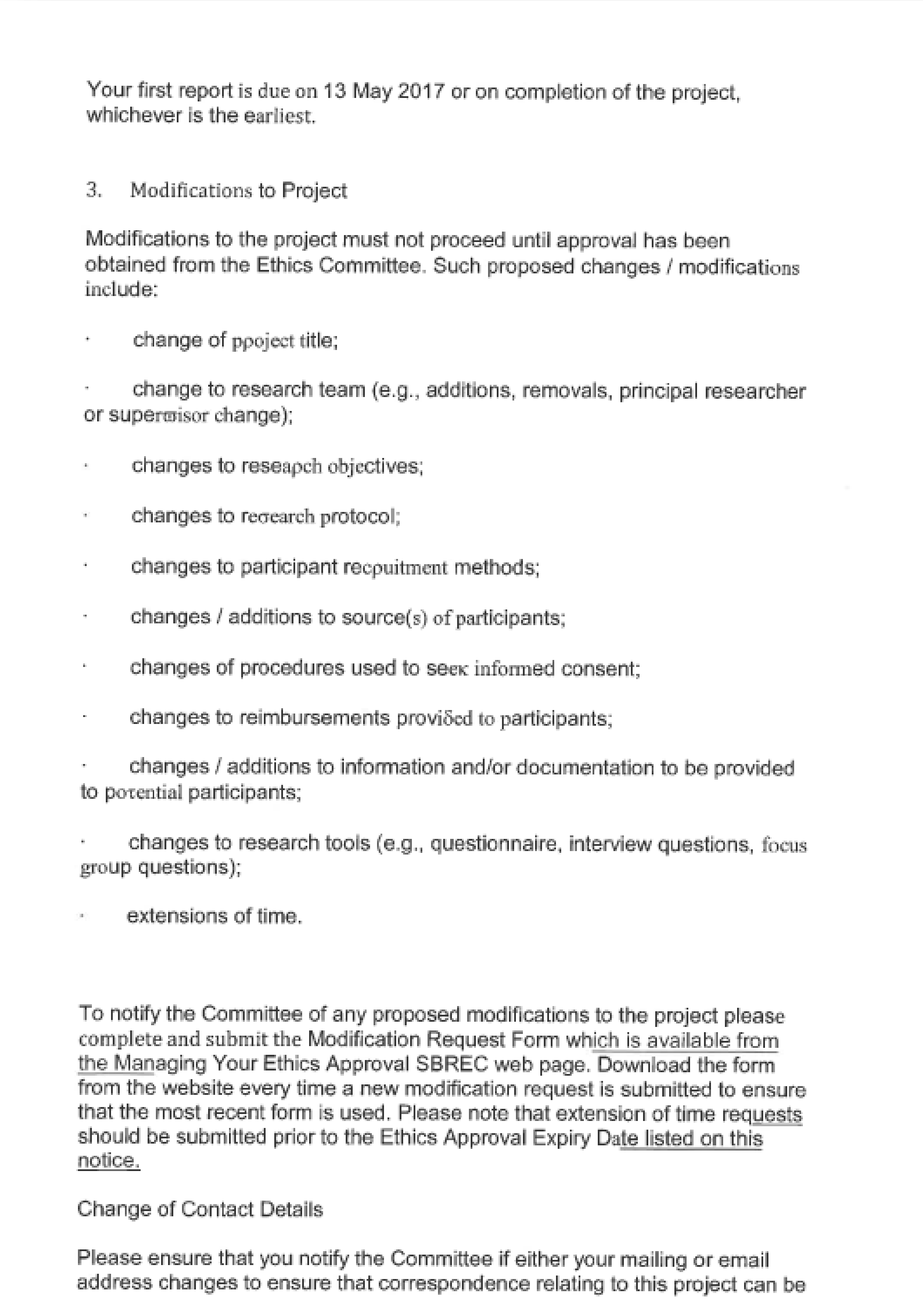
This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the National Statement on Ethical Conduct in Human Research (March 2007) an annual progress report must be submitted each year on the 13 May (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. Please retain this notice for reference when completing annual progress or final reports.
If the project is completed before ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.



Your first report is due on 13 May 2017 or on completion of the project, whichever is the earliest.

3. Modifications to Project

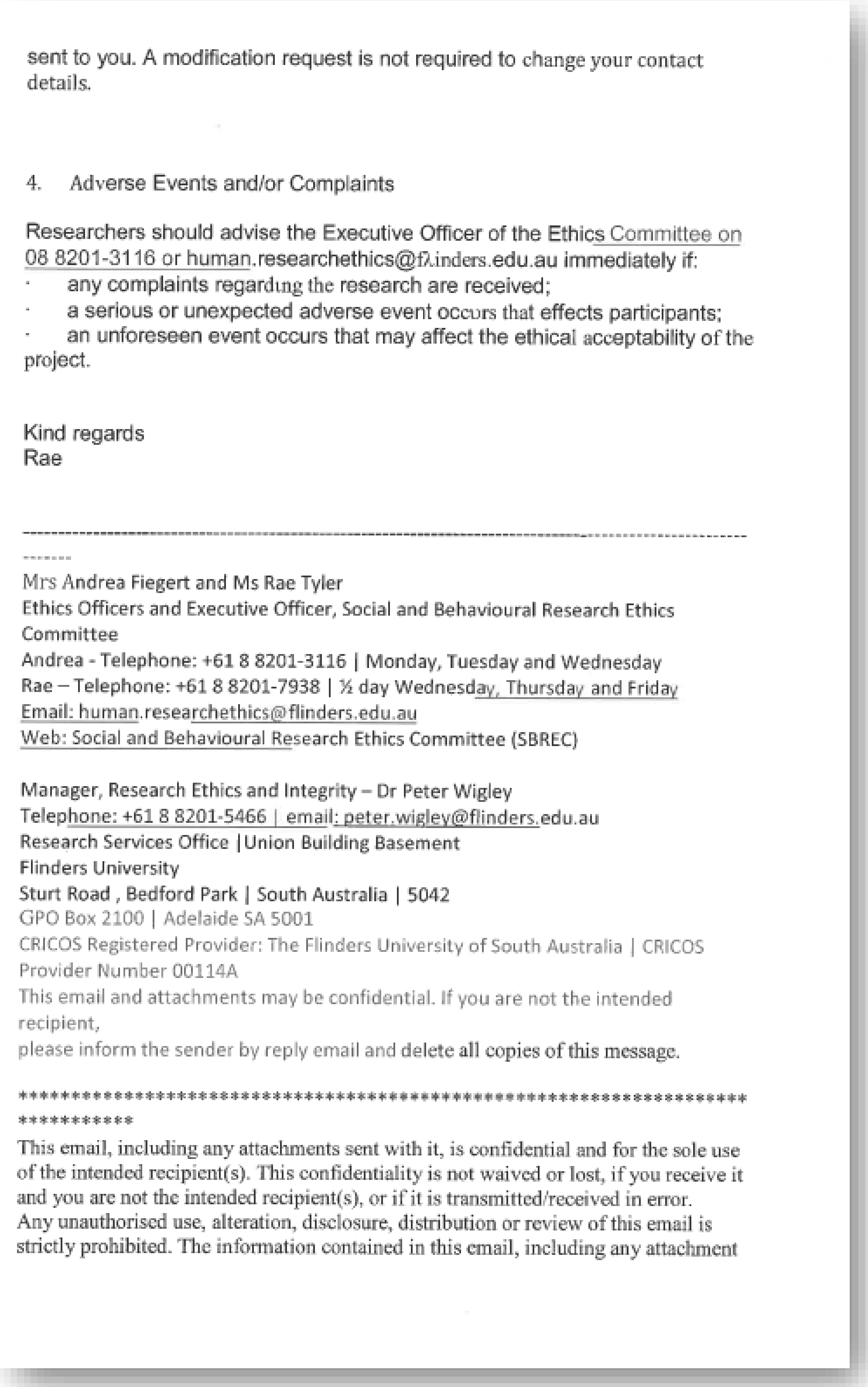
Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the Modification Request Form which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be



sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday
Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
Research Services Office |Union Building Basement
Flinders University
Sturt Road , Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001
CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A

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please inform the sender by reply email and delete all copies of this message.

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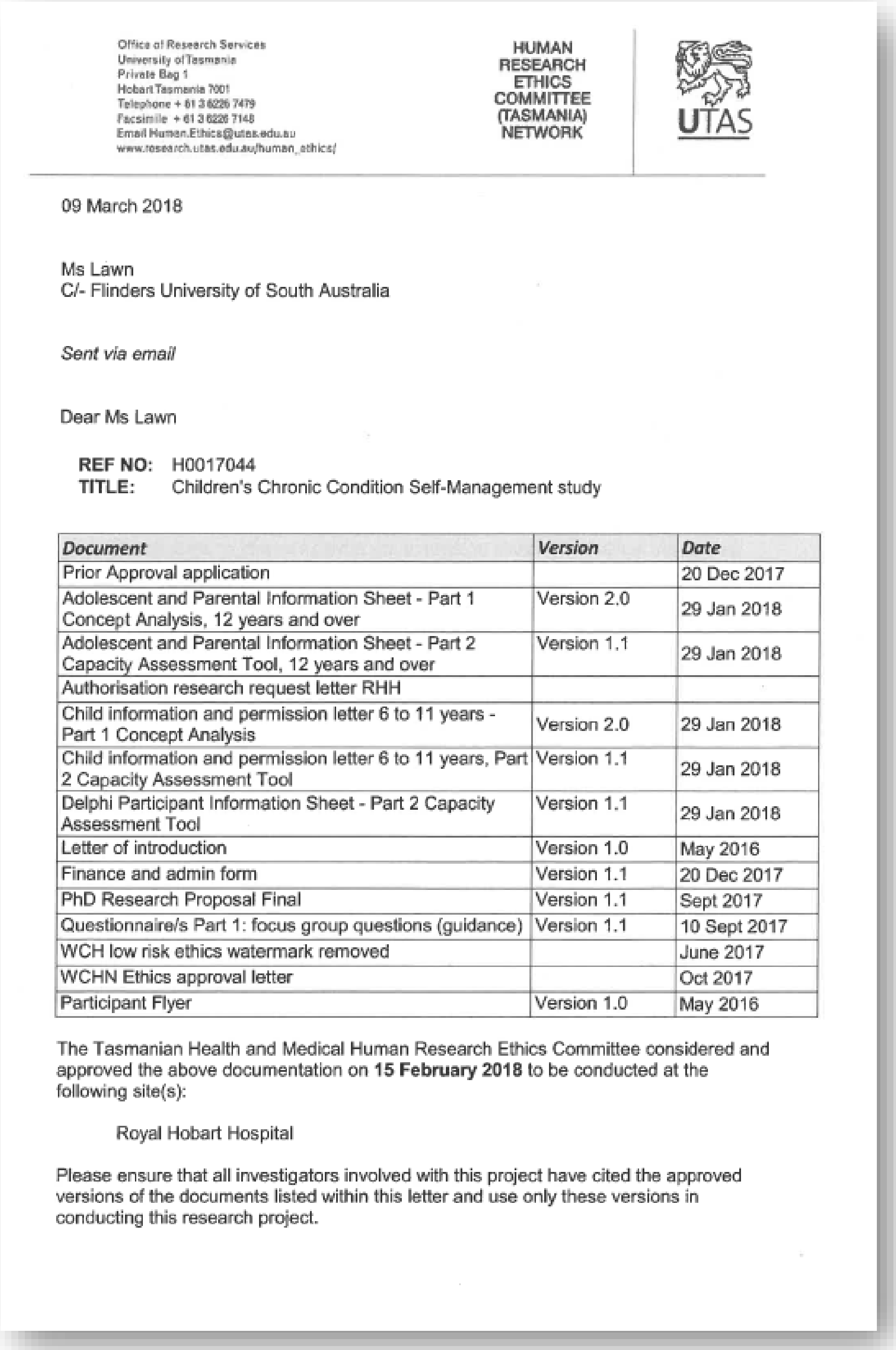
2G) Ethics approval (Tasmanian Health and Medical Human Research Ethics Committee)



Office of Research Services
University of Tasmania
Private Bag 1
Hobart Tasmania 7001
Telephone + 61 3 6226 7479
Facsimile + 61 3 6226 7148
Email Human.Ethics@utas.edu.au
www.research.utas.edu.au/human_ethics/

HUMAN
RESEARCH
ETHICS
COMMITTEE
(TASMANIA)
NETWORK

UTAS

09 March 2018

Ms Lawn
C/- Flinders University of South Australia

Sent via email

Dear Ms Lawn

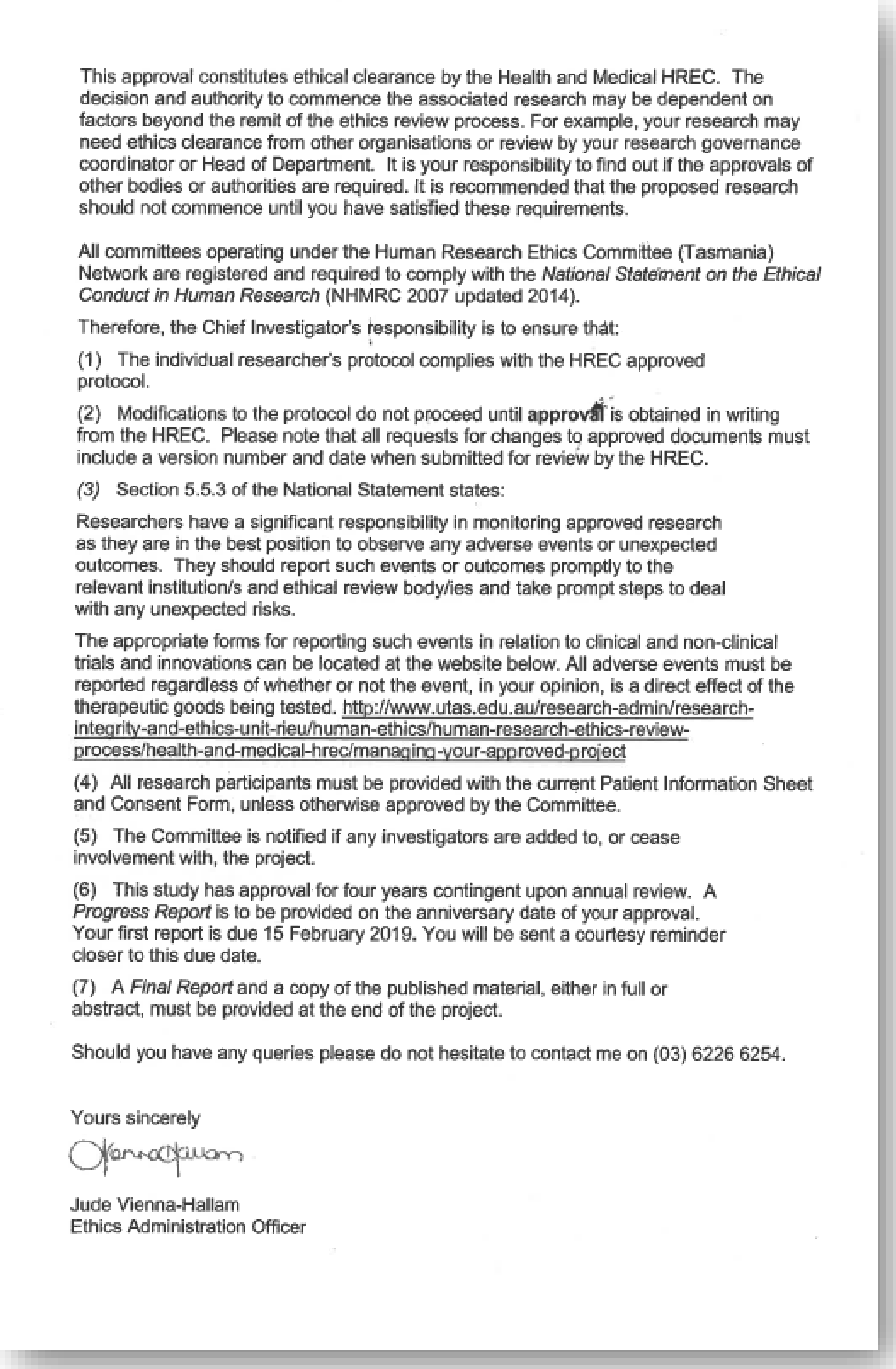
REF NO: H0017044
TITLE: Children's Chronic Condition Self-Management study

Document	*Version*	*Date*
Prior Approval application		20 Dec 2017
Adolescent and Parental Information Sheet - Part 1 Concept Analysis, 12 years and over	Version 2.0	29 Jan 2018
Adolescent and Parental Information Sheet - Part 2 Capacity Assessment Tool, 12 years and over	Version 1.1	29 Jan 2018
Authorisation research request letter RHH		
Child information and permission letter 6 to 11 years - Part 1 Concept Analysis	Version 2.0	29 Jan 2018
Child information and permission letter 6 to 11 years, Part 2 Capacity Assessment Tool	Version 1.1	29 Jan 2018
Delphi Participant Information Sheet - Part 2 Capacity Assessment Tool	Version 1.1	29 Jan 2018
Letter of introduction	Version 1.0	May 2016
Finance and admin form	Version 1.1	20 Dec 2017
PhD Research Proposal Final	Version 1.1	Sept 2017
Questionnaire/s Part 1: focus group questions (guidance)	Version 1.1	10 Sept 2017
WCH low risk ethics watermark removed		June 2017
WCHN Ethics approval letter		Oct 2017
Participant Flyer	Version 1.0	May 2016

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation on **15 February 2018** to be conducted at the following site(s):

Royal Hobart Hospital

Please ensure that all investigators involved with this project have cited the approved versions of the documents listed within this letter and use only these versions in conducting this research project.



This approval constitutes ethical clearance by the Health and Medical HREC. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approvals of other bodies or authorities are required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct in Human Research* (NHMRC 2007 updated 2014).

Therefore, the Chief Investigator's responsibility is to ensure that:

(1) The individual researcher's protocol complies with the HREC approved protocol.

(2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC. Please note that all requests for changes to approved documents must include a version number and date when submitted for review by the HREC.

(3) Section 5.5.3 of the National Statement states:

Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested. http://www.utas.edu.au/research-admin/research-integrity-and-ethics-unit-rieu/human-ethics/human-research-ethics-review-process/health-and-medical-hrec/managing-your-approved-project

(4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.

(5) The Committee is notified if any investigators are added to, or cease involvement with, the project.

(6) This study has approval for four years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due 15 February 2019. You will be sent a courtesy reminder closer to this due date.

(7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 6254.

Yours sincerely

Jude Vienna-Hallam
Ethics Administration Officer

3G) Delphi participant information sheet

Delphi Participant Information Sheet - Part 2 [Tasmanian Version 1.1] [January 2018]

Delphi Participant Information Sheet

Children's Chronic Condition Self-Management Study PART 2: Capacity Assessment Scale

I wish to invite you to participate in a research study on children's chronic condition self-management. Please take your time to read the following information. Feel free to ask the research team about anything you are not clear about.

The study is being conducted by:

☐ Nicole Saxby, PhD Candidate at Flinders University and Paediatric Coordinator Tasmanian Cystic Fibrosis Service, Royal Hobart Hospital

Support is being provided by a team of experienced self-management researchers associated with Flinders University (Prof. Sharon Lawn, Prof. Malcolm Battersby and A/Prof. Sean Beggs).

1. **Research introduction**

In the context of supporting children to become autonomous self-managers, it is crucial that the most efficient, cost effective, and age appropriate capacity assessment measures are employed. It has been highlighted by expert groups such as Kelo (2011) and Hanna and Decker (2010) that, for a measure to be appropriate for children, complex issues need to be negotiated which include: learning capacity, developmental needs of the child, and the shifting of responsibility between the parent/carer and the child for self-management tasks. There are currently no validated generic measures to assess children's chronic condition self-management capacity in existence.

2. **What is the purpose of this study?**

The aim of this study is to get an expert consensus as to the most relevant domains/principles of children's self-management at various ages and developmental stages. The information gathered will be later used to develop a generic self-management assessment scale for children living with chronic conditions, ages 6 to 18 years.

3. What does this study involve?

Your participation in this study will involve taking part in a Delphi Study. A Delphi Study is a structured process for collecting and distilling knowledge from a group of experts. You will be asked to complete a 3 or 4 rounds of online questionnaires exploring which domains/principles best indicate children's capacity to self-manage (e.g. knowledge, illness impact, symptoms management, ability to follow a care plan, healthy lifestyle, support systems). In addition, you will be asked to specify theoretical endpoints for an ideal child self-manager at specified ages. Collective responses for each round will be collated and synthesised by the primary researcher (Nicole Saxby) and will provide material for the next round. Rounds of questionnaires will continue until consensus is reached between experts (70%). Each round will take between 10 to 30 minutes to complete,

depending on the depth of response you wish to contribute.

4. Why have I been invited to participate in this study?

You have been selected as a potential participant in this Delphi study because of your research experience and knowledge in the field of developmentally appropriate children's self-management. Your name and contact details have been obtained from the published literature, your institution's website and/or you contacting me stating your willingness to participate after hearing or reading about this research. As such, your participation is part of a purposive sample of experts in the field.

5. Are there any possible benefits from my participation in this study?

It is not anticipated that there will be any direct benefit to you from participating in this study. However, development of a generic scale to measure children's self-management capacity will allow health professionals to introduce self-management to children and their families and will provide a basis for a checklist of areas of self-management that may help to target developmentally appropriate interventions.

6. Confidentiality

All records containing personal information will remain confidential, and no information which could

lead to your identification will be released, except as required by law.

7. Withdrawal

Your participation in this research is entirely voluntary, and you have the right to withdraw from the study at any time without giving a reason. Although, any contributions you have made towards this Delphi study (up to the point of withdrawal) will be used by the research team.

8. Expenses and payments

There are no costs for participating in this research study, and you will not be paid to participate.

9. What if I have questions about this research?
If you would like to discuss any aspect of this study please contact Nicole Saxby on mobile: 0457 845

189 or email: nicole.saxby@dhhs.tas.gov.au

Thank you for taking the time to consider this study.
Kind regards,

Nicole Saxby, PhD candidate

This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote [H0017044].

Delphi Participant Information Sheet - Part 2 [Tasmanian Version 1.1] [January 2018]

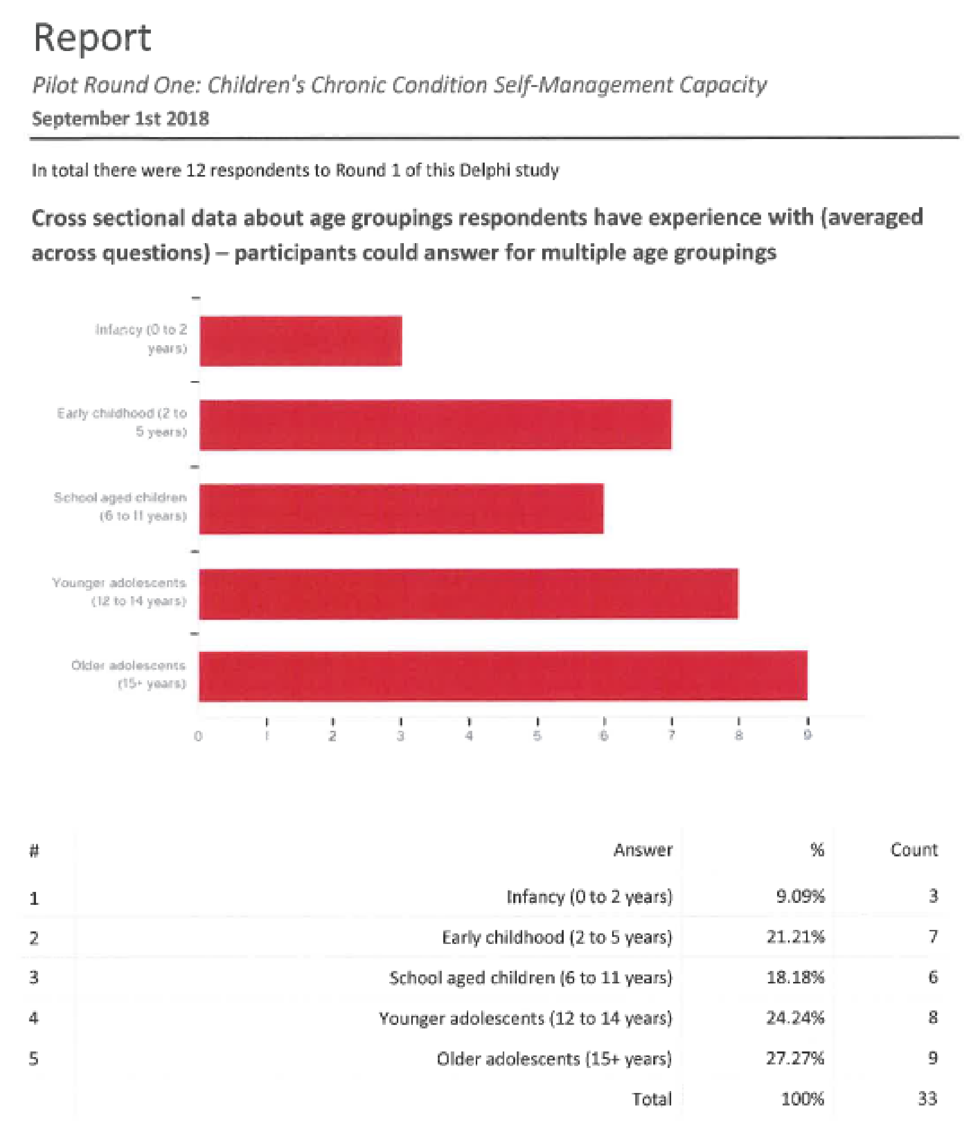
Delphi Participant Online Consent

investigator: Nicole Saxby
PhD Candidate at Flinders University and Paediatric Coordinator Tasmanian Cystic Fibrosis

Service,
mobile: 0457 845 189 or email: nicole.saxby@dhhs.tas.gov.au

By continuing past this point on the online survey, it is understood that you are giving your informed consent to participate. If you give your consent to participate, you will be asked to tick the ‘yes’ box on the first page of each online Delphi questionnaire.

4G) Example of analysis and theming completed for Delphi round 1



Report

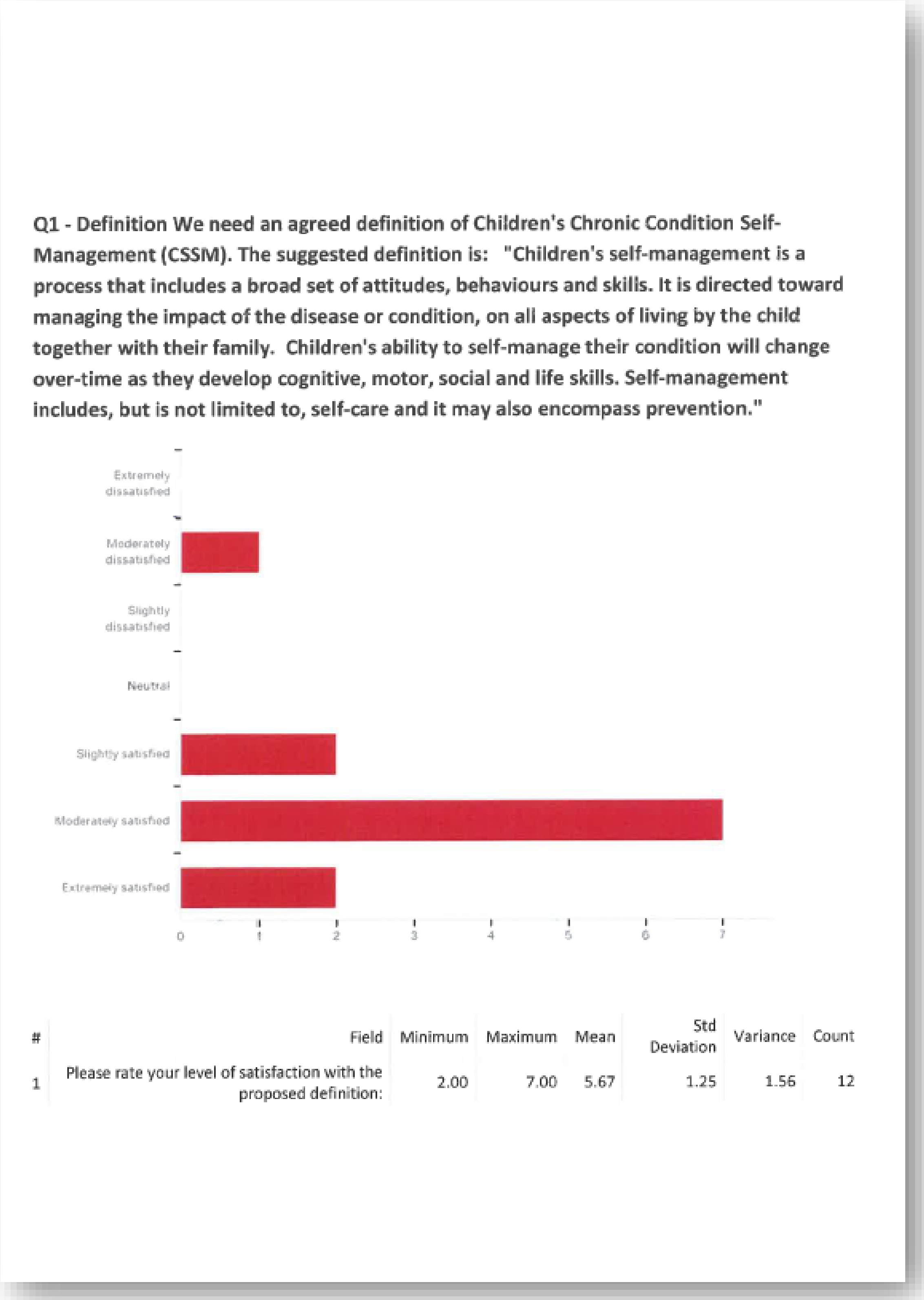
Pilot Round One: Children's Chronic Condition Self-Management Capacity

September 1st 2018

In total there were 12 respondents to Round 1 of this Delphi study

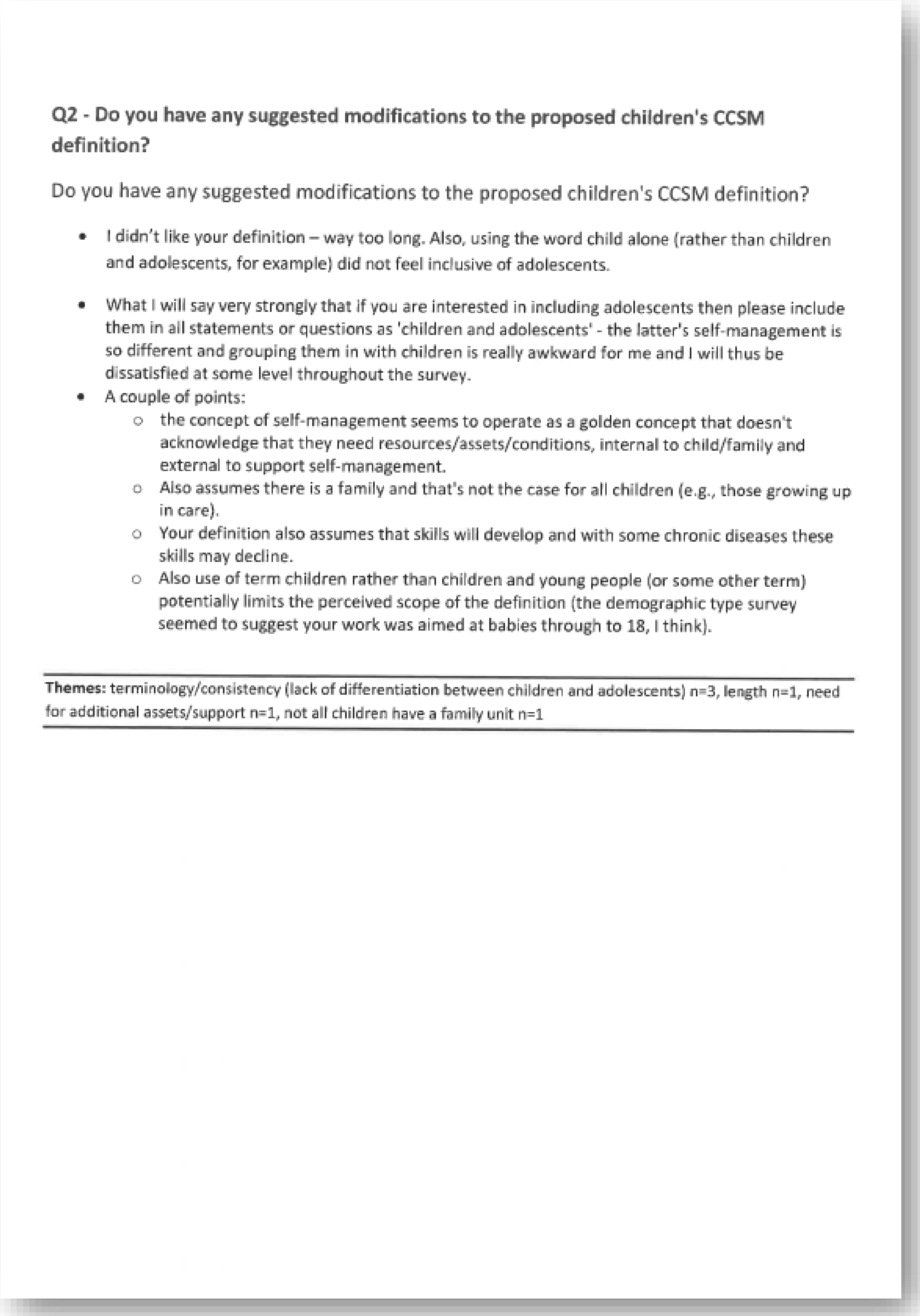
Cross sectional data about age groupings respondents have experience with (averaged across questions) – participants could answer for multiple age groupings

#	Answer	%	Count
1	Infancy (0 to 2 years)	9.09%	3
2	Early childhood (2 to 5 years)	21.21%	7
3	School aged children (6 to 11 years)	18.18%	6
4	Younger adolescents (12 to 14 years)	24.24%	8
5	Older adolescents (15+ years)	27.27%	9
	Total	100%	33



Q1 - Definition We need an agreed definition of Children's Chronic Condition Self-Management (CSSM). The suggested definition is: "Children's self-management is a process that includes a broad set of attitudes, behaviours and skills. It is directed toward managing the impact of the disease or condition, on all aspects of living by the child together with their family. Children's ability to self-manage their condition will change over-time as they develop cognitive, motor, social and life skills. Self-management includes, but is not limited to, self-care and it may also encompass prevention."

#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Please rate your level of satisfaction with the proposed definition:	2.00	7.00	5.67	1.25	1.56	12

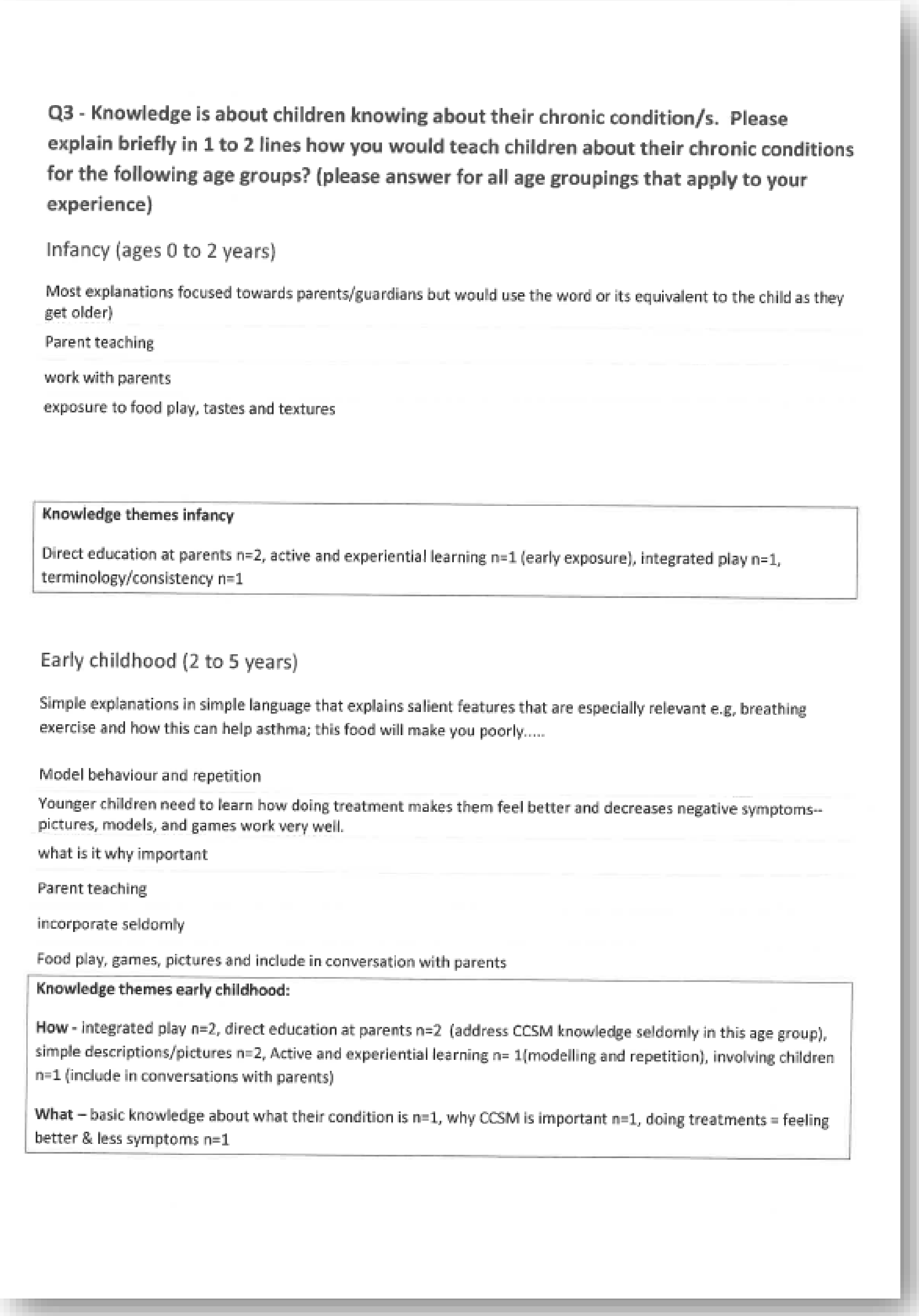


Q2 - Do you have any suggested modifications to the proposed children's CCSM definition?

Do you have any suggested modifications to the proposed children's CCSM definition?

- I didn't like your definition – way too long. Also, using the word child alone (rather than children and adolescents, for example) did not feel inclusive of adolescents.
- What I will say very strongly that if you are interested in including adolescents then please include them in all statements or questions as 'children and adolescents' - the latter's self-management is so different and grouping them in with children is really awkward for me and I will thus be dissatisfied at some level throughout the survey.
- A couple of points:
    - the concept of self-management seems to operate as a golden concept that doesn't acknowledge that they need resources/assets/conditions, internal to child/family and external to support self-management.
    - Also assumes there is a family and that's not the case for all children (e.g., those growing up in care).
    - Your definition also assumes that skills will develop and with some chronic diseases these skills may decline.
    - Also use of term children rather than children and young people (or some other term) potentially limits the perceived scope of the definition (the demographic type survey seemed to suggest your work was aimed at babies through to 18, I think).

Themes: terminology/consistency (lack of differentiation between children and adolescents) n=3, length n=1, need for additional assets/support n=1, not all children have a family unit n=1



Q3 - Knowledge is about children knowing about their chronic condition/s. Please explain briefly in 1 to 2 lines how you would teach children about their chronic conditions for the following age groups? (please answer for all age groupings that apply to your experience)

Infancy (ages 0 to 2 years)

Most explanations focused towards parents/guardians but would use the word or its equivalent to the child as they get older)

Parent teaching

work with parents

exposure to food play, tastes and textures

Knowledge themes infancy

Direct education at parents n=2, active and experiential learning n=1 (early exposure), integrated play n=1, terminology/consistency n=1

Early childhood (2 to 5 years)

Simple explanations in simple language that explains salient features that are especially relevant e.g, breathing exercise and how this can help asthma; this food will make you poorly.....

Model behaviour and repetition

Younger children need to learn how doing treatment makes them feel better and decreases negative symptoms-- pictures, models, and games work very well.

what is it why important

Parent teaching

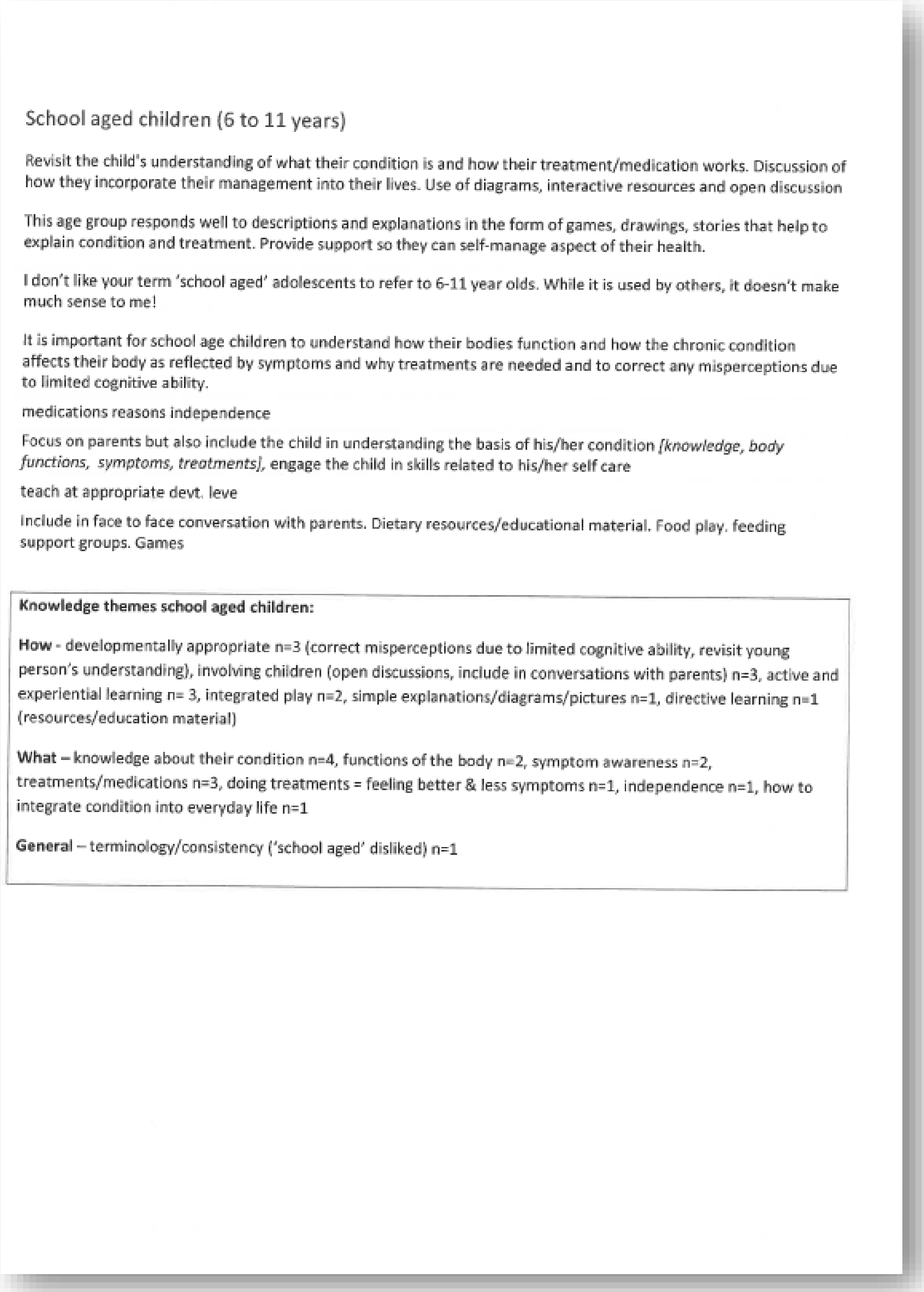
incorporate seldomly

Food play, games, pictures and include in conversation with parents

Knowledge themes early childhood:

How - integrated play n=2, direct education at parents n=2 (address CCSM knowledge seldomly in this age group), simple descriptions/pictures n=2, Active and experiential learning n= 1(modelling and repetition), involving children n=1 (include in conversations with parents)

What – basic knowledge about what their condition is n=1, why CCSM is important n=1, doing treatments = feeling better & less symptoms n=1



School aged children (6 to 11 years)

Revisit the child's understanding of what their condition is and how their treatment/medication works. Discussion of how they incorporate their management into their lives. Use of diagrams, interactive resources and open discussion

This age group responds well to descriptions and explanations in the form of games, drawings, stories that help to explain condition and treatment. Provide support so they can self-manage aspect of their health.

I don't like your term 'school aged' adolescents to refer to 6-11 year olds. While it is used by others, it doesn't make much sense to me!

It is important for school age children to understand how their bodies function and how the chronic condition affects their body as reflected by symptoms and why treatments are needed and to correct any misperceptions due to limited cognitive ability.

medications reasons independence

Focus on parents but also include the child in understanding the basis of his/her condition *[knowledge, body functions, symptoms, treatments]*, engage the child in skills related to his/her self care

teach at appropriate devt. leve

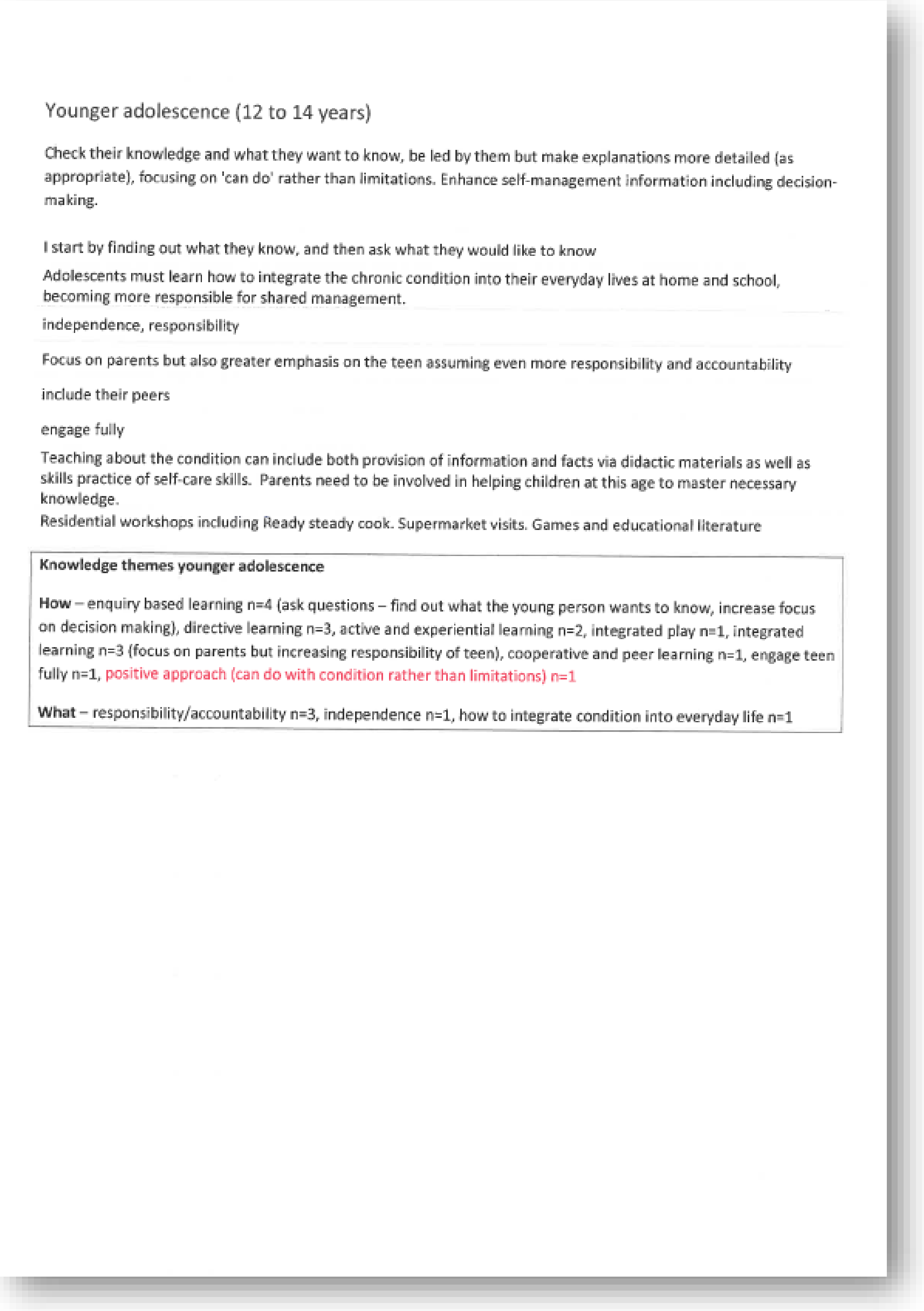
Include in face to face conversation with parents. Dietary resources/educational material. Food play. feeding support groups. Games

Knowledge themes school aged children:

How - developmentally appropriate n=3 (correct misperceptions due to limited cognitive ability, revisit young person's understanding), involving children (open discussions, include in conversations with parents) n=3, active and experiential learning n= 3, integrated play n=2, simple explanations/diagrams/pictures n=1, directive learning n=1 (resources/education material)

What – knowledge about their condition n=4, functions of the body n=2, symptom awareness n=2, treatments/medications n=3, doing treatments = feeling better & less symptoms n=1, independence n=1, how to integrate condition into everyday life n=1

General – terminology/consistency ('school aged' disliked) n=1



Younger adolescence (12 to 14 years)

Check their knowledge and what they want to know, be led by them but make explanations more detailed (as appropriate), focusing on 'can do' rather than limitations. Enhance self-management information including decision-making.

I start by finding out what they know, and then ask what they would like to know

Adolescents must learn how to integrate the chronic condition into their everyday lives at home and school, becoming more responsible for shared management.

independence, responsibility

Focus on parents but also greater emphasis on the teen assuming even more responsibility and accountability

include their peers

engage fully

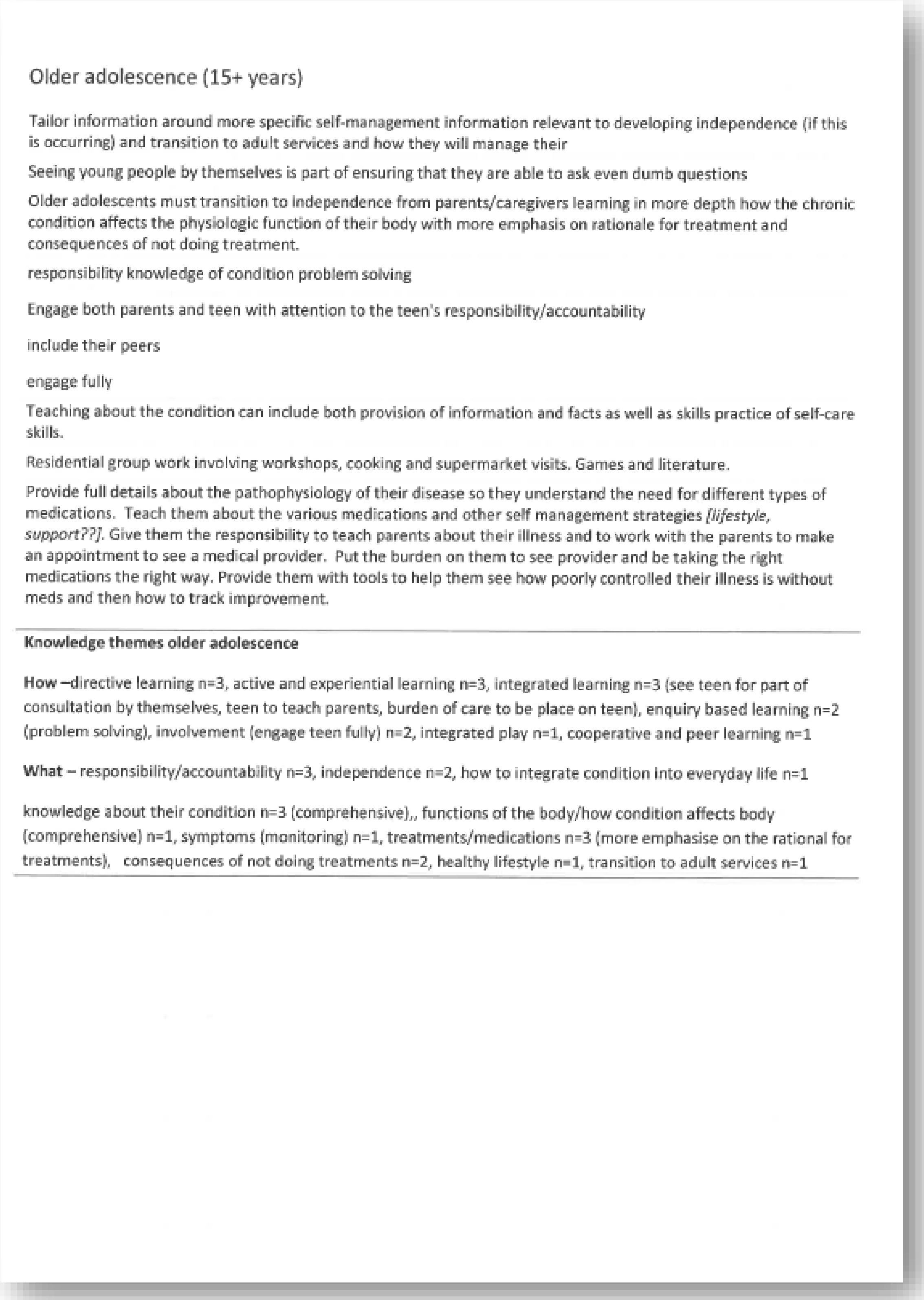
Teaching about the condition can include both provision of information and facts via didactic materials as well as skills practice of self-care skills. Parents need to be involved in helping children at this age to master necessary knowledge.

Residential workshops including Ready steady cook. Supermarket visits. Games and educational literature

Knowledge themes younger adolescence

How – enquiry based learning n=4 (ask questions – find out what the young person wants to know, increase focus on decision making), directive learning n=3, active and experiential learning n=2, integrated play n=1, integrated learning n=3 (focus on parents but increasing responsibility of teen), cooperative and peer learning n=1, engage teen fully n=1, positive approach (can do with condition rather than limitations) n=1

What – responsibility/accountability n=3, independence n=1, how to integrate condition into everyday life n=1



Older adolescence (15+ years)

Tailor information around more specific self-management information relevant to developing independence (if this is occurring) and transition to adult services and how they will manage their

Seeing young people by themselves is part of ensuring that they are able to ask even dumb questions

Older adolescents must transition to independence from parents/caregivers learning in more depth how the chronic condition affects the physiologic function of their body with more emphasis on rationale for treatment and consequences of not doing treatment.

responsibility knowledge of condition problem solving

Engage both parents and teen with attention to the teen's responsibility/accountability

include their peers

engage fully

Teaching about the condition can include both provision of information and facts as well as skills practice of self-care skills.

Residential group work involving workshops, cooking and supermarket visits. Games and literature.

Provide full details about the pathophysiology of their disease so they understand the need for different types of medications. Teach them about the various medications and other self management strategies *[lifestyle, support??]*. Give them the responsibility to teach parents about their illness and to work with the parents to make an appointment to see a medical provider. Put the burden on them to see provider and be taking the right medications the right way. Provide them with tools to help them see how poorly controlled their illness is without meds and then how to track improvement.

Knowledge themes older adolescence

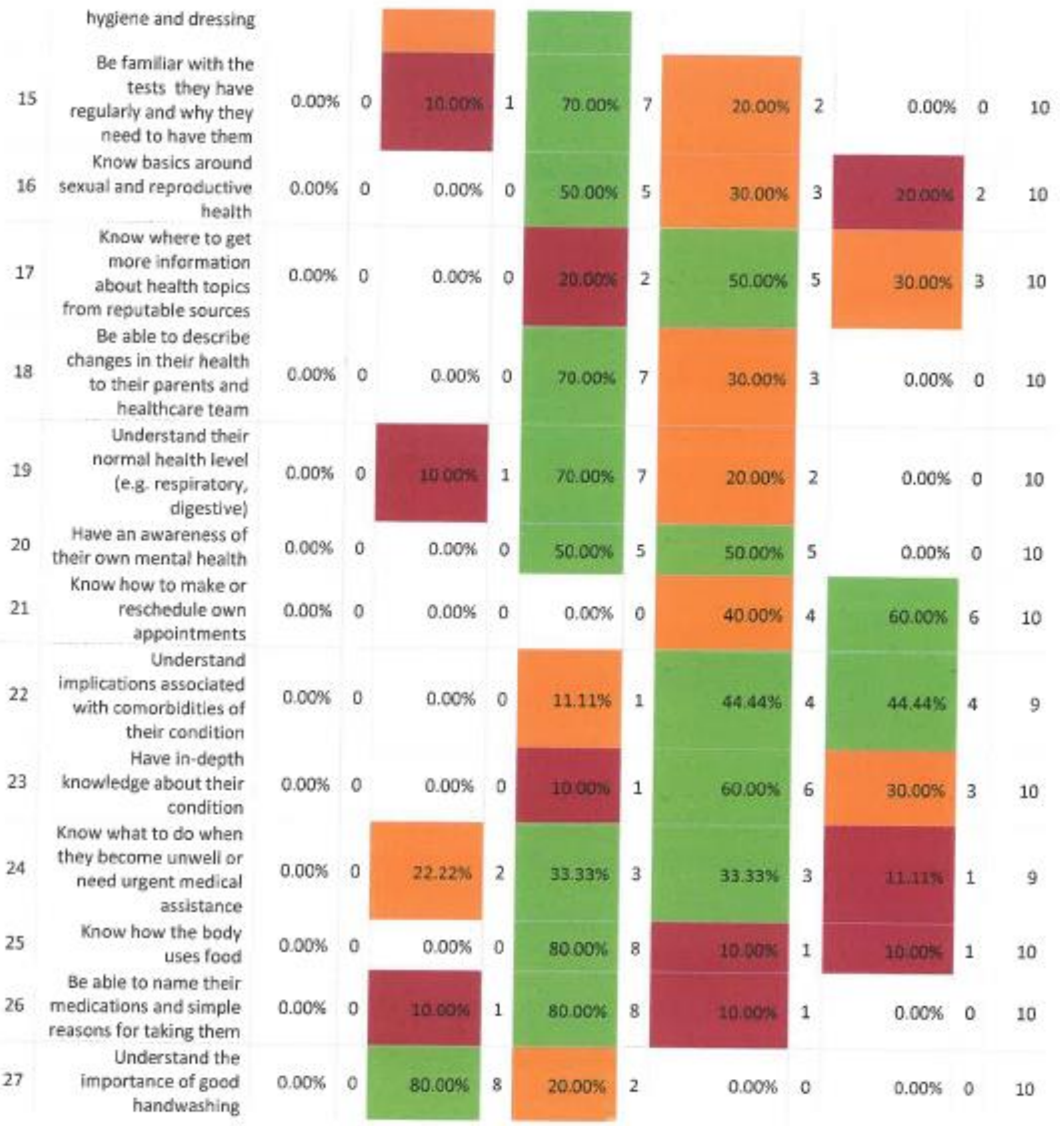
How –directive learning n=3, active and experiential learning n=3, integrated learning n=3 (see teen for part of consultation by themselves, teen to teach parents, burden of care to be place on teen), enquiry based learning n=2 (problem solving), involvement (engage teen fully) n=2, integrated play n=1, cooperative and peer learning n=1

What – responsibility/accountability n=3, independence n=2, how to integrate condition into everyday life n=1

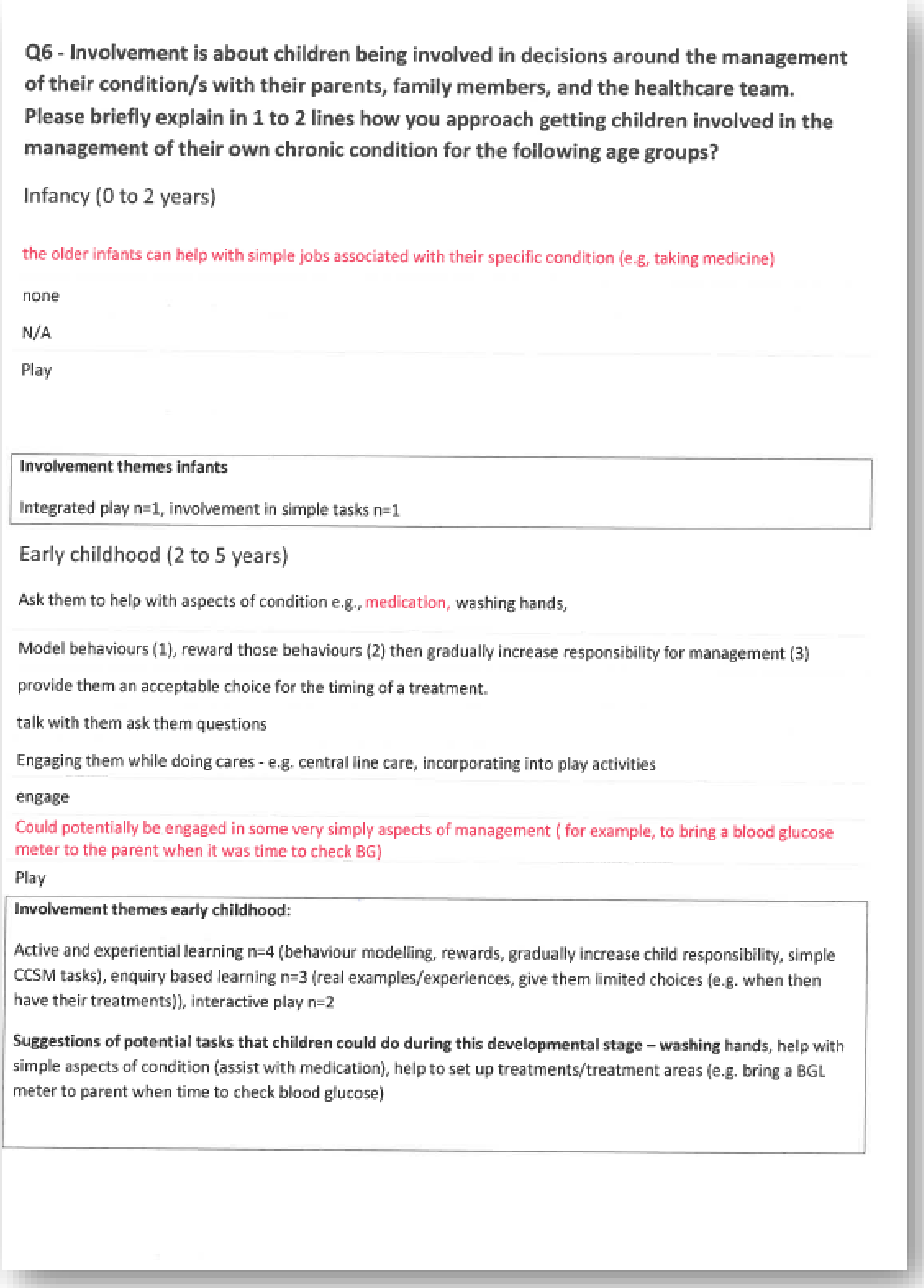
knowledge about their condition n=3 (comprehensive),, functions of the body/how condition affects body (comprehensive) n=1, symptoms (monitoring) n=1, treatments/medications n=3 (more emphasise on the rational for treatments), consequences of not doing treatments n=2, healthy lifestyle n=1, transition to adult services n=1

Q4 - Knowledge   When would you expect children to possess the following knowledge?

#	Question	Infancy (0 to 2)		Early childhood (2 to 5)		School aged children (6 to 11)		Younger adolescence (12 to 14)		Older adolescence (15+)		Total
1	Know that they have allergies and how to manage them	0.00%	0	20.00%	2	40.00%	4	40.00%	4	0.00%	0	10
2	Know the names of the people in their healthcare team	0.00%	0	10.00%	1	60.00%	6	20.00%	2	10.00%	1	10
3	Be able to list and name their own contact information	0.00%	0	20.00%	2	80.00%	8	0.00%	0	0.00%	0	10
4	Be aware of side effects and restrictions of the medications they take	0.00%	0	10.00%	1	30.00%	3	40.00%	4	20.00%	2	10
5	Know the equipment needed for treatment and what they are used for	0.00%	0	10.00%	1	70.00%	7	20.00%	2	0.00%	0	10
6	Know how to reorder/arrange medications and other treatments	0.00%	0	0.00%	0	30.00%	3	10.00%	1	60.00%	6	10
7	Know who to contact in case of an emergency	0.00%	0	20.00%	2	60.00%	6	20.00%	2	0.00%	0	10
8	Be able to fill in a calendar with their date of birth and other important dates in their life	0.00%	0	0.00%	0	70.00%	7	30.00%	3	0.00%	0	10
9	Be able to describe their chronic condition in 2 to 3 simple sentences	0.00%	0	10.00%	1	80.00%	8	10.00%	1	0.00%	0	10
10	Know about the general principles of a balanced diet and exercise	0.00%	0	0.00%	0	60.00%	6	40.00%	4	0.00%	0	10
11	Know the names of each member of their healthcare team and understand what they do	0.00%	0	0.00%	0	30.00%	3	30.00%	3	40.00%	4	10
12	Know the names of their medications, dosages and what the medications are for	0.00%	0	0.00%	0	20.00%	2	70.00%	7	10.00%	1	10
13	Be able to describe how they are feeling when asked	0.00%	0	60.00%	6	40.00%	4	0.00%	0	0.00%	0	10
14	Understand the importance of self-care activities such as	0.00%	0	30.00%	3	70.00%	7	0.00%	0	0.00%	0	10



	hygiene and dressing											
15	Be familiar with the tests they have regularly and why they need to have them	0.00%	0	10.00%	1	70.00%	7	20.00%	2	0.00%	0	10
16	Know basics around sexual and reproductive health	0.00%	0	0.00%	0	50.00%	5	30.00%	3	20.00%	2	10
17	Know where to get more information about health topics from reputable sources	0.00%	0	0.00%	0	20.00%	2	50.00%	5	30.00%	3	10
18	Be able to describe changes in their health to their parents and healthcare team	0.00%	0	0.00%	0	70.00%	7	30.00%	3	0.00%	0	10
19	Understand their normal health level (e.g. respiratory, digestive)	0.00%	0	10.00%	1	70.00%	7	20.00%	2	0.00%	0	10
20	Have an awareness of their own mental health	0.00%	0	0.00%	0	50.00%	5	50.00%	5	0.00%	0	10
21	Know how to make or reschedule own appointments	0.00%	0	0.00%	0	0.00%	0	40.00%	4	60.00%	6	10
22	Understand implications associated with comorbidities of their condition	0.00%	0	0.00%	0	11.11%	1	44.44%	4	44.44%	4	9
23	Have in-depth knowledge about their condition	0.00%	0	0.00%	0	10.00%	1	60.00%	6	30.00%	3	10
24	Know what to do when they become unwell or need urgent medical assistance	0.00%	0	22.22%	2	33.33%	3	33.33%	3	11.11%	1	9
25	Know how the body uses food	0.00%	0	0.00%	0	80.00%	8	10.00%	1	10.00%	1	10
26	Be able to name their medications and simple reasons for taking them	0.00%	0	10.00%	1	80.00%	8	10.00%	1	0.00%	0	10
27	Understand the importance of good handwashing	0.00%	0	80.00%	8	20.00%	2	0.00%	0	0.00%	0	10



Q6 - Involvement is about children being involved in decisions around the management of their condition/s with their parents, family members, and the healthcare team. Please briefly explain in 1 to 2 lines how you approach getting children involved in the management of their own chronic condition for the following age groups?

Infancy (0 to 2 years)

the older infants can help with simple jobs associated with their specific condition (e.g, taking medicine)

none

N/A

Play

Involvement themes infants

Integrated play n=1, involvement in simple tasks n=1

Early childhood (2 to 5 years)

Ask them to help with aspects of condition e.g., medication, washing hands,

Model behaviours (1), reward those behaviours (2) then gradually increase responsibility for management (3)

provide them an acceptable choice for the timing of a treatment.

talk with them ask them questions

Engaging them while doing cares - e.g. central line care, incorporating into play activities

engage

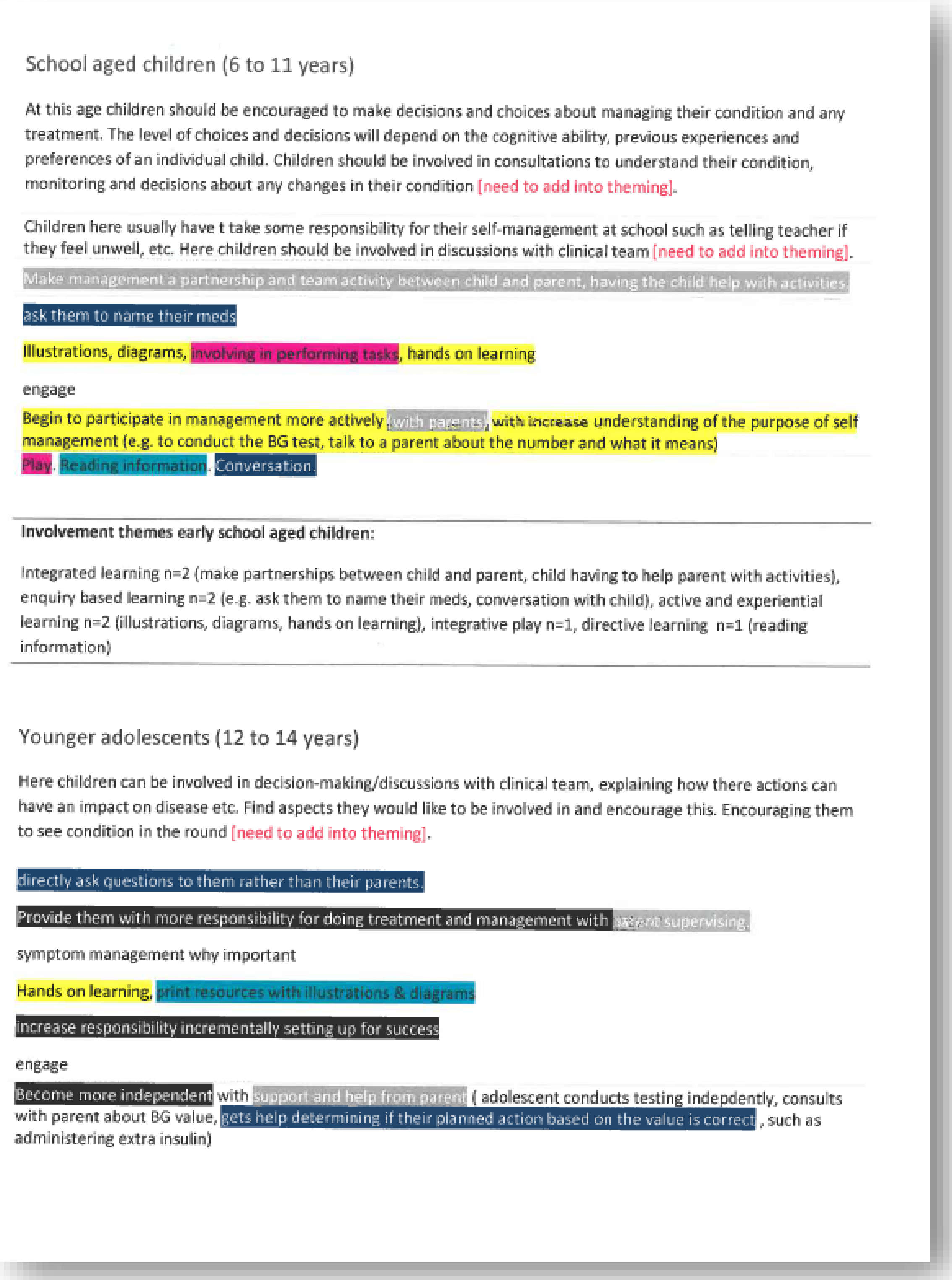
Could potentially be engaged in some very simply aspects of management (for example, to bring a blood glucose meter to the parent when it was time to check BG)

Play

Involvement themes early childhood:

Active and experiential learning n=4 (behaviour modelling, rewards, gradually increase child responsibility, simple CCSM tasks), enquiry based learning n=3 (real examples/experiences, give them limited choices (e.g. when then have their treatments)), interactive play n=2

Suggestions of potential tasks that children could do during this developmental stage – washing hands, help with simple aspects of condition (assist with medication), help to set up treatments/treatment areas (e.g. bring a BGL meter to parent when time to check blood glucose)



School aged children (6 to 11 years)

At this age children should be encouraged to make decisions and choices about managing their condition and any treatment. The level of choices and decisions will depend on the cognitive ability, previous experiences and preferences of an individual child. Children should be involved in consultations to understand their condition, monitoring and decisions about any changes in their condition [need to add into theming].

Children here usually have t take some responsibility for their self-management at school such as telling teacher if they feel unwell, etc. Here children should be involved in discussions with clinical team [need to add into theming].

Make management a partnership and team activity between child and parent, having the child help with activities.

ask them to name their meds

Illustrations, diagrams, involving in performing tasks, hands on learning

engage

Begin to participate in management more actively (with parents), with increase understanding of the purpose of self management (e.g. to conduct the BG test, talk to a parent about the number and what it means)
Play. Reading information. Conversation.

Involvement themes early school aged children:

Integrated learning n=2 (make partnerships between child and parent, child having to help parent with activities), enquiry based learning n=2 (e.g. ask them to name their meds, conversation with child), active and experiential learning n=2 (illustrations, diagrams, hands on learning), integrative play n=1, directive learning n=1 (reading information)

Younger adolescents (12 to 14 years)

Here children can be involved in decision-making/discussions with clinical team, explaining how there actions can have an impact on disease etc. Find aspects they would like to be involved in and encourage this. Encouraging them to see condition in the round [need to add into theming].

directly ask questions to them rather than their parents.

Provide them with more responsibility for doing treatment and management with parent supervising.

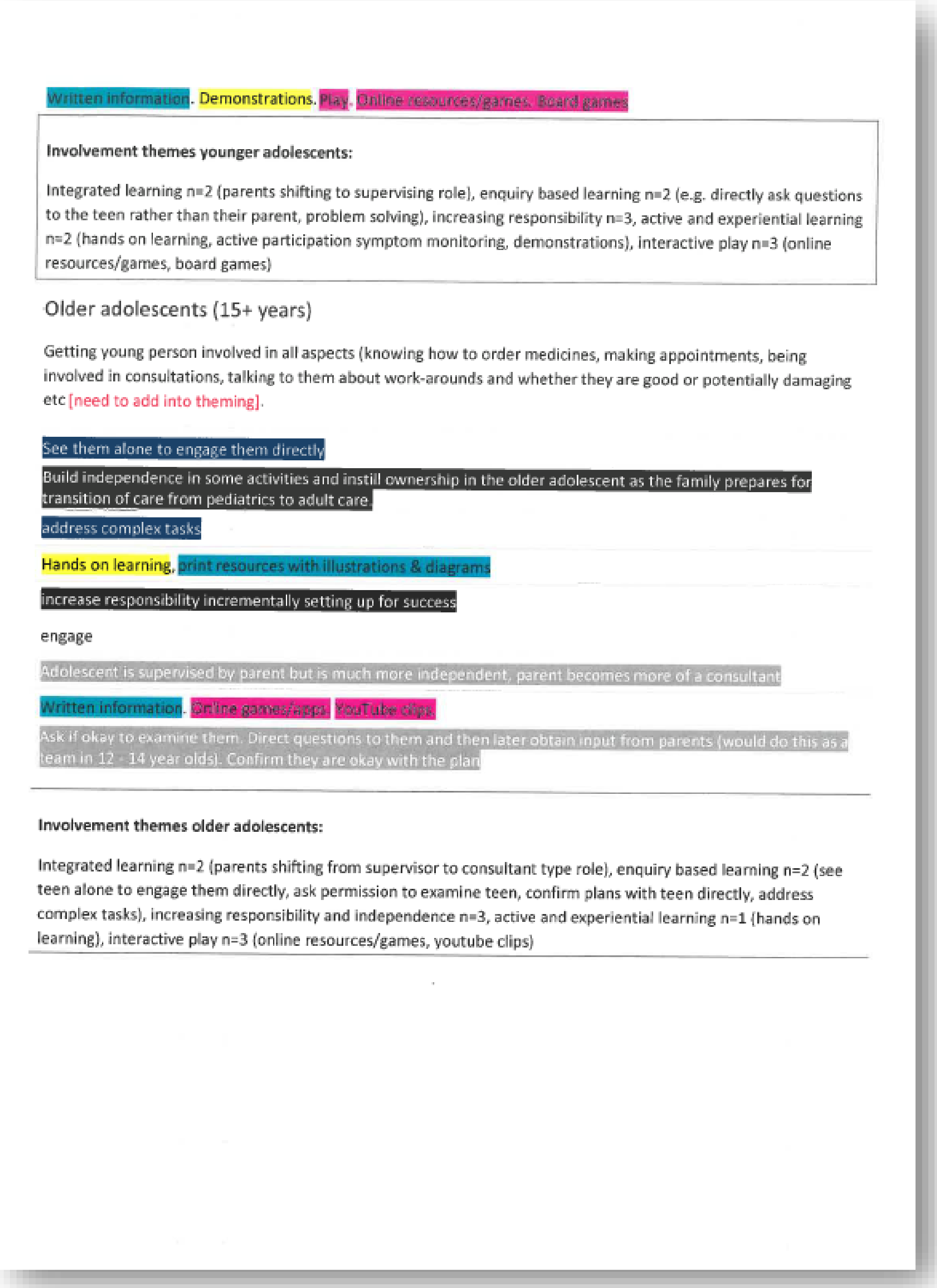
symptom management why important

Hands on learning, print resources with illustrations & diagrams

increase responsibility incrementally setting up for success

engage

Become more independent with support and help from parent (adolescent conducts testing indepdently, consults with parent about BG value, gets help determining if their planned action based on the value is correct , such as administering extra insulin)



Written information. Demonstrations. Play. Online resources/games. Board games

Involvement themes younger adolescents:

Integrated learning n=2 (parents shifting to supervising role), enquiry based learning n=2 (e.g. directly ask questions to the teen rather than their parent, problem solving), increasing responsibility n=3, active and experiential learning n=2 (hands on learning, active participation symptom monitoring, demonstrations), interactive play n=3 (online resources/games, board games)

Older adolescents (15+ years)

Getting young person involved in all aspects (knowing how to order medicines, making appointments, being involved in consultations, talking to them about work-arounds and whether they are good or potentially damaging etc [need to add into theming].

See them alone to engage them directly

Build independence in some activities and instill ownership in the older adolescent as the family prepares for transition of care from pediatrics to adult care.

address complex tasks

Hands on learning, print resources with illustrations & diagrams

increase responsibility incrementally setting up for success

engage

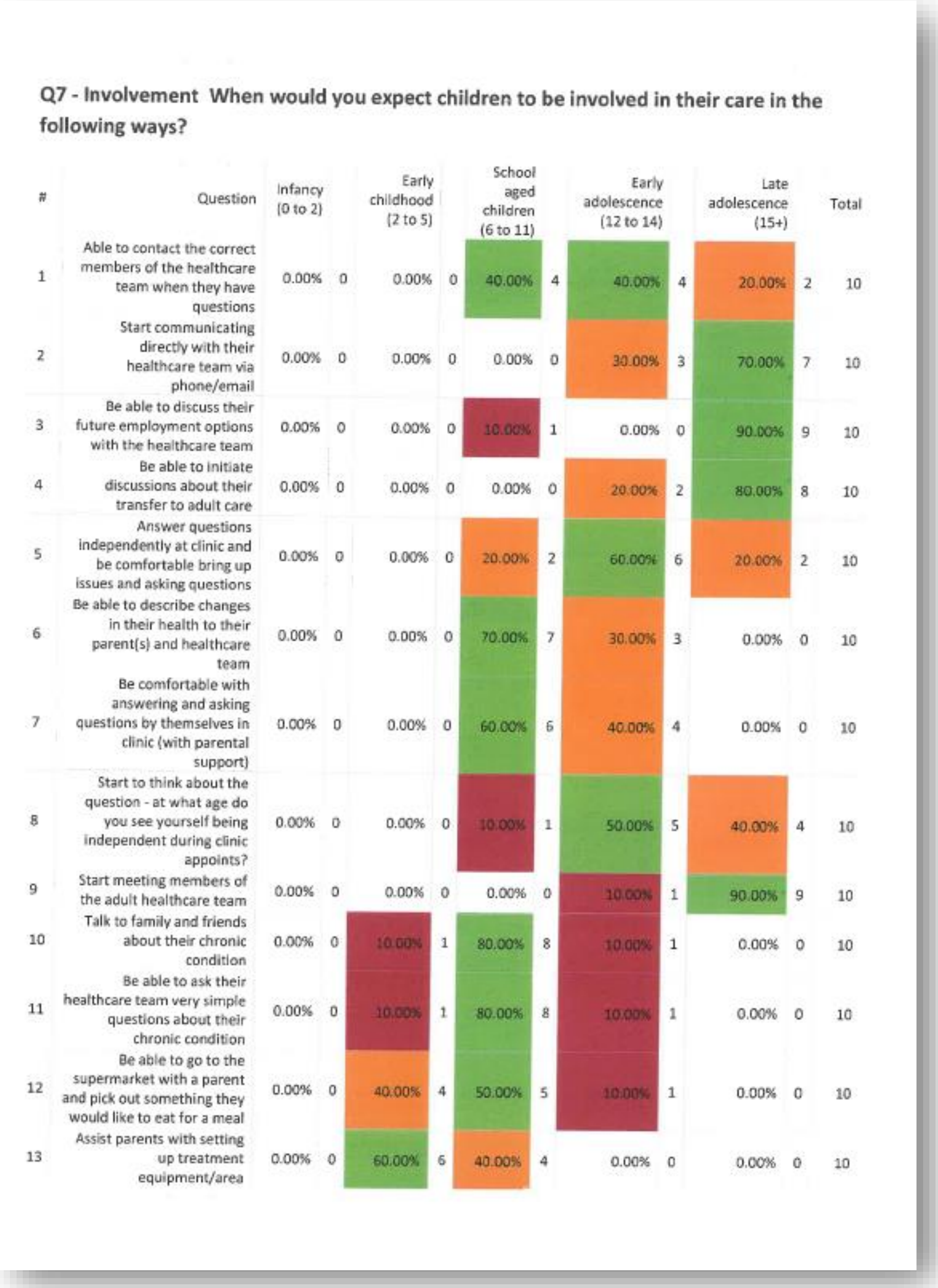
Adolescent is supervised by parent but is much more independent, parent becomes more of a consultant

Written information. Online games/apps. YouTube clips.

Ask if okay to examine them. Direct questions to them and then later obtain input from parents (would do this as a team in 12 - 14 year olds). Confirm they are okay with the plan

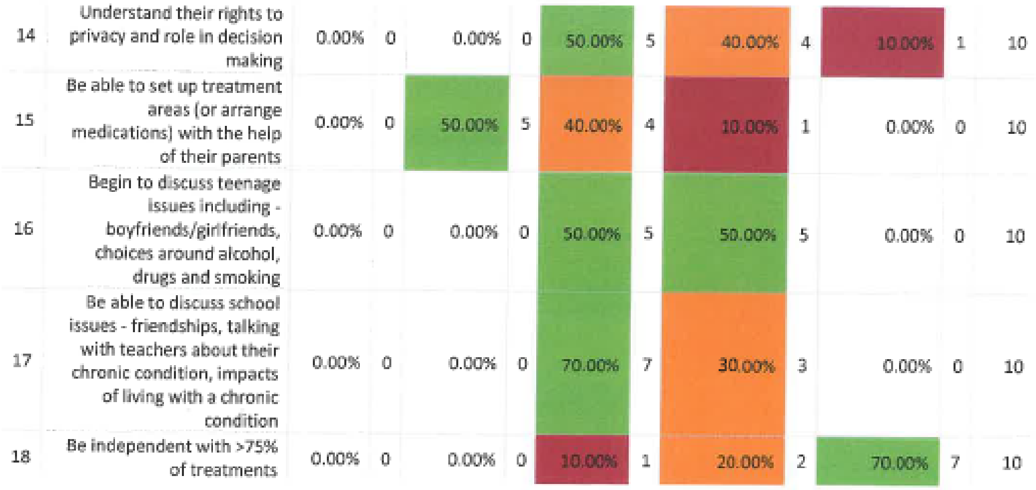
Involvement themes older adolescents:

Integrated learning n=2 (parents shifting from supervisor to consultant type role), enquiry based learning n=2 (see teen alone to engage them directly, ask permission to examine teen, confirm plans with teen directly, address complex tasks), increasing responsibility and independence n=3, active and experiential learning n=1 (hands on learning), interactive play n=3 (online resources/games, youtube clips)

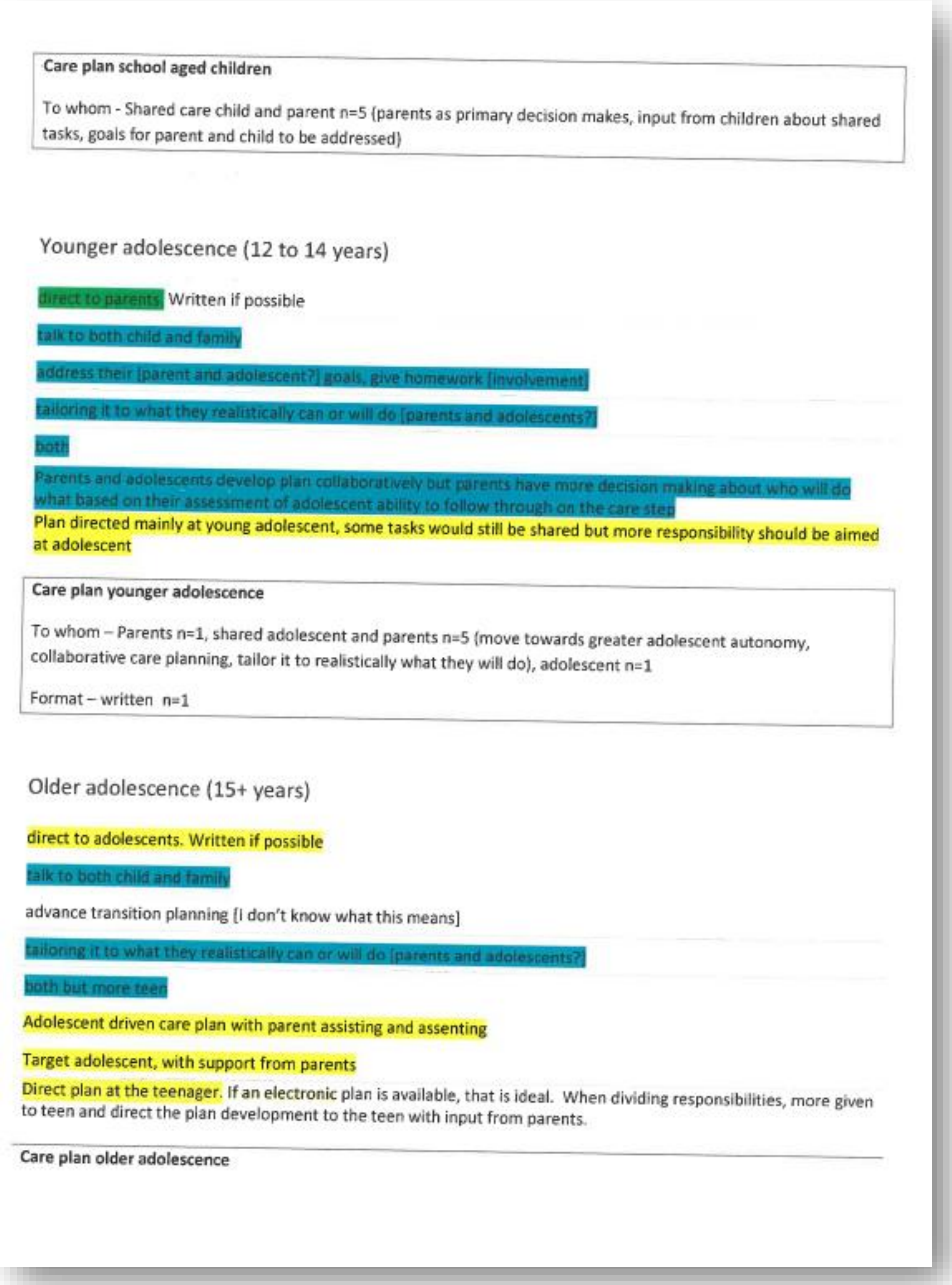


Q7 - Involvement When would you expect children to be involved in their care in the following ways?

#	Question	Infancy (0 to 2)		Early childhood (2 to 5)		School aged children (6 to 11)		Early adolescence (12 to 14)		Late adolescence (15+)		Total
1	Able to contact the correct members of the healthcare team when they have questions	0.00%	0	0.00%	0	40.00%	4	40.00%	4	20.00%	2	10
2	Start communicating directly with their healthcare team via phone/email	0.00%	0	0.00%	0	0.00%	0	30.00%	3	70.00%	7	10
3	Be able to discuss their future employment options with the healthcare team	0.00%	0	0.00%	0	10.00%	1	0.00%	0	90.00%	9	10
4	Be able to initiate discussions about their transfer to adult care	0.00%	0	0.00%	0	0.00%	0	20.00%	2	80.00%	8	10
5	Answer questions independently at clinic and be comfortable bring up issues and asking questions	0.00%	0	0.00%	0	20.00%	2	60.00%	6	20.00%	2	10
6	Be able to describe changes in their health to their parent(s) and healthcare team	0.00%	0	0.00%	0	70.00%	7	30.00%	3	0.00%	0	10
7	Be comfortable with answering and asking questions by themselves in clinic (with parental support)	0.00%	0	0.00%	0	60.00%	6	40.00%	4	0.00%	0	10
8	Start to think about the question - at what age do you see yourself being independent during clinic appoints?	0.00%	0	0.00%	0	10.00%	1	50.00%	5	40.00%	4	10
9	Start meeting members of the adult healthcare team	0.00%	0	0.00%	0	0.00%	0	10.00%	1	90.00%	9	10
10	Talk to family and friends about their chronic condition	0.00%	0	10.00%	1	80.00%	8	10.00%	1	0.00%	0	10
11	Be able to ask their healthcare team very simple questions about their chronic condition	0.00%	0	10.00%	1	80.00%	8	10.00%	1	0.00%	0	10
12	Be able to go to the supermarket with a parent and pick out something they would like to eat for a meal	0.00%	0	40.00%	4	50.00%	5	10.00%	1	0.00%	0	10
13	Assist parents with setting up treatment equipment/area	0.00%	0	60.00%	6	40.00%	4	0.00%	0	0.00%	0	10



14	Understand their rights to privacy and role in decision making	0.00%	0	0.00%	0	50.00%	5	40.00%	4	10.00%	1	10
15	Be able to set up treatment areas (or arrange medications) with the help of their parents	0.00%	0	50.00%	5	40.00%	4	10.00%	1	0.00%	0	10
16	Begin to discuss teenage issues including - boyfriends/girlfriends, choices around alcohol, drugs and smoking	0.00%	0	0.00%	0	50.00%	5	50.00%	5	0.00%	0	10
17	Be able to discuss school issues - friendships, talking with teachers about their chronic condition, impacts of living with a chronic condition	0.00%	0	0.00%	0	70.00%	7	30.00%	3	0.00%	0	10
18	Be independent with >75% of treatments	0.00%	0	0.00%	0	10.00%	1	20.00%	2	70.00%	7	10



Care plan school aged children

To whom - Shared care child and parent n=5 (parents as primary decision makes, input from children about shared tasks, goals for parent and child to be addressed)

Younger adolescence (12 to 14 years)

direct to parents. Written if possible

talk to both child and family

address their [parent and adolescent?] goals, give homework [involvement]

tailoring it to what they realistically can or will do [parents and adolescents?]

both

Parents and adolescents develop plan collaboratively but parents have more decision making about who will do what based on their assessment of adolescent ability to follow through on the care step
Plan directed mainly at young adolescent, some tasks would still be shared but more responsibility should be aimed at adolescent

Care plan younger adolescence

To whom – Parents n=1, shared adolescent and parents n=5 (move towards greater adolescent autonomy, collaborative care planning, tailor it to realistically what they will do), adolescent n=1

Format – written n=1

Older adolescence (15+ years)

direct to adolescents. Written if possible

talk to both child and family

advance transition planning [I don't know what this means]

tailoring it to what they realistically can or will do [parents and adolescents?]

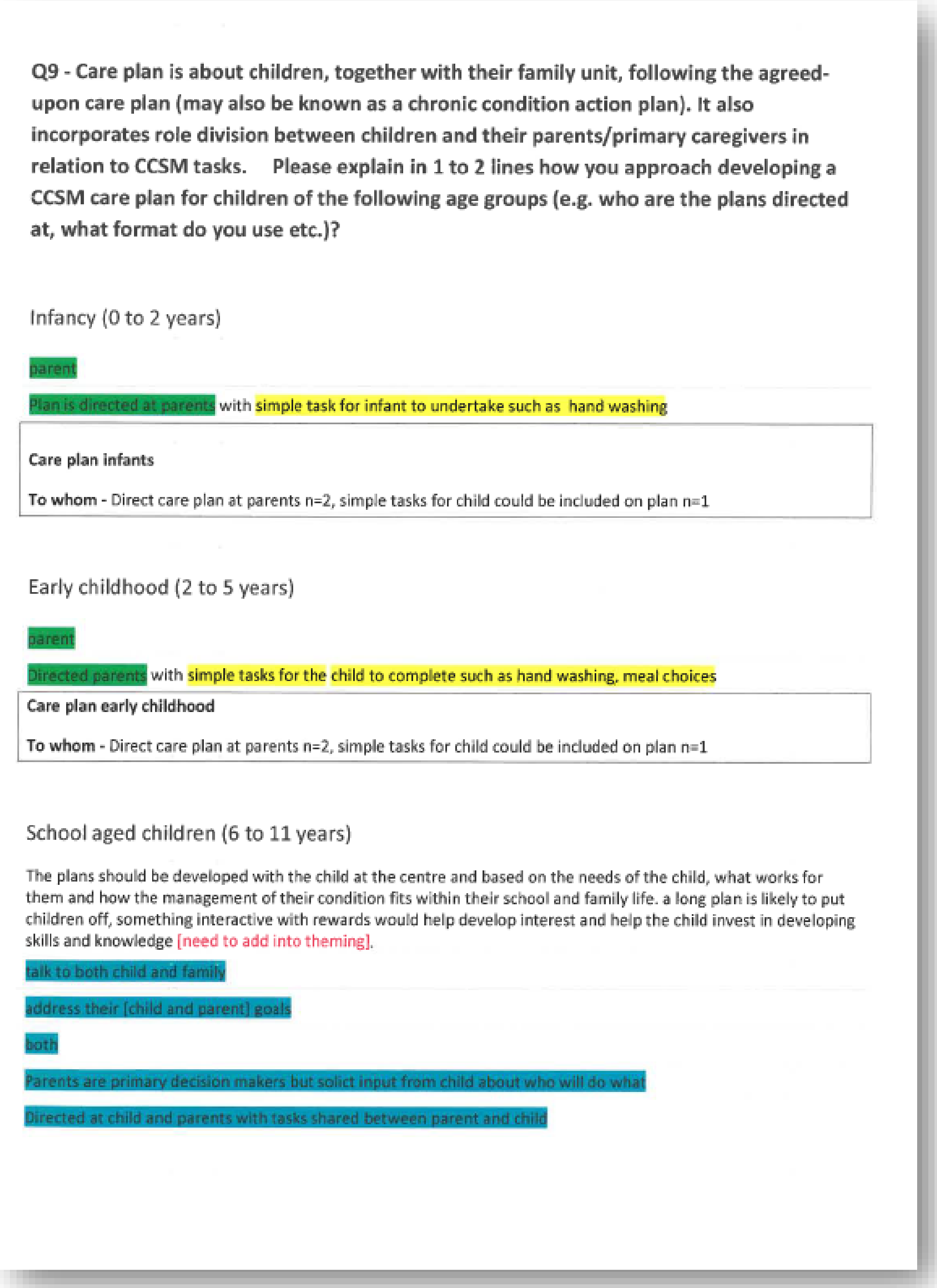
both but more teen

Adolescent driven care plan with parent assisting and assenting

Target adolescent, with support from parents

Direct plan at the teenager. If an electronic plan is available, that is ideal. When dividing responsibilities, more given to teen and direct the plan development to the teen with input from parents.

Care plan older adolescence



Q9 - Care plan is about children, together with their family unit, following the agreed-upon care plan (may also be known as a chronic condition action plan). It also incorporates role division between children and their parents/primary caregivers in relation to CCSM tasks. Please explain in 1 to 2 lines how you approach developing a CCSM care plan for children of the following age groups (e.g. who are the plans directed at, what format do you use etc.)?

Infancy (0 to 2 years)

parent

Plan is directed at parents with simple task for infant to undertake such as hand washing

Care plan infants

To whom - Direct care plan at parents n=2, simple tasks for child could be included on plan n=1

Early childhood (2 to 5 years)

parent

Directed parents with simple tasks for the child to complete such as hand washing, meal choices

Care plan early childhood

To whom - Direct care plan at parents n=2, simple tasks for child could be included on plan n=1

School aged children (6 to 11 years)

The plans should be developed with the child at the centre and based on the needs of the child, what works for them and how the management of their condition fits within their school and family life. a long plan is likely to put children off, something interactive with rewards would help develop interest and help the child invest in developing skills and knowledge [need to add into theming].

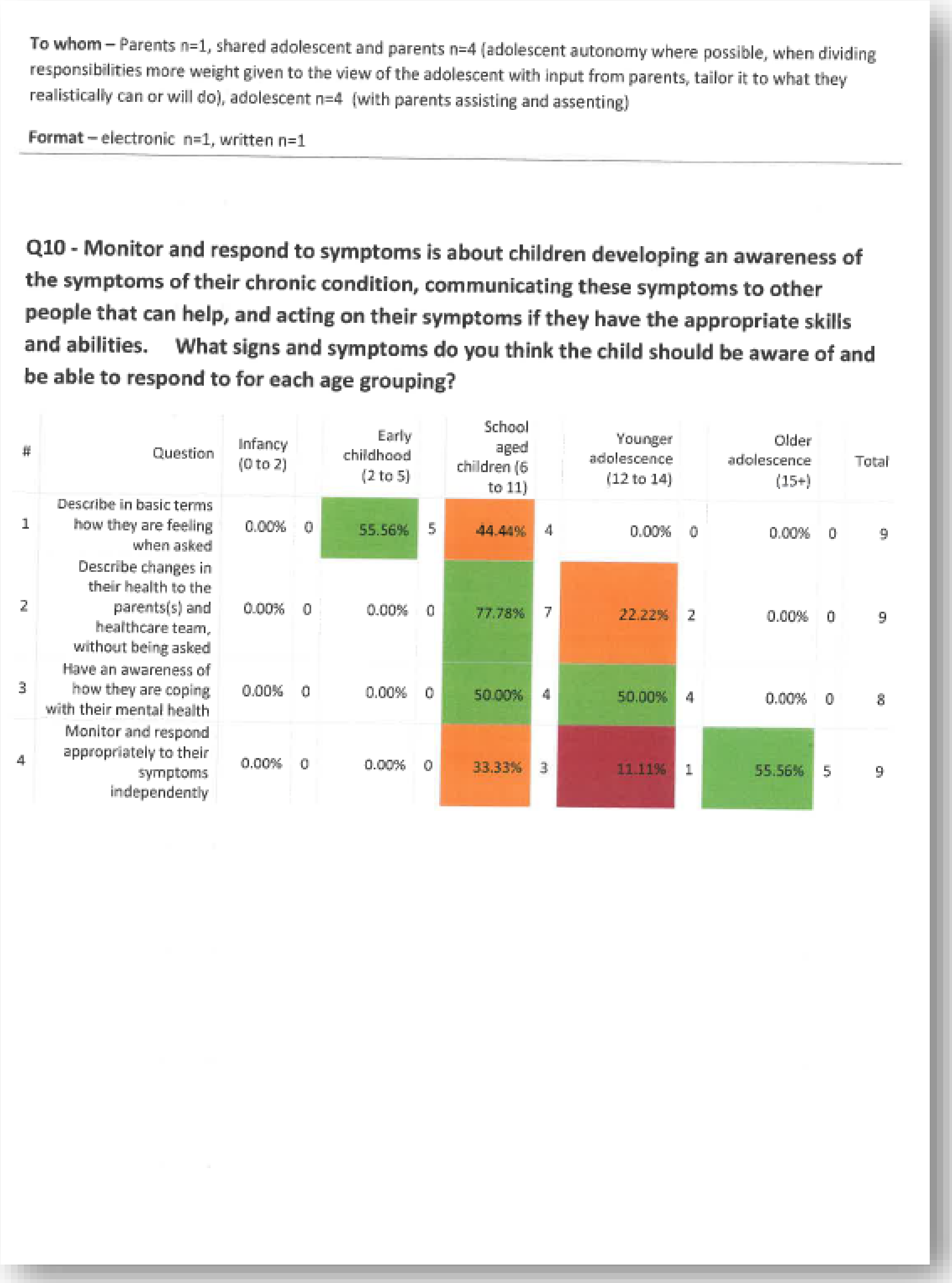
talk to both child and family

address their [child and parent] goals

both

Parents are primary decision makers but solict input from child about who will do what

Directed at child and parents with tasks shared between parent and child

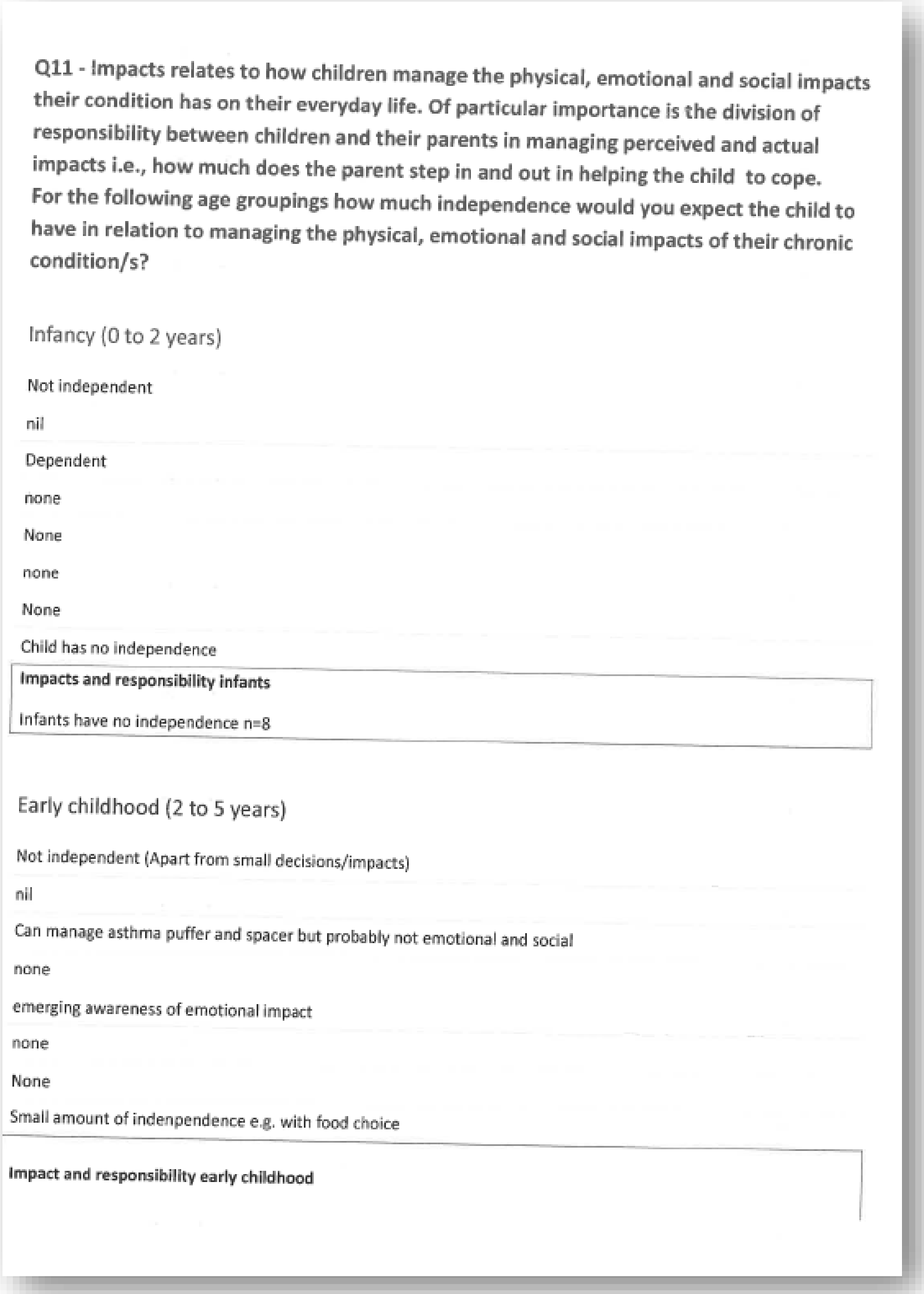


To whom – Parents n=1, shared adolescent and parents n=4 (adolescent autonomy where possible, when dividing responsibilities more weight given to the view of the adolescent with input from parents, tailor it to what they realistically can or will do), adolescent n=4 (with parents assisting and assenting)

Format – electronic n=1, written n=1

Q10 - Monitor and respond to symptoms is about children developing an awareness of the symptoms of their chronic condition, communicating these symptoms to other people that can help, and acting on their symptoms if they have the appropriate skills and abilities. What signs and symptoms do you think the child should be aware of and be able to respond to for each age grouping?

#	Question	Infancy (0 to 2)		Early childhood (2 to 5)		School aged children (6 to 11)		Younger adolescence (12 to 14)		Older adolescence (15+)		Total
1	Describe in basic terms how they are feeling when asked	0.00%	0	55.56%	5	44.44%	4	0.00%	0	0.00%	0	9
2	Describe changes in their health to the parents(s) and healthcare team, without being asked	0.00%	0	0.00%	0	77.78%	7	22.22%	2	0.00%	0	9
3	Have an awareness of how they are coping with their mental health	0.00%	0	0.00%	0	50.00%	4	50.00%	4	0.00%	0	8
4	Monitor and respond appropriately to their symptoms independently	0.00%	0	0.00%	0	33.33%	3	11.11%	1	55.56%	5	9



Q11 - Impacts relates to how children manage the physical, emotional and social impacts their condition has on their everyday life. Of particular importance is the division of responsibility between children and their parents in managing perceived and actual impacts i.e., how much does the parent step in and out in helping the child to cope. For the following age groupings how much independence would you expect the child to have in relation to managing the physical, emotional and social impacts of their chronic condition/s?

Infancy (0 to 2 years)

Not independent

nil

Dependent

none

None

none

None

Child has no independence

Impacts and responsibility infants

Infants have no independence n=8

Early childhood (2 to 5 years)

Not independent (Apart from small decisions/impacts)

nil

Can manage asthma puffer and spacer but probably not emotional and social

none

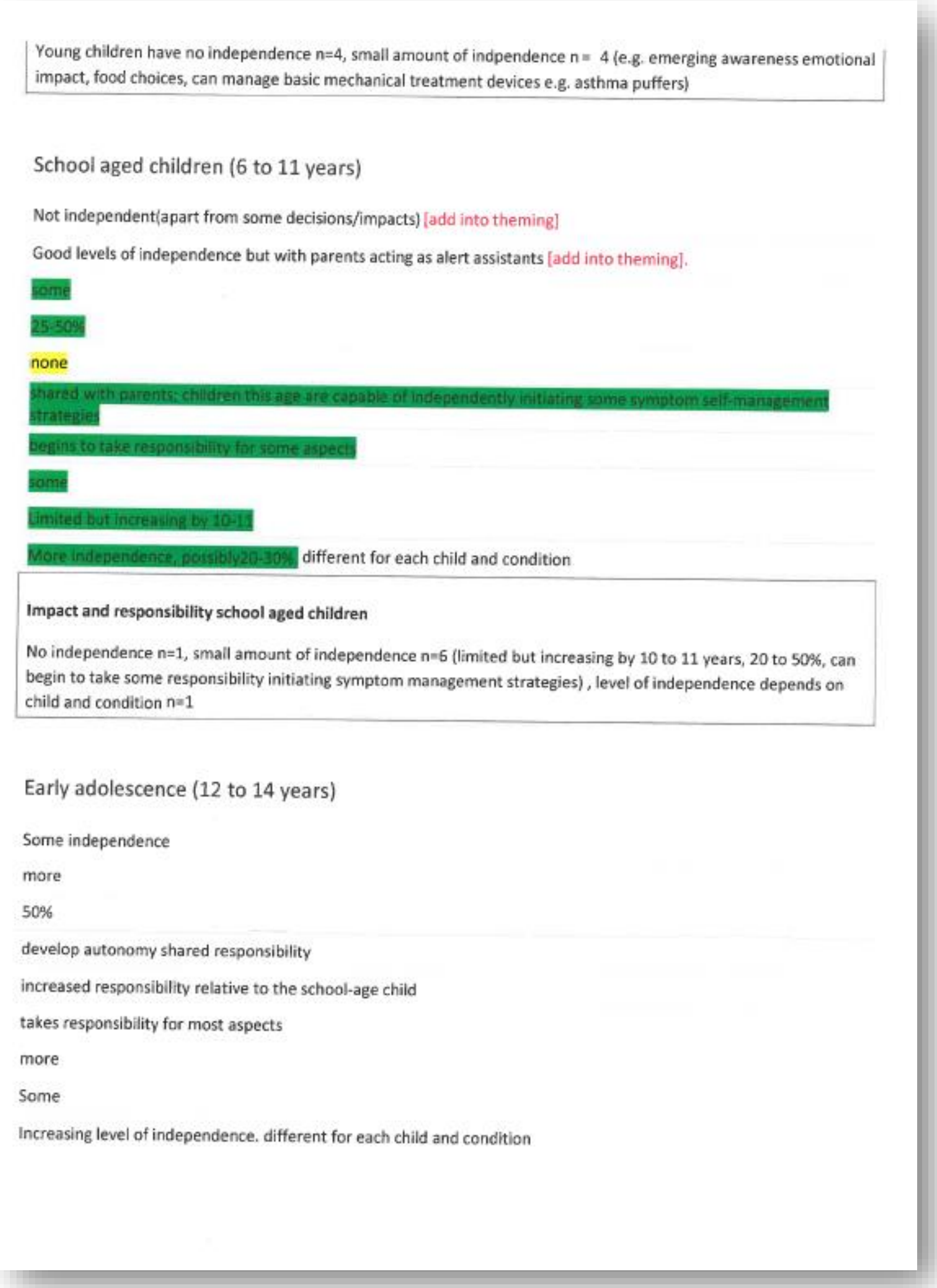
emerging awareness of emotional impact

none

None

Small amount of indenpendence e.g. with food choice

Impact and responsibility early childhood



Young children have no independence n=4, small amount of indpendence n = 4 (e.g. emerging awareness emotional impact, food choices, can manage basic mechanical treatment devices e.g. asthma puffers)

School aged children (6 to 11 years)

Not independent(apart from some decisions/impacts) [add into theming]

Good levels of independence but with parents acting as alert assistants [add into theming].

some

25-50%

none

shared with parents; children this age are capable of independently initiating some symptom self-management strategies

begins to take responsibility for some aspects

some

Limited but increasing by 10-11

More independence, possibly20-30% different for each child and condition

Impact and responsibility school aged children

No independence n=1, small amount of independence n=6 (limited but increasing by 10 to 11 years, 20 to 50%, can begin to take some responsibility initiating symptom management strategies) , level of independence depends on child and condition n=1

Early adolescence (12 to 14 years)

Some independence

more

50%

develop autonomy shared responsibility

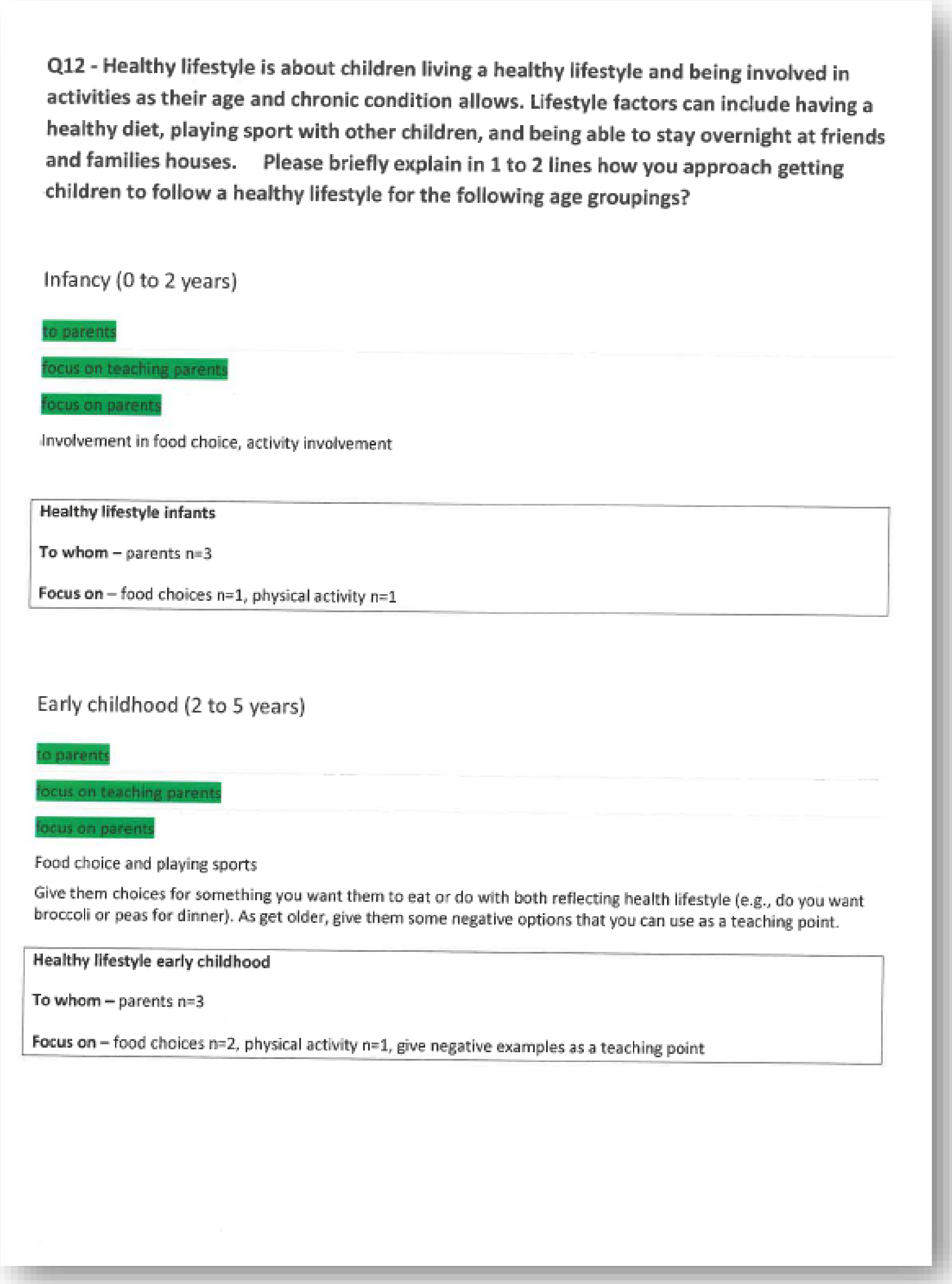
increased responsibility relative to the school-age child

takes responsibility for most aspects

more

Some

Increasing level of independence. different for each child and condition



Q12 - Healthy lifestyle is about children living a healthy lifestyle and being involved in activities as their age and chronic condition allows. Lifestyle factors can include having a healthy diet, playing sport with other children, and being able to stay overnight at friends and families houses. Please briefly explain in 1 to 2 lines how you approach getting children to follow a healthy lifestyle for the following age groupings?

Infancy (0 to 2 years)

to parents

focus on teaching parents

focus on parents

Involvement in food choice, activity involvement

Healthy lifestyle infants

To whom – parents n=3

Focus on – food choices n=1, physical activity n=1

Early childhood (2 to 5 years)

to parents

focus on teaching parents

focus on parents

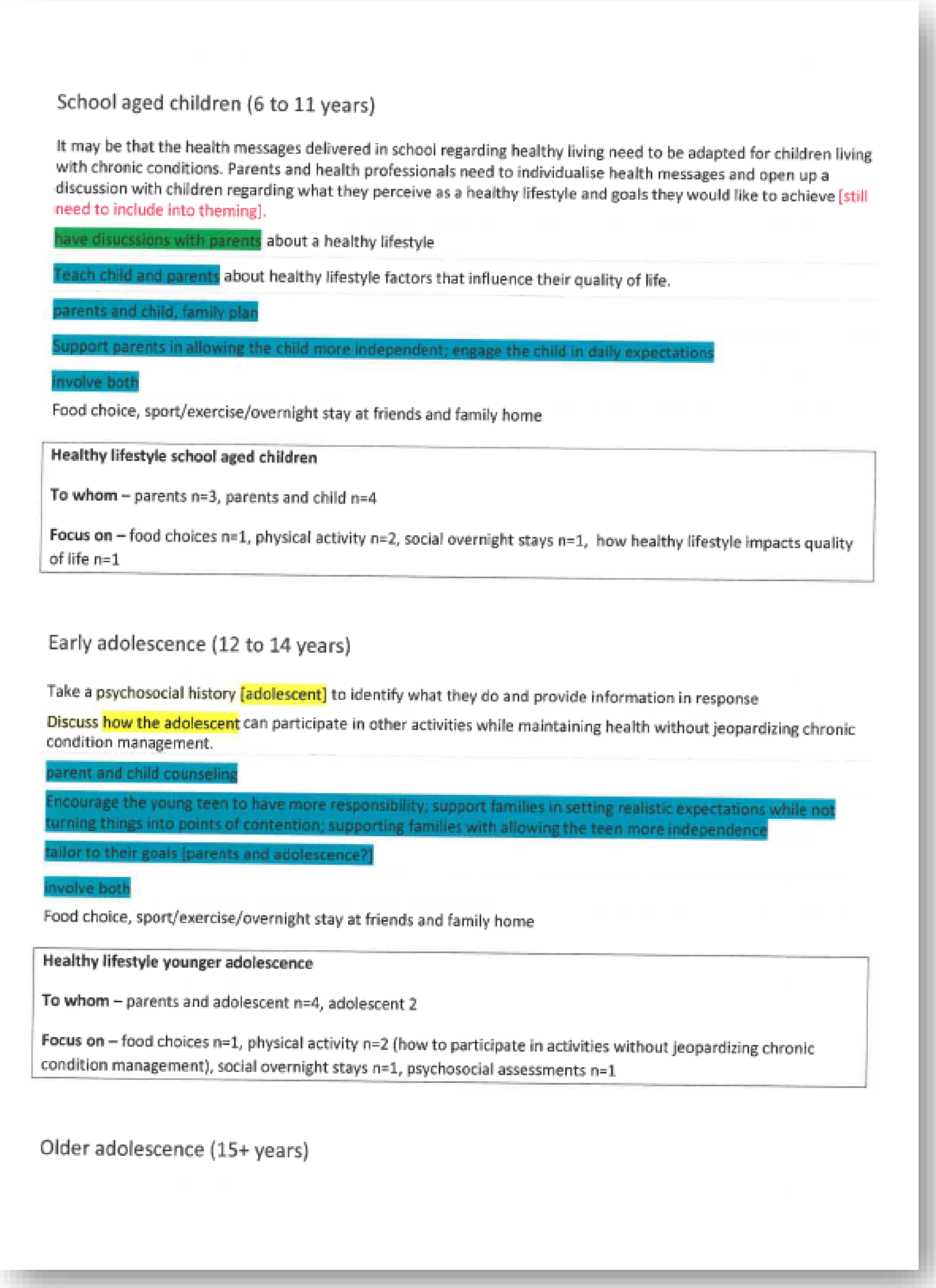
Food choice and playing sports

Give them choices for something you want them to eat or do with both reflecting health lifestyle (e.g., do you want broccoli or peas for dinner). As get older, give them some negative options that you can use as a teaching point.

Healthy lifestyle early childhood

To whom – parents n=3

Focus on – food choices n=2, physical activity n=1, give negative examples as a teaching point



School aged children (6 to 11 years)

It may be that the health messages delivered in school regarding healthy living need to be adapted for children living with chronic conditions. Parents and health professionals need to individualise health messages and open up a discussion with children regarding what they perceive as a healthy lifestyle and goals they would like to achieve [still need to include into theming].

have disucssions with parents about a healthy lifestyle

Teach child and parents about healthy lifestyle factors that influence their quality of life.

parents and child, family plan

Support parents in allowing the child more independent; engage the child in daily expectations

involve both

Food choice, sport/exercise/overnight stay at friends and family home

Healthy lifestyle school aged children

To whom – parents n=3, parents and child n=4

Focus on – food choices n=1, physical activity n=2, social overnight stays n=1, how healthy lifestyle impacts quality of life n=1

Early adolescence (12 to 14 years)

Take a psychosocial history [adolescent] to identify what they do and provide information in response

Discuss how the adolescent can participate in other activities while maintaining health without jeopardizing chronic condition management.

parent and child counseling

Encourage the young teen to have more responsibility; support families in setting realistic expectations while not turning things into points of contention; supporting families with allowing the teen more independence

tailor to their goals [parents and adolescence?]

involve both

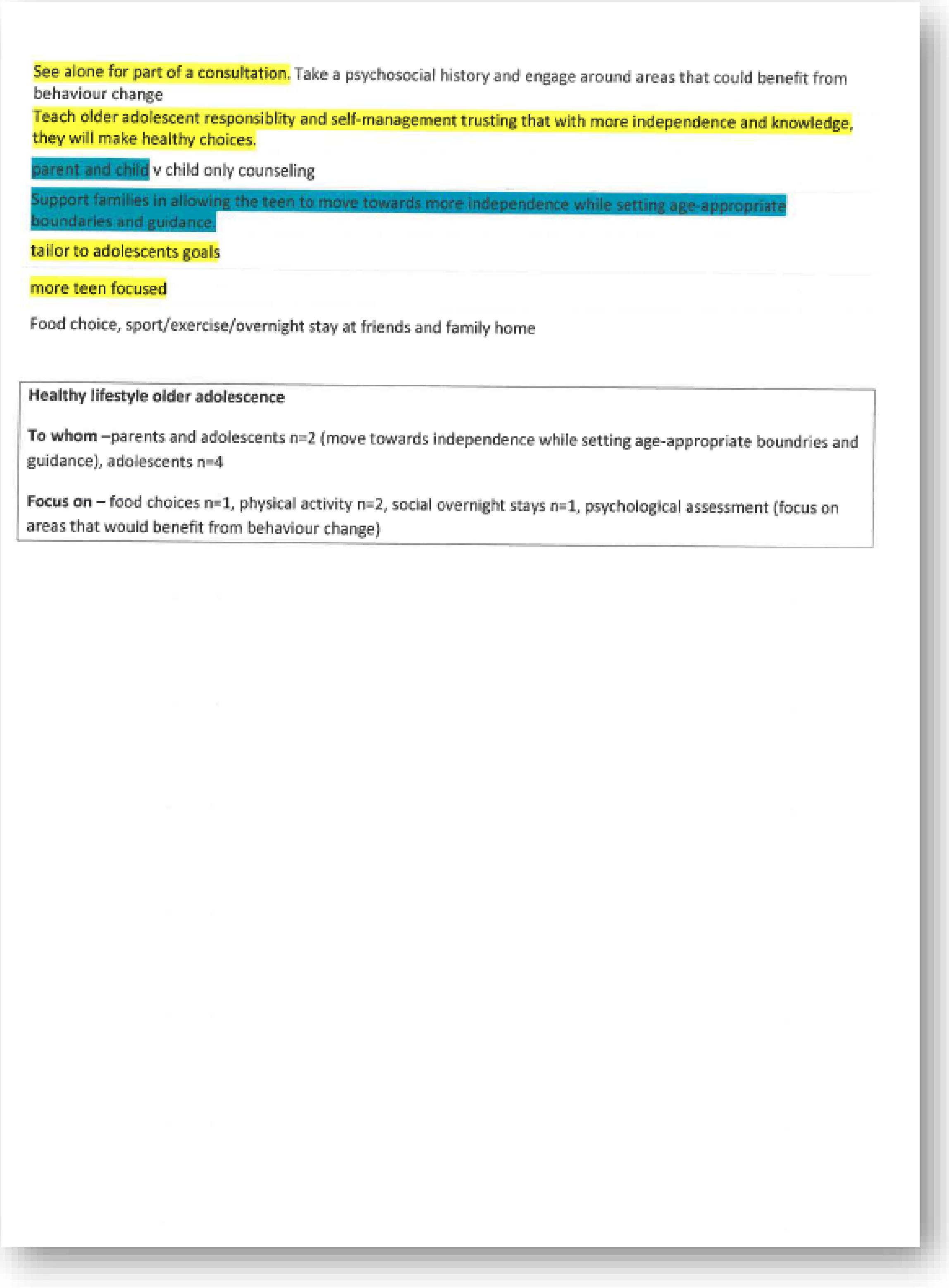
Food choice, sport/exercise/overnight stay at friends and family home

Healthy lifestyle younger adolescence

To whom – parents and adolescent n=4, adolescent 2

Focus on – food choices n=1, physical activity n=2 (how to participate in activities without jeopardizing chronic condition management), social overnight stays n=1, psychosocial assessments n=1

Older adolescence (15+ years)



See alone for part of a consultation. Take a psychosocial history and engage around areas that could benefit from behaviour change

Teach older adolescent responsiblity and self-management trusting that with more independence and knowledge, they will make healthy choices.

parent and child v child only counseling

Support families in allowing the teen to move towards more independence while setting age-appropriate boundaries and guidance.

tailor to adolescents goals

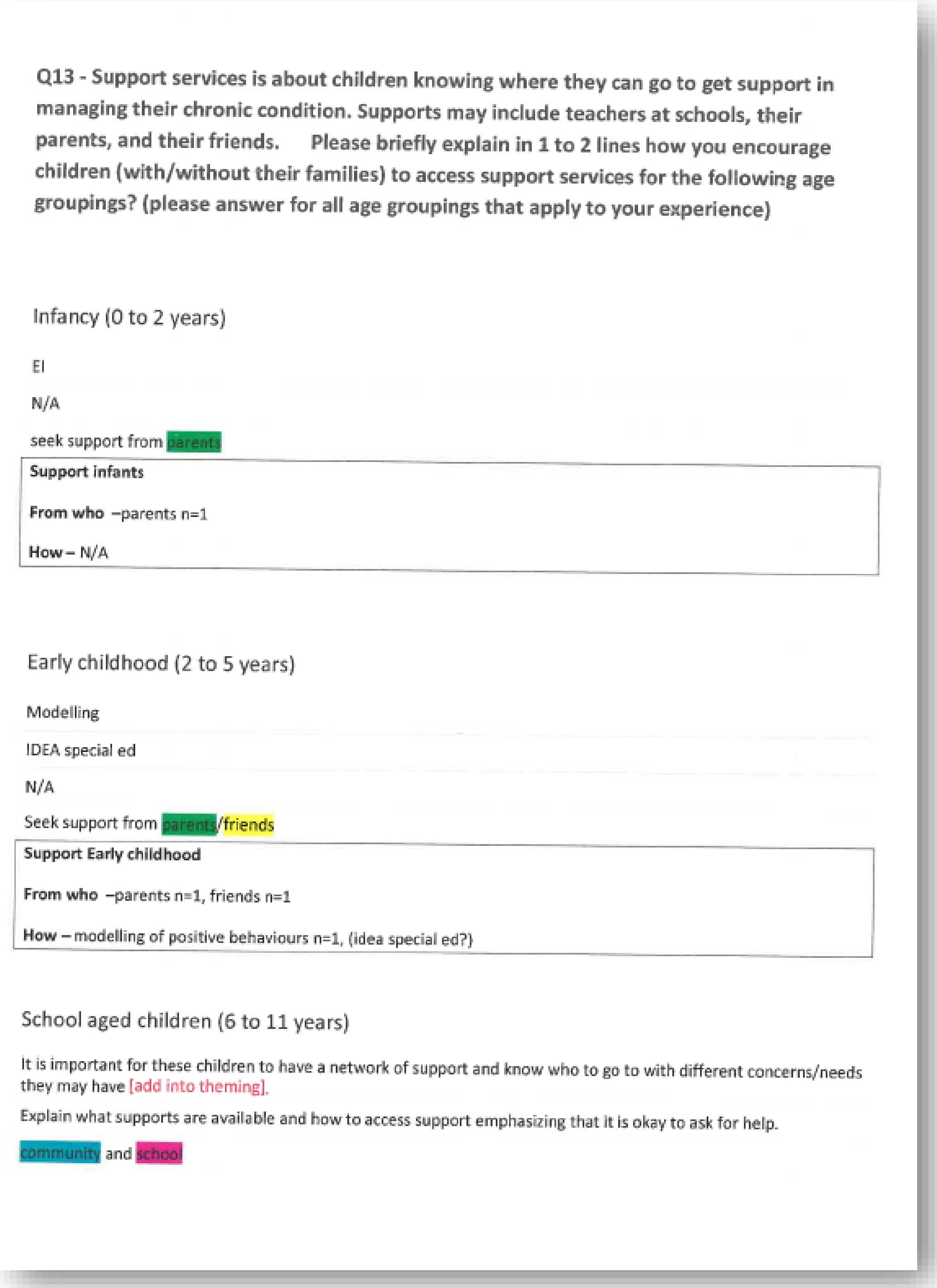
more teen focused

Food choice, sport/exercise/overnight stay at friends and family home

Healthy lifestyle older adolescence

To whom –parents and adolescents n=2 (move towards independence while setting age-appropriate boundries and guidance), adolescents n=4

Focus on – food choices n=1, physical activity n=2, social overnight stays n=1, psychological assessment (focus on areas that would benefit from behaviour change)



Q13 - Support services is about children knowing where they can go to get support in managing their chronic condition. Supports may include teachers at schools, their parents, and their friends. Please briefly explain in 1 to 2 lines how you encourage children (with/without their families) to access support services for the following age groupings? (please answer for all age groupings that apply to your experience)

Infancy (0 to 2 years)

EI

N/A

seek support from parents

Support infants

From who –parents n=1

How – N/A

Early childhood (2 to 5 years)

Modelling

IDEA special ed

N/A

Seek support from parents/friends

Support Early childhood

From who –parents n=1, friends n=1

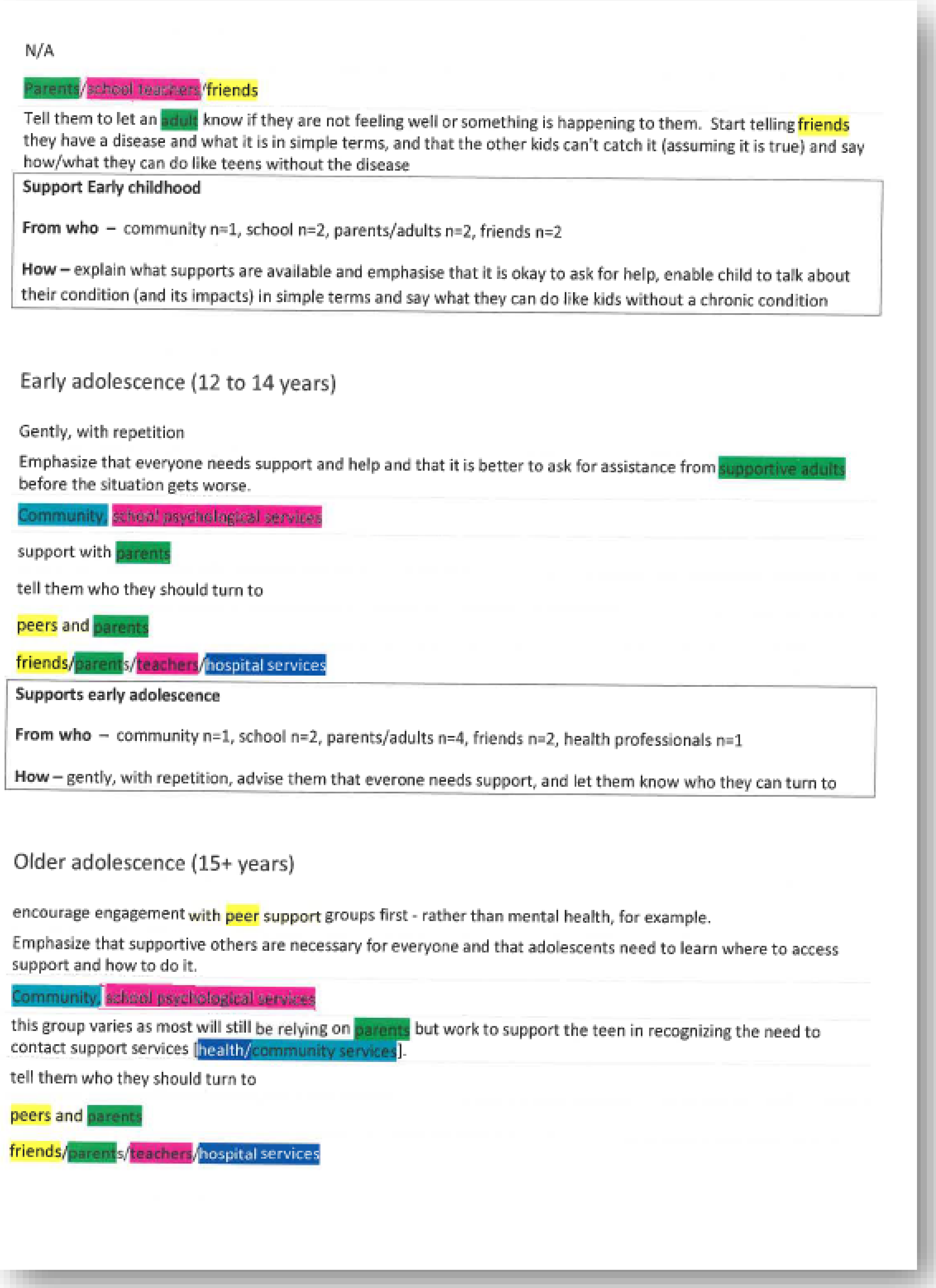
How – modelling of positive behaviours n=1, (idea special ed?)

School aged children (6 to 11 years)

It is important for these children to have a network of support and know who to go to with different concerns/needs they may have [add into theming].

Explain what supports are available and how to access support emphasizing that it is okay to ask for help.

community and school



N/A

Parents/school teachers/friends

Tell them to let an adult know if they are not feeling well or something is happening to them. Start telling friends they have a disease and what it is in simple terms, and that the other kids can't catch it (assuming it is true) and say how/what they can do like teens without the disease

Support Early childhood

From who – community n=1, school n=2, parents/adults n=2, friends n=2

How – explain what supports are available and emphasise that it is okay to ask for help, enable child to talk about their condition (and its impacts) in simple terms and say what they can do like kids without a chronic condition

Early adolescence (12 to 14 years)

Gently, with repetition

Emphasize that everyone needs support and help and that it is better to ask for assistance from supportive adults before the situation gets worse.

Community, school psychological services

support with parents

tell them who they should turn to

peers and parents

friends/parents/teachers/hospital services

Supports early adolescence

From who – community n=1, school n=2, parents/adults n=4, friends n=2, health professionals n=1

How – gently, with repetition, advise them that everone needs support, and let them know who they can turn to

Older adolescence (15+ years)

encourage engagement with peer support groups first - rather than mental health, for example.

Emphasize that supportive others are necessary for everyone and that adolescents need to learn where to access support and how to do it.

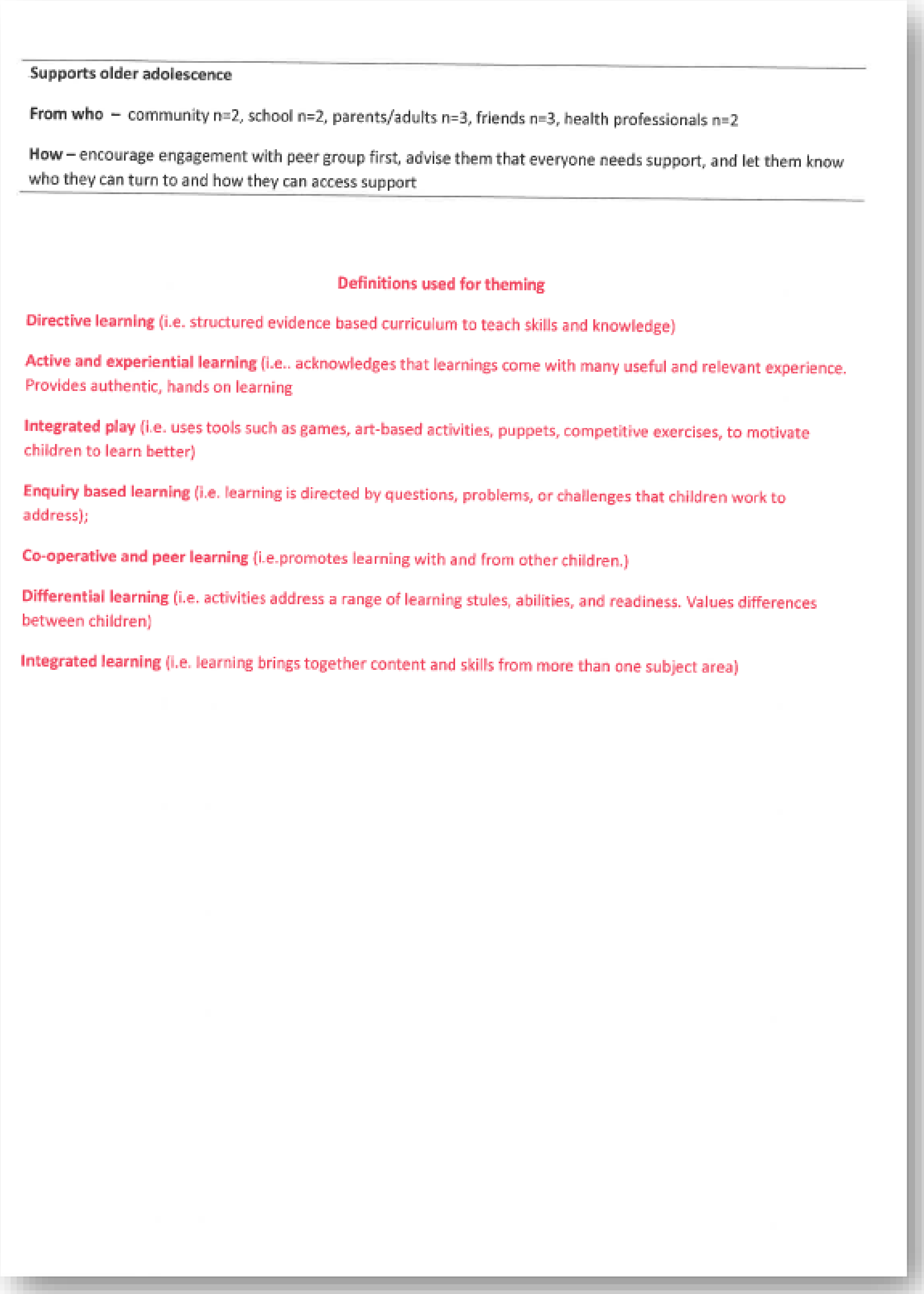
Community, school psychological services

this group varies as most will still be relying on parents but work to support the teen in recognizing the need to contact support services [health/community services].

tell them who they should turn to

peers and parents

friends/parents/teachers/hospital services



Supports older adolescence

From who – community n=2, school n=2, parents/adults n=3, friends n=3, health professionals n=2

How – encourage engagement with peer group first, advise them that everyone needs support, and let them know who they can turn to and how they can access support

Definitions used for theming

Directive learning (i.e. structured evidence based curriculum to teach skills and knowledge)

Active and experiential learning (i.e.. acknowledges that learnings come with many useful and relevant experience. Provides authentic, hands on learning

Integrated play (i.e. uses tools such as games, art-based activities, puppets, competitive exercises, to motivate children to learn better)

Enquiry based learning (i.e. learning is directed by questions, problems, or challenges that children work to address);

Co-operative and peer learning (i.e.promotes learning with and from other children.)

Differential learning (i.e. activities address a range of learning stules, abilities, and readiness. Values differences between children)

Integrated learning (i.e. learning brings together content and skills from more than one subject area)

5G) Publication

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Developmentally appropriate supported self-management for children and young people with chronic conditions: A consensus

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A B S T R A C T

Objective/s: To create a consensus list of self-management definitions, recommendations, and endpoints for children and young people (0–20 years) with chronic conditions.
Methods: This study used a Delphi technique. Based on the number of relevant peer-reviewed publications, clinical academics were invited to participate in three survey rounds. Round one contained open-ended and multiple-choice questions eliciting general opinions on self-management. For round two, results were provided to the interdisciplinary expert panel as statements for rating their agreement using a 7-point Likert scale, with consensus predefined as moderately or extremely satisfied by ≥70% of participants. Statements not meeting consensus were re-presented in round three, with group feedback incorporated. Finalised statements informed creation of the 'Partners in Health: Self-Management Consensus List for Children and Young People'.
Results: Sixteen clinical academics participated; 12 completed round one; 14 completed round two; and 12 completed round three. Of 101 statements, 90 reached consensus, with statements separated into five developmentally appropriate groups. Statements covered broad self-management and self-management support domains including knowledge, involvement, monitoring/responding to symptoms, transition, impact, lifestyle, and support. Division of responsibility and autonomy were distinct themes.
Conclusion and practice implications: This research provides consensus-based guidance for clinicians providing paediatric self-management support.

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1. Introduction

Worldwide, chronic conditions affect the everyday lives of somewhere between 15–40% of people from birth to 20 years [1,2]. Chronic conditions (i.e., those lasting 6 months or more) in children and young people can develop at any time; and may be the result of genetic conditions, and/or environmental factors [3,4]. Common chronic conditions include asthma, cystic fibrosis, and diabetes [3]. Whilst these conditions differ in terms of severity and complexity of treatment regimens, they all require daily management and monitoring (i.e. self-management) [5].

'Supported self-management' that is developmentally appropriate is the key concept in this study. For children and young people "supported self-management" is an appropriate delineation from the more familiar concept of self-management which implies that an individual manages their chronic condition themselves. Children, especially infants and very young children, cannot self-manage alone. They are on a trajectory of developing self-management skills. As stated by Lozano and Houtrow [6] "*children depend on parents and caregivers for some or all of their care so paediatric care nearly always involves >1 agent of self-management*". This is a view widely supported in the literature [5,7–9].

Childhood development encompasses five main areas of development including cognitive, motor, language, social and emotional skills [10]. By its very nature, childhood development is a fluid concept; it adapts to changing conditions and experiences over time [10]. Thus, at any point in time, a child's/young person's capacity to self-manage is evolving [6].

Paediatric best-practice guidelines recommend that self-management support be provided in a developmentally appropriate way; however, these guidelines provide little practical detail about how to operationalise such an approach with children and

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young people [11]. A recent systematic review completed by our research group showed that developmentally appropriate self-management education interventions targeted at children and young people with asthma, cystic fibrosis and diabetes result in many positive health outcomes [12]. More specifically, developmentally appropriate chronic condition self-management education interventions lead to improvements in children and young people's: chronic condition self-management skills, abilities, and behaviours [13–18]; chronic condition knowledge [13,19–21] cooperation/communication [14–16,22]; ability to share in decision making [15,16,22]; self-efficacy [13,15,18,23,24], and in quality of life [18,19]. Teaching developmentally appropriate self-management skills may also help to improve the young person's transition from paediatric to adult health care settings [25].

This Delphi study fills a gap in previous literature and knowledge by focusing on and detailing the developmental aspects of teaching and support approaches delivered to children and young people to support their chronic condition self-management. Currently, developmentally appropriate recommendations about 'supported self-management' and divisions of self-management responsibility between children/young people and their families are scarce and are usually limited by a focus on a specific chronic condition. Furthermore, there a lack of evidence to guide tailoring chronic condition self-management support approaches to different developmental stages [6]. Practical tools are needed to guide clinicians to provide developmentally appropriate self-management support. In the current study, the Delphi technique was used to draw on the practical experience and expertise needed to guide the development of a practical tool for use in this field.

Originally developed in the 1950s to forecast new technologies, the Delphi technique is a validated method of gathering data from experts in their field of expertise [26,27]. There are many examples of the Delphi technique being used in the healthcare literature to gain consensus and provide consensus-based practice recommendations [28–30]. As children's and young people's self-management is a relatively small and emerging research area (particularly from a developmental perspective), prior to commencing this study it was anticipated that recruitment of appropriate experts would be challenging and that expert panel numbers would be small. Delphi expert panel sizes are known to range from four to over 1000 participants [26,31], with Lindstone et al. suggesting that seven participants is the minimum panel size to conduct a successful Delphi study [32].

The Delphi technique was chosen for this study because: 1) it allowed easy access to international experts; 2) it was inexpensive to conduct the research due to its internet-based nature; and, 3) experts were able to stay anonymous to each other [26,27]. Other methods commonly used to achieve consensus (e.g. consensus development conferences) were not feasible due to the international nature of this study [26,27].

1.1. Aims and objectives

The aims of this Delphi study were to define 'supported self-management' for children and young people with chronic conditions, and to create a consensus list of developmentally appropriate self-management tasks that can be completed by children and young people, and self-management support practices for clinicians.

2. Material and methods

2.1. Expert panel selection

Clinical academics from around the world with backgrounds in medicine, nursing, allied-health including developmental/paediatric psychology, or teaching were invited to be part of the expert panel. Clinical academics are important as they offer a bridge between research and practice. Experts were initially identified in a Medline search as authors with the highest number of peer reviewed publications specifically related to children's/young people's self-management from a developmental perspective. Conflict of interest declarations were reviewed by the first author prior to confirming inclusion of experts. No honoraria were paid to experts for their participation. Experts were also invited to suggest additional potential experts.

Participants were included as experts if they met the following criteria: had authored two or more relevant peer-reviewed papers (first, second or last author published within the last 10 years), held related postgraduate qualifications; and, were recognised as an expert in the field by peers (e.g. invitation to participate in a relevant symposium, focus group, conference or another event). Participants were excluded if they had insufficient experience, did not consider themselves to be experts, had an identified conflict of interest, or were unable to commit enough time to complete the Delphi process.

2.2. Developmental stages

According to the 1989 United Nations Convention on the Rights of the Child, childhood spans the ages of birth through to 18 years [33]. In clinical practice, however, childhood can range from birth to the time point at which children/young people are transferred to adult care which is usually around the age of 20 years [34]. For this study, children and young people from birth to 20 years were included and were further classified into five distinct stages:

- Infancy - birth to two years;
- Early childhood - ages two to five years;
- Middle childhood - ages six to 11 years;
- Younger adolescence - ages 12–14 years; and,
- Older adolescence - ages 15–20 years.

These developmental stages broadly align with Piaget's theory of cognitive development; with adolescents being further classified into younger and older adolescent groups [34].

2.3. Definition of consensus and statistical analysis

Expert consensus was pre-defined as rating *moderately* or *extremely satisfied* by at least 70% [35,36].

Descriptive statistics were calculated for each statement presented in the Delphi. Using Microsoft Excel for Macintosh [37] for the quantitative analysis, Likert scale responses were coded numerically as: *extremely dissatisfied* = 1, *moderately dissatisfied* = 2, *slightly dissatisfied* = 3, *neither satisfied nor dissatisfied* = 4, *slightly satisfied* = 5, *moderately satisfied* = 6, *extremely satisfied* = 7. Statistics are presented as: round, consensus%, median, mean and SD. Likert scale equivalents in words have been included for mean and median values.

2.4. Enhancing response rates

To prevent participant fatigue, the expert panel had 10 days to complete each Delphi round. After seven days, participants were sent a friendly reminder or a thank you email.

2.5. Data collection

It was forecast that three to four Delphi rounds would be required. At the end of Delphi round three, the research team

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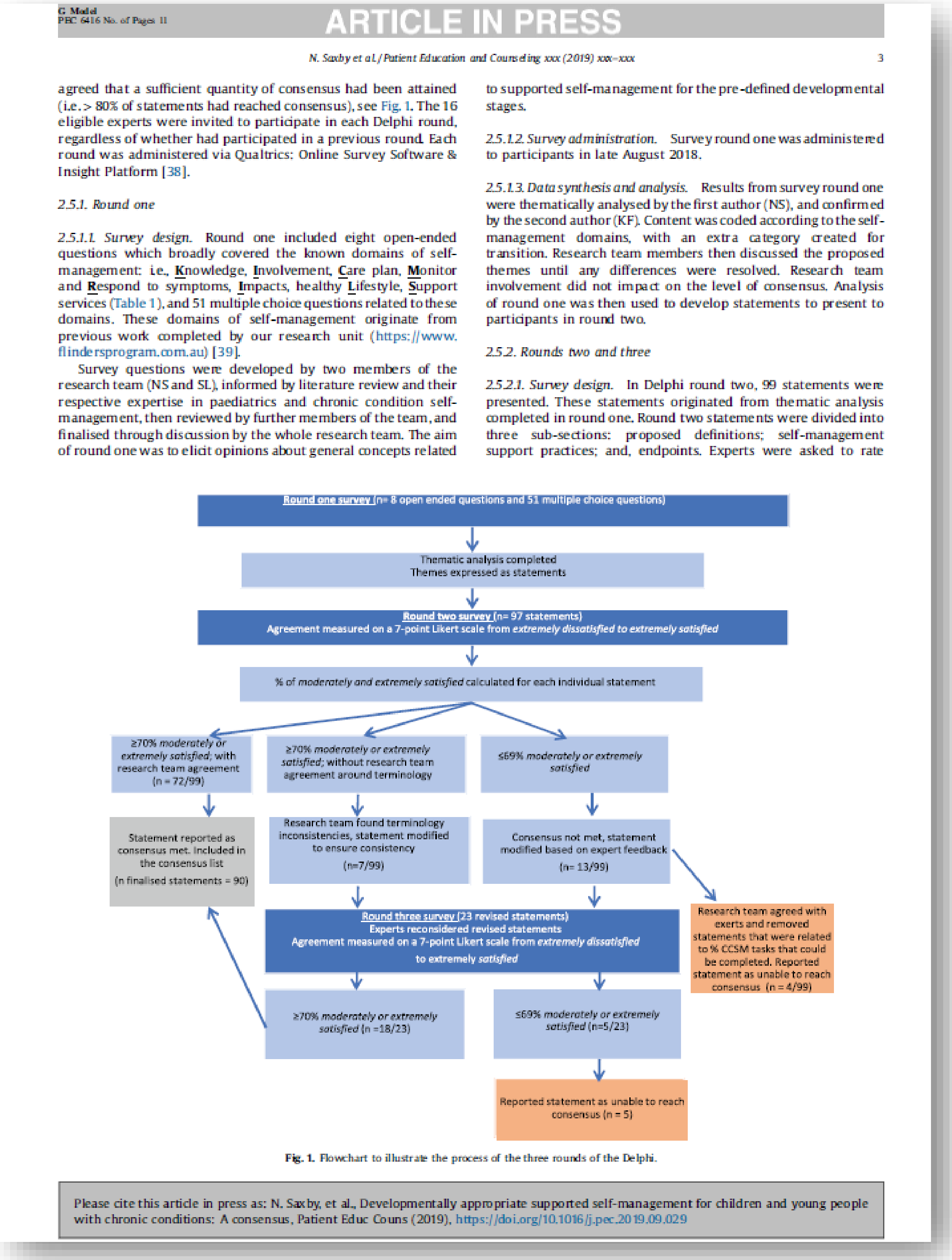

agreed that a sufficient quantity of consensus had been attained (i.e. > 80% of statements had reached consensus), see Fig. 1. The 16 eligible experts were invited to participate in each Delphi round, regardless of whether had participated in a previous round. Each round was administered via Qualtrics: Online Survey Software & Insight Platform [38].

2.5.1. Round one

2.5.1.1. Survey design. Round one included eight open-ended questions which broadly covered the known domains of self-management: i.e., **K**nowledge, **I**nvolvement, **C**are plan, **M**onitor and **R**espond to symptoms, **I**mpacts, healthy **L**ifestyle, **S**upport services (Table 1), and 51 multiple choice questions related to these domains. These domains of self-management originate from previous work completed by our research unit (https://www.flindersprogram.com.au) [39].

Survey questions were developed by two members of the research team (NS and SL), informed by literature review and their respective expertise in paediatrics and chronic condition self-management, then reviewed by further members of the team, and finalised through discussion by the whole research team. The aim of round one was to elicit opinions about general concepts related to supported self-management for the pre-defined developmental stages.

2.5.1.2. Survey administration. Survey round one was administered to participants in late August 2018.

2.5.1.3. Data synthesis and analysis. Results from survey round one were thematically analysed by the first author (NS), and confirmed by the second author (KF). Content was coded according to the self-management domains, with an extra category created for transition. Research team members then discussed the proposed themes until any differences were resolved. Research team involvement did not impact on the level of consensus. Analysis of round one was then used to develop statements to present to participants in round two.

2.5.2. Rounds two and three

2.5.2.1. Survey design. In Delphi round two, 99 statements were presented. These statements originated from thematic analysis completed in round one. Round two statements were divided into three sub-sections: proposed definitions; self-management support practices; and, endpoints. Experts were asked to rate

Fig. 1. Flowchart to illustrate the process of the three rounds of the Delphi.

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Table 1
Open ended questions presented to expert panel in Delphi round 1.

Domain	Definition	Open ended question asked
N/A	N/A	We need a definition of children's [and young people's] chronic condition self-management. The suggested definition is: *"Children's self-management is a process that includes a broad set of attitudes, behaviours and skills. It is directed towards managing the impact of the disease or condition, on all aspects of living by the child/young person and their family. Children and young people's ability to self-manage their condition will change over time as they develop cognitive, motor, social and life skills. Self-management, includes but is not limited to, self-care and it may also encompass prevention"* Do you have any suggested modifications to the proposed definition?
1 Knowledge **(K)**	Knowledge is about children and young people knowing about their chronic condition/s.	Please briefly explain how you would teach children and young people about their chronic conditions for the predefined developmental stages?[a]
2 Involvement **(I)**	Involvement is about children and young people being involved in the decisions around the management of their condition/s with their parents, family members, and the healthcare team.	Please briefly explain how you approach getting children and young people involved in the management of their own chronic conditions for the predefined developmental stages?[a]
3 Care plan **(C)**	Care plan is about children and young people, together with their family unit, following the agreed-upon care plan (which may also be known as a chronic condition action plan). It also incorporates role division between children and their parents/primary caregivers in relation to self-management tasks.	Please briefly explain how you approach developing a care plan for children and young people for the predefined developmental stages (e.g. who are the plans directed at, what format do you use etc.)?[a]
4 Monitor and respond to symptoms **(MR)**	Monitoring and responding to symptoms is about children/young people developing an awareness of the symptoms of their chronic condition/s, communicating these symptoms to other people that can help, and acting on their symptoms if they have the appropriate skills and abilities.	What signs and symptoms do you think that children and young people should be aware of and be able to respond for each predefined developmental stage?[a]
5 Impacts **(Im)**	Impacts relate to how children and young people manage the physical, emotional and social impacts their condition has on their everyday life. Of particular importance is the division of responsibility between children and their parents in managing perceived and actual impacts (i.e. how much does the parent step in and out in helping the child/young person to cope)	For each of the predetermined developmental stages, how much independence would you expect the child to have in relation to managing the physical, emotional and social impacts of their chronic condition/s?[a]
6 Healthy lifestyle **(L)**	Healthy lifestyle is about children and young people being involved in activities as their age and chronic condition allows. Lifestyle factors can include having a healthy diet, playing sport with others, and being able to stay overnight at friends and families houses.	Please briefly explain how you approach getting children and young people to follow a healthy lifestyle for each predefined developmental stage?[a]
7 Support services **(S)**	Support services is about children and young people knowing where they can get support in managing their chronic conditions. Supports may include teachers at schools, their parents, and their friends.	Please briefly explain how you encourage children and young people (with/without their families) to access support services for each predefined developmental stage?[a]

[a] Expert participants were asked to answer questions for all developmental stages that applied to their experience.

their level of agreement to each statement using a 7-point Likert scale from *extremely dissatisfied* to *extremely satisfied*.

In survey round three, participants were presented with 23 revised statements where consensus was not reached in the previous round (feedback incorporated), plus seven statements where the research team had found terminology inconsistencies. All revised statements had consistent numbering with the results reported from Delphi round two.

2.5.2.2. Survey administration. Round two and three surveys were administered in September 2018 and October 2018.

2.6. Consensus list development

Statements were considered finalised when both the following criteria were met: expert consensus reached; and, research team in agreement with the expert consensus. Where participants agreed that statements were relevant regardless of developmental stage, these were collated under the heading 'all stages'. Finalised statements were then synthesised into the 'Partners in Health: Consensus List for Children and Young People'. This list defines supported self-management for the range of developmental stages and supports clinical practice approaches.

A consultancy company (Literally Inspired, Hobart-Australia) reviewed the finalised consensus list in relation to health literacy. This review ensured that the final list was easy to read, clearly understandable, and suitable for use across paediatric healthcare settings.

2.7. Ethics

Ethical approval for this study granted by the Flinders University Social and Behavioural Research Ethics Committee (#7205).

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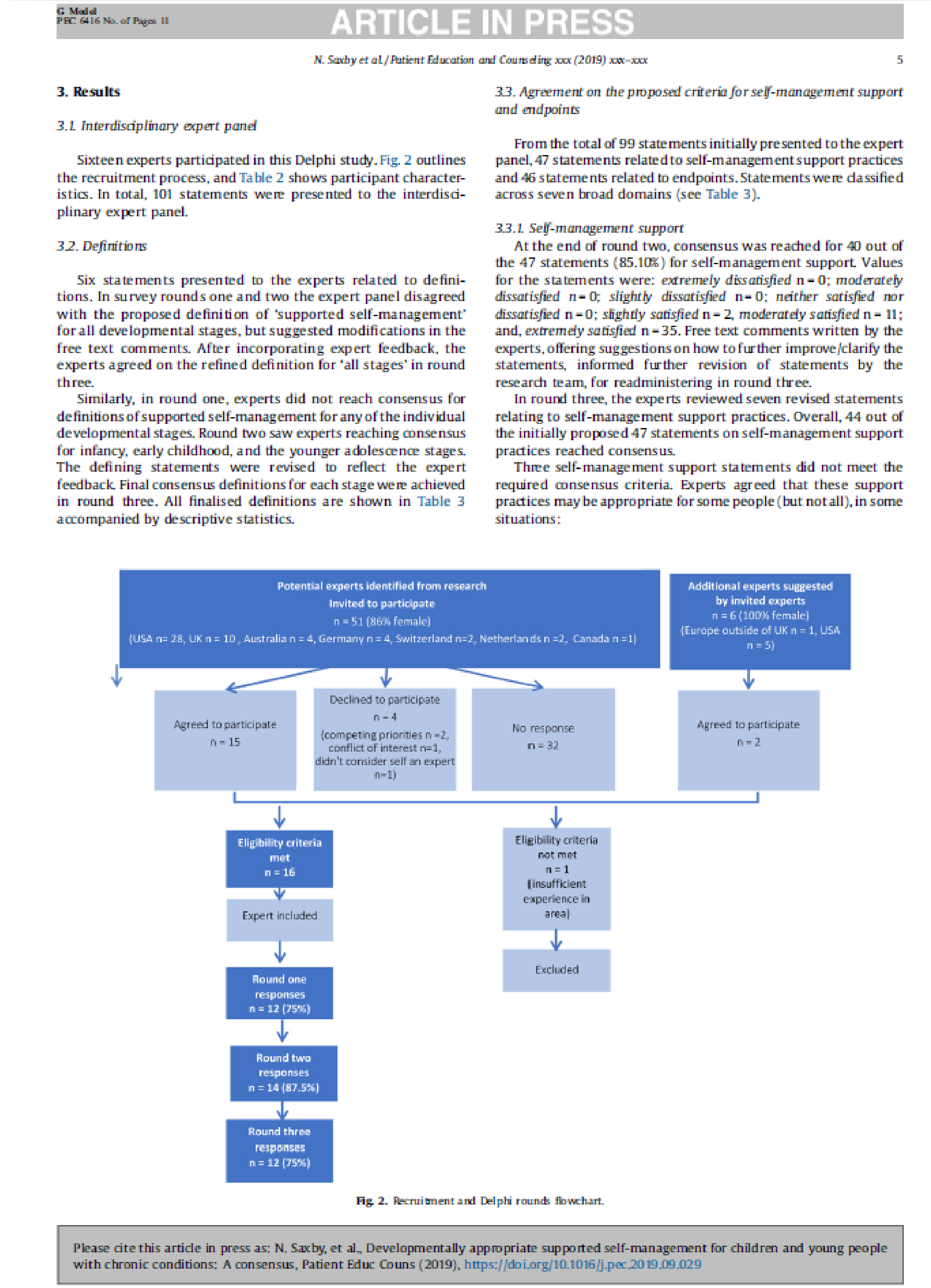

3. Results

3.1. Interdisciplinary expert panel

Sixteen experts participated in this Delphi study. Fig. 2 outlines the recruitment process, and Table 2 shows participant characteristics. In total, 101 statements were presented to the interdisciplinary expert panel.

3.2. Definitions

Six statements presented to the experts related to definitions. In survey rounds one and two the expert panel disagreed with the proposed definition of 'supported self-management' for all developmental stages, but suggested modifications in the free text comments. After incorporating expert feedback, the experts agreed on the refined definition for 'all stages' in round three.

Similarly, in round one, experts did not reach consensus for definitions of supported self-management for any of the individual developmental stages. Round two saw experts reaching consensus for infancy, early childhood, and the younger adolescence stages. The defining statements were revised to reflect the expert feedback. Final consensus definitions for each stage were achieved in round three. All finalised definitions are shown in Table 3 accompanied by descriptive statistics.

3.3. Agreement on the proposed criteria for self-management support and endpoints

From the total of 99 statements initially presented to the expert panel, 47 statements related to self-management support practices and 46 statements related to endpoints. Statements were classified across seven broad domains (see Table 3).

3.3.1. Self-management support

At the end of round two, consensus was reached for 40 out of the 47 statements (85.10%) for self-management support. Values for the statements were: *extremely dissatisfied* n = 0; *moderately dissatisfied* n = 0; *slightly dissatisfied* n = 0; *neither satisfied nor dissatisfied* n = 0; *slightly satisfied* n = 2, *moderately satisfied* n = 11; and, *extremely satisfied* n = 35. Free text comments written by the experts, offering suggestions on how to further improve/clarify the statements, informed further revision of statements by the research team, for readministering in round three.

In round three, the experts reviewed seven revised statements relating to self-management support practices. Overall, 44 out of the initially proposed 47 statements on self-management support practices reached consensus.

Three self-management support statements did not meet the required consensus criteria. Experts agreed that these support practices may be appropriate for some people (but not all), in some situations:

Fig. 2. Recruitment and Delphi rounds flowchart.

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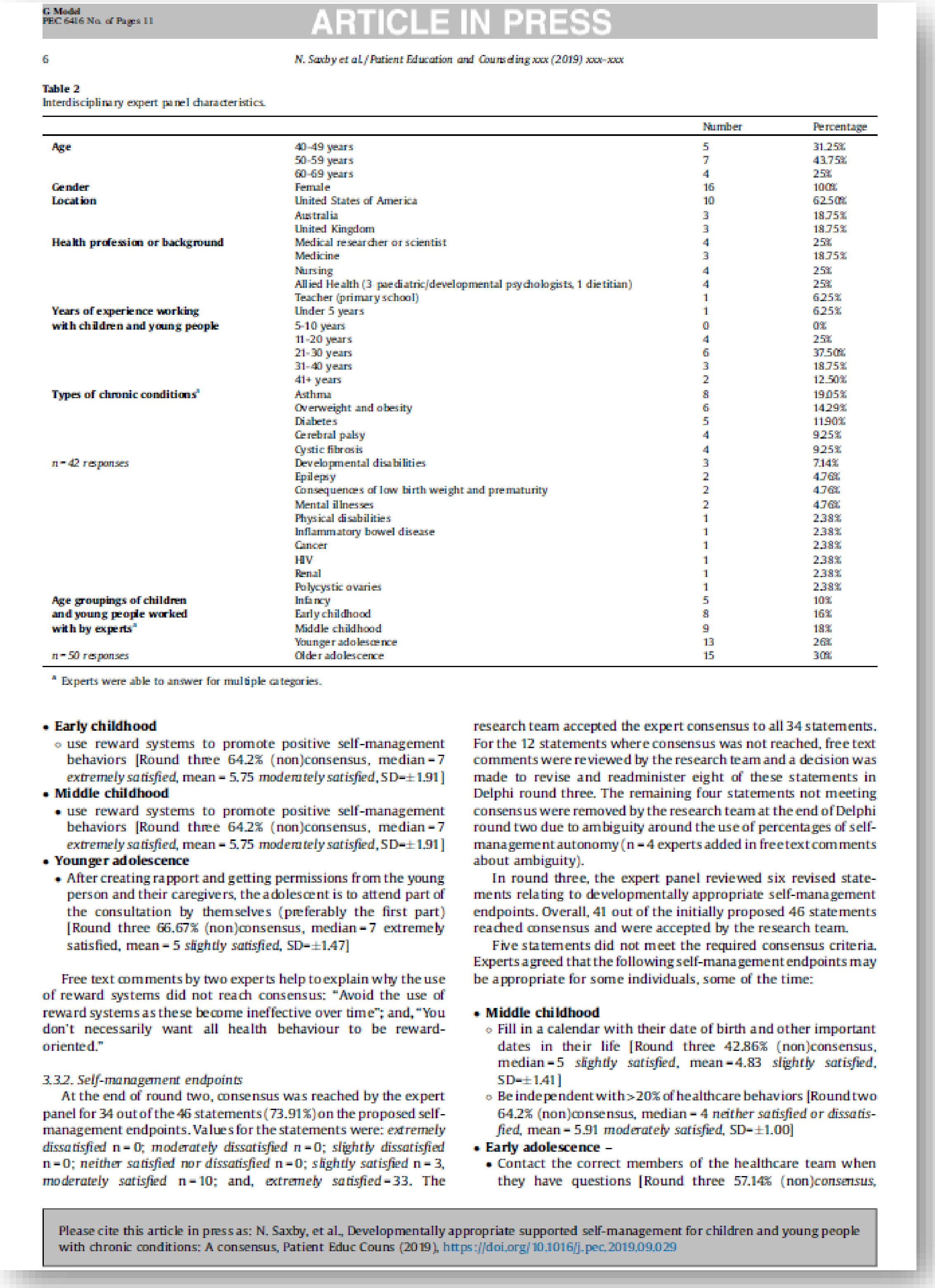

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Table 2
Interdisciplinary expert panel characteristics.

		Number	Percentage
Age	40–49 years	5	31.25%
	50–59 years	7	43.75%
	60–69 years	4	25%
Gender	Female	16	100%
Location	United States of America	10	62.50%
	Australia	3	18.75%
	United Kingdom	3	18.75%
Health profession or background	Medical researcher or scientist	4	25%
	Medicine	3	18.75%
	Nursing	4	25%
	Allied Health (3 paediatric/developmental psychologists, 1 dietitian)	4	25%
	Teacher (primary school)	1	6.25%
Years of experience working with children and young people	Under 5 years	1	6.25%
	5–10 years	0	0%
	11–20 years	4	25%
	21–30 years	6	37.50%
	31–40 years	3	18.75%
	41+ years	2	12.50%
Types of chronic conditions[a]	Asthma	8	19.05%
	Overweight and obesity	6	14.29%
	Diabetes	5	11.90%
	Cerebral palsy	4	9.25%
	Cystic fibrosis	4	9.25%
n = 42 *responses*	Developmental disabilities	3	7.14%
	Epilepsy	2	4.76%
	Consequences of low birth weight and prematurity	2	4.76%
	Mental illnesses	2	4.76%
	Physical disabilities	1	2.38%
	Inflammatory bowel disease	1	2.38%
	Cancer	1	2.38%
	HIV	1	2.38%
	Renal	1	2.38%
	Polycystic ovaries	1	2.38%
Age groupings of children and young people worked with by experts[a]	Infancy	5	10%
	Early childhood	8	16%
	Middle childhood	9	18%
	Younger adolescence	13	26%
n = 50 *responses*	Older adolescence	15	30%

[a] Experts were able to answer for multiple categories.

- **Early childhood**
  - use reward systems to promote positive self-management behaviors [Round three 64.2% (non)consensus, median = 7 *extremely satisfied*, mean = 5.75 *moderately satisfied*, SD=±1.91]
- **Middle childhood**
  - use reward systems to promote positive self-management behaviors [Round three 64.2% (non)consensus, median = 7 *extremely satisfied*, mean = 5.75 *moderately satisfied*, SD=±1.91]
- **Younger adolescence**
  - After creating rapport and getting permissions from the young person and their caregivers, the adolescent is to attend part of the consultation by themselves (preferably the first part) [Round three 66.67% (non)consensus, median = 7 extremely satisfied, mean = 5 *slightly satisfied*, SD=±1.47]

Free text comments by two experts help to explain why the use of reward systems did not reach consensus: "Avoid the use of reward systems as these become ineffective over time"; and, "You don't necessarily want all health behaviour to be reward-oriented."

3.3.2. *Self-management endpoints*

At the end of round two, consensus was reached by the expert panel for 34 out of the 46 statements (73.91%) on the proposed self-management endpoints. Values for the statements were: *extremely dissatisfied* n = 0; *moderately dissatisfied* n = 0; *slightly dissatisfied* n = 0; *neither satisfied nor dissatisfied* n = 0; *slightly satisfied* n = 3, *moderately satisfied* n = 10; and, *extremely satisfied* = 33. The research team accepted the expert consensus to all 34 statements. For the 12 statements where consensus was not reached, free text comments were reviewed by the research team and a decision was made to revise and readminister eight of these statements in Delphi round three. The remaining four statements not meeting consensus were removed by the research team at the end of Delphi round two due to ambiguity around the use of percentages of self-management autonomy (n = 4 experts added in free text comments about ambiguity).

In round three, the expert panel reviewed six revised statements relating to developmentally appropriate self-management endpoints. Overall, 41 out of the initially proposed 46 statements reached consensus and were accepted by the research team.

Five statements did not meet the required consensus criteria. Experts agreed that the following self-management endpoints may be appropriate for some individuals, some of the time:

- **Middle childhood**
  - Fill in a calendar with their date of birth and other important dates in their life [Round three 42.86% (non)consensus, median = 5 *slightly satisfied*, mean = 4.83 *slightly satisfied*, SD=±1.41]
  - Be independent with >20% of healthcare behaviors [Round two 64.2% (non)consensus, median = 4 *neither satisfied or dissatisfied*, mean = 5.91 *moderately satisfied*, SD=±1.00]
- **Early adolescence** –
  - Contact the correct members of the healthcare team when they have questions [Round three 57.14% (non)*consensus*,

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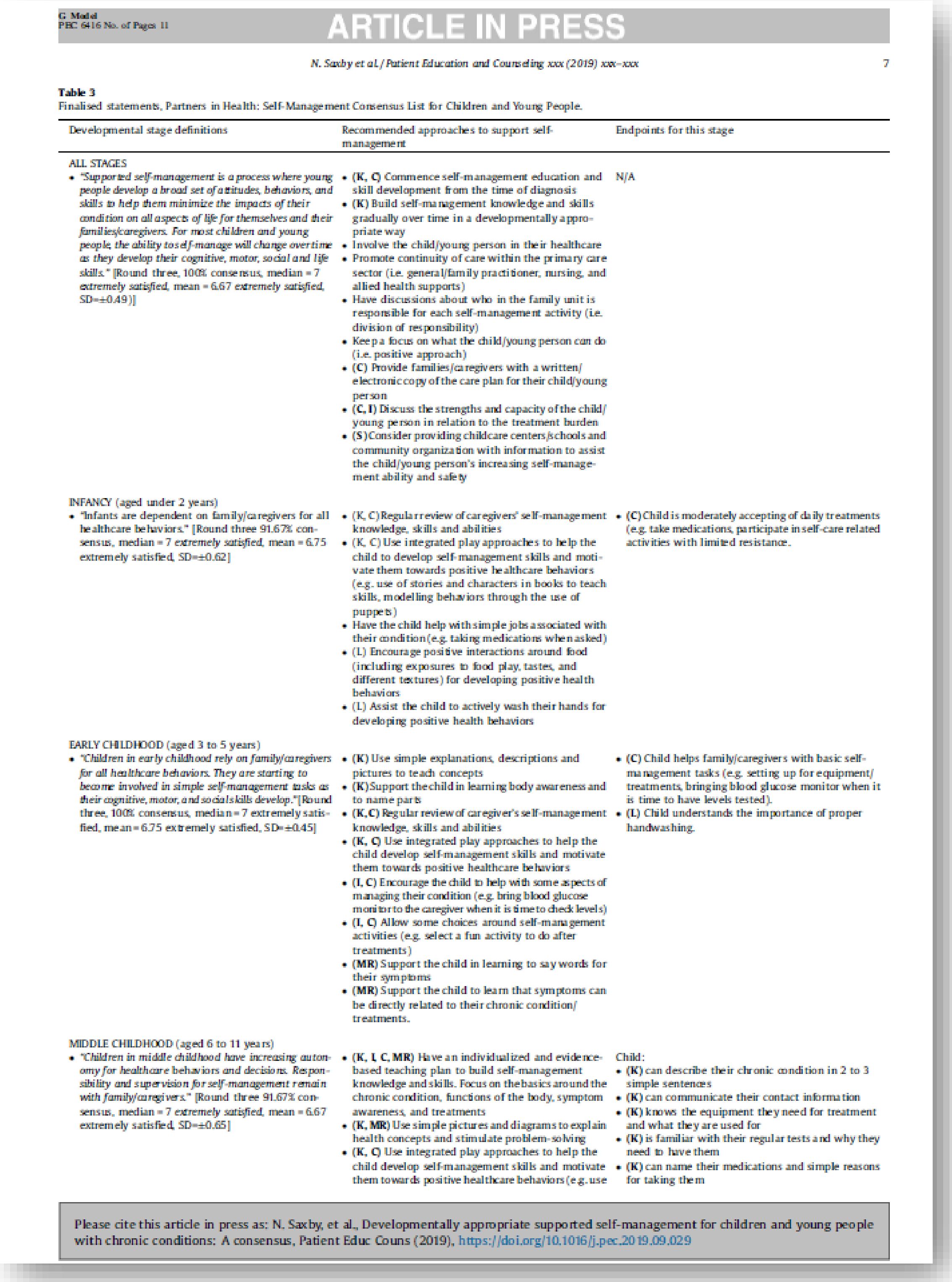

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Table 3
Finalised statements, Partners in Health: Self-Management Consensus List for Children and Young People.

Developmental stage definitions	Recommended approaches to support self-management	Endpoints for this stage
ALL STAGES • *"Supported self-management is a process where young people develop a broad set of attitudes, behaviors, and skills to help them minimize the impacts of their condition on all aspects of life for themselves and their families/caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills."* [Round three, 100% consensus, median = 7 *extremely satisfied*, mean = 6.67 *extremely satisfied*, SD=±0.49)]	• **(K, C)** Commence self-management education and skill development from the time of diagnosis • **(K)** Build self-management knowledge and skills gradually over time in a developmentally appropriate way • Involve the child/young person in their healthcare • Promote continuity of care within the primary care sector (i.e. general/family practitioner, nursing, and allied health supports) • Have discussions about who in the family unit is responsible for each self-management activity (i.e. division of responsibility) • Keep a focus on what the child/young person *can* do (i.e. positive approach) • **(C)** Provide families/caregivers with a written/electronic copy of the care plan for their child/young person • **(C, I)** Discuss the strengths and capacity of the child/young person in relation to the treatment burden • **(S)** Consider providing childcare centers/schools and community organization with information to assist the child/young person's increasing self-management ability and safety	N/A
INFANCY (aged under 2 years) • "Infants are dependent on family/caregivers for all healthcare behaviors." [Round three 91.67% consensus, median = 7 *extremely satisfied*, mean = 6.75 extremely satisfied, SD=±0.62]	• (K, C) Regular review of caregivers' self-management knowledge, skills and abilities • (K, C) Use integrated play approaches to help the child to develop self-management skills and motivate them towards positive healthcare behaviors (e.g. use of stories and characters in books to teach skills, modelling behaviors through the use of puppets) • Have the child help with simple jobs associated with their condition (e.g. taking medications when asked) • (L) Encourage positive interactions around food (including exposures to food play, tastes, and different textures) for developing positive health behaviors • (L) Assist the child to actively wash their hands for developing positive health behaviors	• **(C)** Child is moderately accepting of daily treatments (e.g. take medications, participate in self-care related activities with limited resistance.
EARLY CHILDHOOD (aged 3 to 5 years) • *"Children in early childhood rely on family/caregivers for all healthcare behaviors. They are starting to become involved in simple self-management tasks as their cognitive, motor, and social skills develop."* [Round three, 100% consensus, median = 7 extremely satisfied, mean = 6.75 extremely satisfied, SD=±0.45]	• **(K)** Use simple explanations, descriptions and pictures to teach concepts • **(K)** Support the child in learning body awareness and to name parts • **(K, C)** Regular review of caregiver's self-management knowledge, skills and abilities • **(K, C)** Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviors • **(I, C)** Encourage the child to help with some aspects of managing their condition (e.g. bring blood glucose monitor to the caregiver when it is time to check levels) • **(I, C)** Allow some choices around self-management activities (e.g. select a fun activity to do after treatments) • **(MR)** Support the child in learning to say words for their symptoms • **(MR)** Support the child to learn that symptoms can be directly related to their chronic condition/treatments.	• **(C)** Child helps family/caregivers with basic self-management tasks (e.g. setting up for equipment/treatments, bringing blood glucose monitor when it is time to have levels tested). • **(L)** Child understands the importance of proper handwashing.
MIDDLE CHILDHOOD (aged 6 to 11 years) • *"Children in middle childhood have increasing autonomy for healthcare* behaviors *and decisions. Responsibility and supervision for self-management remain with family/caregivers."* [Round three 91.67% consensus, median = 7 *extremely satisfied*, mean = 6.67 extremely satisfied, SD=±0.65]	• **(K, I, C, MR)** Have an individualized and evidence-based teaching plan to build self-management knowledge and skills. Focus on the basics around the chronic condition, functions of the body, symptom awareness, and treatments • **(K, MR)** Use simple pictures and diagrams to explain health concepts and stimulate problem-solving • **(K, C)** Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviors (e.g. use	Child: • **(K)** can describe their chronic condition in 2 to 3 simple sentences • **(K)** can communicate their contact information • **(K)** knows the equipment they need for treatment and what they are used for • **(K)** is familiar with their regular tests and why they need to have them • **(K)** can name their medications and simple reasons for taking them

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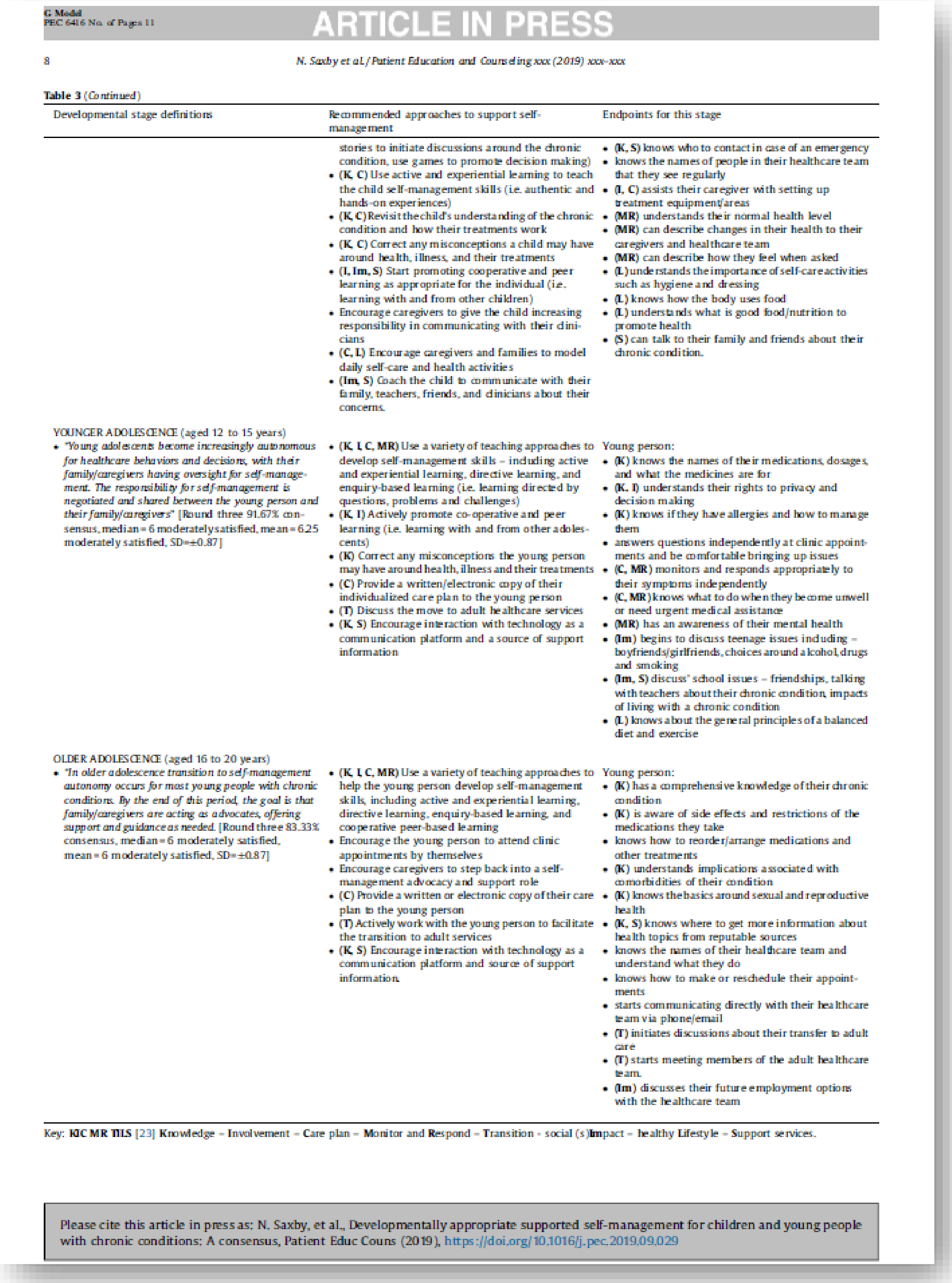

Table 3 (*Continued*)

Developmental stage definitions	Recommended approaches to support self-management	Endpoints for this stage
	stories to initiate discussions around the chronic condition, use games to promote decision making) • **(K, C)** Use active and experiential learning to teach the child self-management skills (i.e. authentic and hands-on experiences) • **(K, C)** Revisit the child's understanding of the chronic condition and how their treatments work • **(K, C)** Correct any misconceptions a child may have around health, illness, and their treatments • **(I, Im, S)** Start promoting cooperative and peer learning as appropriate for the individual (i.e. learning with and from other children) • Encourage caregivers to give the child increasing responsibility in communicating with their clinicians • **(C, L)** Encourage caregivers and families to model daily self-care and health activities • **(Im, S)** Coach the child to communicate with their family, teachers, friends, and clinicians about their concerns.	• **(K, S)** knows who to contact in case of an emergency • knows the names of people in their healthcare team that they see regularly • **(I, C)** assists their caregiver with setting up treatment equipment/areas • **(MR)** understands their normal health level • **(MR)** can describe changes in their health to their caregivers and healthcare team • **(MR)** can describe how they feel when asked • **(L)** understands the importance of self-care activities such as hygiene and dressing • **(L)** knows how the body uses food • **(L)** understands what is good food/nutrition to promote health • **(S)** can talk to their family and friends about their chronic condition.
YOUNGER ADOLESCENCE (aged 12 to 15 years) • *"Young adolescents become increasingly autonomous for healthcare behaviors and decisions, with their family/caregivers having oversight for self-management. The responsibility for self-management is negotiated and shared between the young person and their family/caregivers"* [Round three 91.67% consensus, median = 6 moderately satisfied, mean = 6.25 moderately satisfied, SD = ±0.87]	• **(K, I, C, MR)** Use a variety of teaching approaches to develop self-management skills – including active and experiential learning, directive learning, and enquiry-based learning (i.e. learning directed by questions, problems and challenges) • **(K, I)** Actively promote co-operative and peer learning (i.e. learning with and from other adolescents) • **(K)** Correct any misconceptions the young person may have around health, illness and their treatments • **(C)** Provide a written/electronic copy of their individualized care plan to the young person • **(T)** Discuss the move to adult healthcare services • **(K, S)** Encourage interaction with technology as a communication platform and a source of support information	Young person: • **(K)** knows the names of their medications, dosages, and what the medicines are for • **(K, I)** understands their rights to privacy and decision making • **(K)** knows if they have allergies and how to manage them • answers questions independently at clinic appointments and be comfortable bringing up issues • **(C, MR)** monitors and responds appropriately to their symptoms independently • **(C, MR)** knows what to do when they become unwell or need urgent medical assistance • **(MR)** has an awareness of their mental health • **(Im)** begins to discuss teenage issues including – boyfriends/girlfriends, choices around alcohol, drugs and smoking • **(Im, S)** discuss' school issues – friendships, talking with teachers about their chronic condition, impacts of living with a chronic condition • **(L)** knows about the general principles of a balanced diet and exercise
OLDER ADOLESCENCE (aged 16 to 20 years) • *"In older adolescence transition to self-management autonomy occurs for most young people with chronic conditions. By the end of this period, the goal is that family/caregivers are acting as advocates, offering support and guidance as needed.* [Round three 83.33% consensus, median = 6 moderately satisfied, mean = 6 moderately satisfied, SD = ±0.87]	• **(K, I, C, MR)** Use a variety of teaching approaches to help the young person develop self-management skills, including active and experiential learning, directive learning, enquiry-based learning, and cooperative peer-based learning • Encourage the young person to attend clinic appointments by themselves • Encourage caregivers to step back into a self-management advocacy and support role • **(C)** Provide a written or electronic copy of their care plan to the young person • **(T)** Actively work with the young person to facilitate the transition to adult services • **(K, S)** Encourage interaction with technology as a communication platform and source of support information.	Young person: • **(K)** has a comprehensive knowledge of their chronic condition • **(K)** is aware of side effects and restrictions of the medications they take • knows how to reorder/arrange medications and other treatments • **(K)** understands implications associated with comorbidities of their condition • **(K)** knows the basics around sexual and reproductive health • **(K, S)** knows where to get more information about health topics from reputable sources • knows the names of their healthcare team and understand what they do • knows how to make or reschedule their appointments • starts communicating directly with their healthcare team via phone/email • **(T)** initiates discussions about their transfer to adult care • **(T)** starts meeting members of the adult healthcare team. • **(Im)** discusses their future employment options with the healthcare team

Key: **KIC MR TILS** [23] **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – **T**ransition - social (s)**Im**pact – healthy **L**ifestyle – **S**upport services.

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median = 5 slightly satisfied, mean = 5.35 slightly satisfied, SD=±1.50]
  - *Be independent with >50% of healthcare behaviors [Round two 64.2% (non)consensus, median = 6.moderately satisfied,* mean = 5.91 *moderately satisfied,* SD=±1.00]
- **Older adolescence –**
  - Be independent with >75% of healthcare behaviors [Round two 64.2% (non)consensus, median = 6.*moderately satisfied* mean = 5.86 *slightly satisfied*, SD=±1.29]
  - Be independent with 100% of healthcare behaviors Round two 64.2% (non)consensus, median = 6.*moderately satisfied* mean = 5.5 *moderately satisfied*, SD=±1.87]

It was apparent that the experts did not want health professionals to relate level of autonomy against pre-defined percentage targets. The following expert comments written as free text provide sound reasoning: "*Independence could vary based on cognitive and physical abilities*"; and, "*Being independent in [X]% of health care* behaviours *depends on what you include in the tally*".

3.4. Statement synthesis

The 90 statements on which consensus agreement was reached were combined to create 'Partners in Health: Self-Management Consensus List for Children and Young People' as shown in Table 3. This tool includes six definitional statements, 43 self-management support statements, and 41 self-management endpoint statements.

3.5. Suggested changes to terminology and age groupings

Based on expert feedback, the terminology used to describe individuals within the age range of birth to 20 years changed over the three Delphi rounds. The experts agreed that using the terms 'children' and 'young people' best reflected individuals aged birth to 20 years (rather than 'children', 'children and adolescents', and 'youth'). In addition, the term 'middle childhood' was preferred over 'school-aged children'.

Demographic age groupings were also debated amongst the expert interdisciplinary panel, with agreement being reached in round three for the following age groupings: birth to 23 months; two to five years; six to 11 years; 12–15 years; and, 16–20 years.

4. Discussion and conclusion

4.1. Discussion

This Delphi study explored the opinions of clinical academics with expertise in supported self-management, from a developmental perspective. A three-round Delphi process was employed, with consensus being reached for 90 (out of 99) statements by the interdisciplinary expert panel. Together, these 90 statements formed the 'Partners in Health: Self-Management Consensus list for Children and Young People'. This new tool fills an important practice and knowledge gap by providing consensus advice to clinicians about how to deliver developmentally appropriate self-management support.

Another important contribution of this study is the clear delineation from family management (i.e. in infancy and early childhood), to supported self-management by the child/young person (i.e. in middle childhood, early adolescence, and older adolescence), to autonomous self-management by the young person (i.e. at the point of transfer to adult healthcare services at approximately 18 to 20 years of age). It is important to remember, however, that children/young people are expected to achieve self-management milestones at varying rates. Thus, the age estimates suggested in the 'Partners in Health: Self-Management Consensus List for Children and young People' should only be used as an approximation as for when self-management skills may be developed.

One of the strong messages from the expert panel was the importance of having an individualised and person-centred approach to supported self-management, provided in a positive way (i.e., what the child/young person can do), and focused on health behaviour goals that are relevant to the child/young person. It is therefore important that throughout the developmental trajectory, the child/young person is involved in the self-management of their condition/s, and that their family/caregivers are also considered [5]. Clinicians, however, need to be aware that the child's/young person's views towards self-management may be different to that of their family/caregivers [40].

The statements which did not reach expert consensus were also of interest to the research team, particularly in respect to reward system appropriateness. Reward systems are commonly used by parents and are promoted in paediatric health and educational settings [41,42]. This area requires further research given the common use of reward systems in fields such as paediatric psychology.

4.1.1. Strengths and limitations

This Delphi study has several strengths. Firstly, the consensus definition is applicable to paediatric self-management support across multiple chronic conditions, which substantially increases potential for clinical usability. Secondly, the expert panel came from three countries and encompassed a variety of individuals with health and educational backgrounds which supports a more globally representative definition. Thirdly, carefully-worded open-ended questions in survey round one were used to avoid biasing responses. Furthermore, there were high response rates for all survey rounds.

There are also limitations to study methodology. Whilst the Delphi technique enabled the researchers to summarise the existing knowledge of experts in the field of developmentally appropriate self-management, it is not a method that could be used to create new evidence. The type of data collected from experts in this study could have also been constrained by using the self-management domains within the Flinders Program [39] as an underlying conceptual model. Furthermore, the research team acknowledges using age guides to separate the developmental stages has limitations. Categorisation using age does not take into consideration cognitive development, experience and exposure, or age at diagnosis.

Other limitations include, a low participation rate of 28.5% of invited experts (n = 16/56), an all-female expert panel residing in only English-speaking high income countries, and lengthy survey rounds (i.e. survey rounds one and two took >20 min for experts to complete) which may have been a barrier to participation for other experts who were approached but declined participation. It is worth noting that the consensus tool created through this Delphi study was not designed to fit absolutely every childhood chronic condition. The 'Partners in Health: Self-Management Consensus List for Children and Young People' provides broad guidance only. Further refinement for specific areas is required, particularly in relation to complex chronic conditions (e.g. developmental delay, presence of multiple co-morbidities).

4.2. Conclusions and next steps

The results of this study can be used in paediatric clinical practice where it may be useful to support children/young people in developing self-management skills and positive health behaviours appropriate to their developmental stage.

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Supported self-management from a developmental perspective remains an under-researched area. More work is required to evaluate whether the new tool (i.e. 'Partners in Health: Self-Management Consensus List for Children and Young People') is useful in clinical practice. Gathering feedback from children/young people, their families and caregivers about the format and appropriateness of this new tool would also be a potential future research project. Furthermore, researchers need to test when a child/young person can actually perform each self-management task.

4.3. Practice implications

It is recommended that paediatric clinicians from various disciplines use the self-management support approaches and endpoints outlined in the 'Partners in Health: Self-Management Consensus List for Children and Young People' tool as a guide in providing care for children and young people with chronic conditions.

A multifaceted strategy will be used to disseminate and implement this new consensus tool, initially through the Tasmanian Health Service in Australia and then more widely on request. Strategies will include use of education materials for health professionals, distribution of the tool to children/young people and their caregivers at paediatric clinics, and through providing a link to the tool on a purpose-built website.

Declaration of Competing Interest

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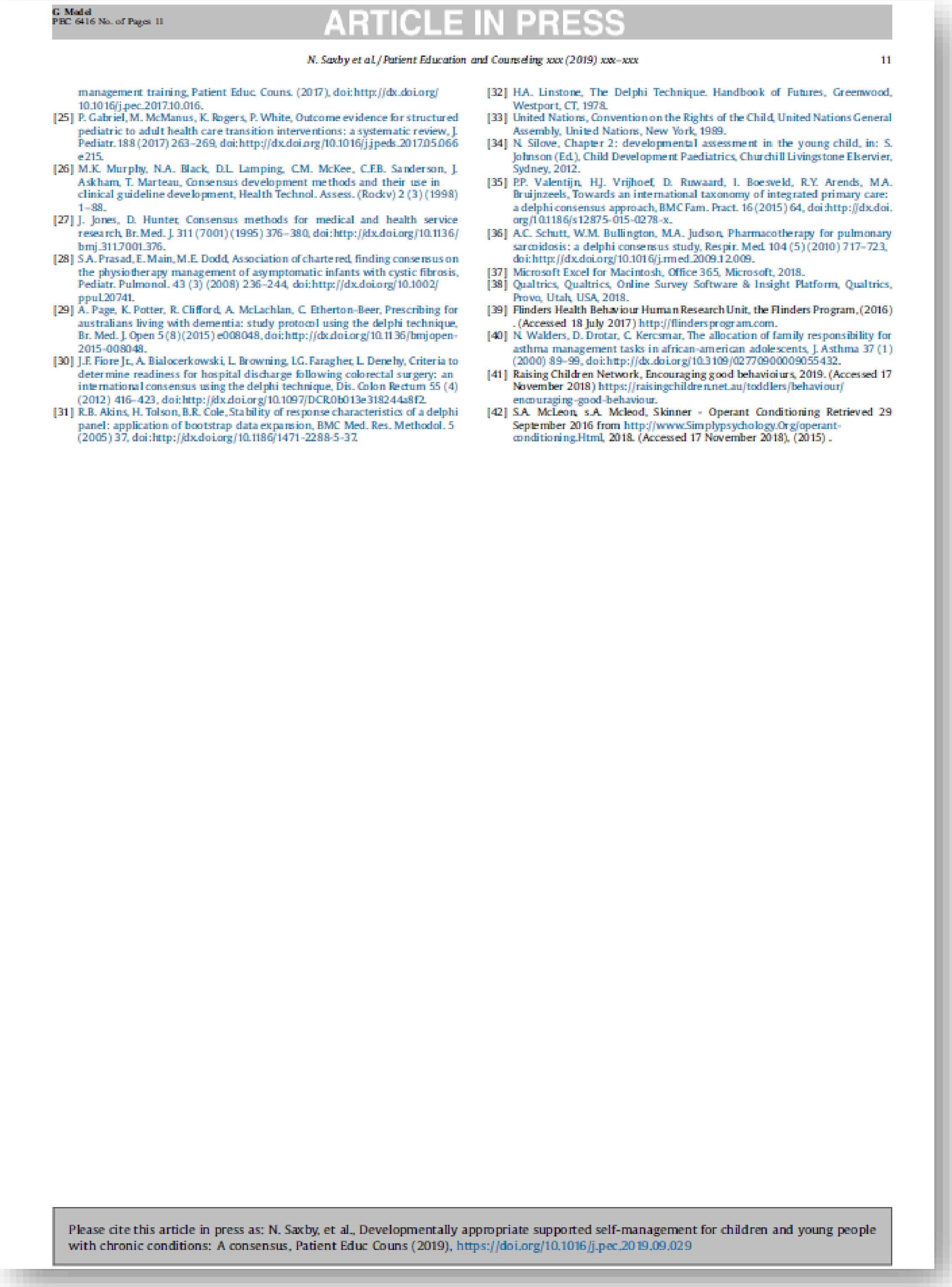

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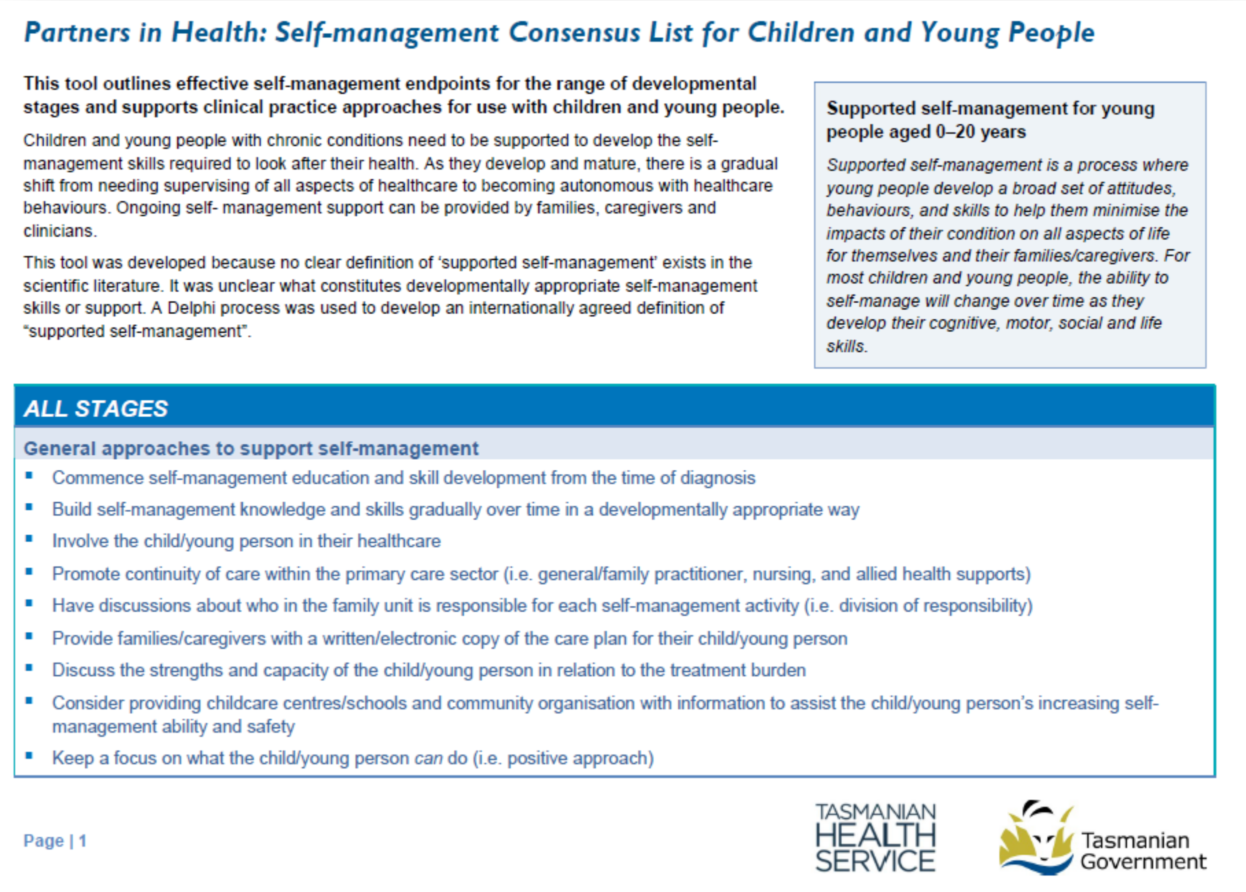
6G) Clinical tool produced for paediatric clinicians working across Tasmania



Partners in Health: Self-management Consensus List for Children and Young People

This tool outlines effective self-management endpoints for the range of developmental stages and supports clinical practice approaches for use with children and young people.

Children and young people with chronic conditions need to be supported to develop the self-management skills required to look after their health. As they develop and mature, there is a gradual shift from needing supervising of all aspects of healthcare to becoming autonomous with healthcare behaviours. Ongoing self- management support can be provided by families, caregivers and clinicians.

This tool was developed because no clear definition of 'supported self-management' exists in the scientific literature. It was unclear what constitutes developmentally appropriate self-management skills or support. A Delphi process was used to develop an internationally agreed definition of "supported self-management".

Supported self-management for young people aged 0–20 years

Supported self-management is a process where young people develop a broad set of attitudes, behaviours, and skills to help them minimise the impacts of their condition on all aspects of life for themselves and their families/caregivers. For most children and young people, the ability to self-manage will change over time as they develop their cognitive, motor, social and life skills.

ALL STAGES

General approaches to support self-management

- Commence self-management education and skill development from the time of diagnosis
- Build self-management knowledge and skills gradually over time in a developmentally appropriate way
- Involve the child/young person in their healthcare
- Promote continuity of care within the primary care sector (i.e. general/family practitioner, nursing, and allied health supports)
- Have discussions about who in the family unit is responsible for each self-management activity (i.e. division of responsibility)
- Provide families/caregivers with a written/electronic copy of the care plan for their child/young person
- Discuss the strengths and capacity of the child/young person in relation to the treatment burden
- Consider providing childcare centres/schools and community organisation with information to assist the child/young person's increasing self-management ability and safety
- Keep a focus on what the child/young person *can* do (i.e. positive approach)

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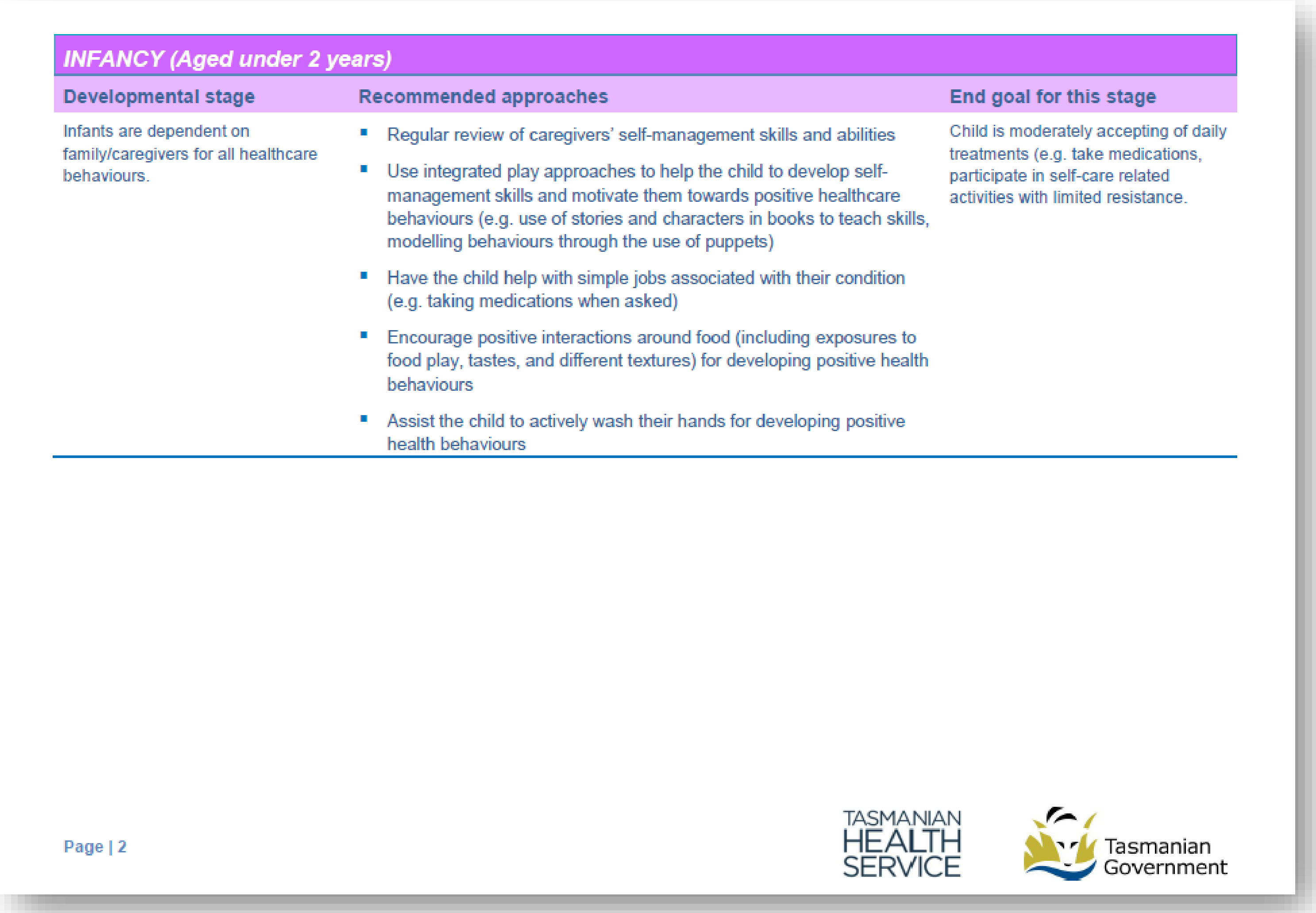
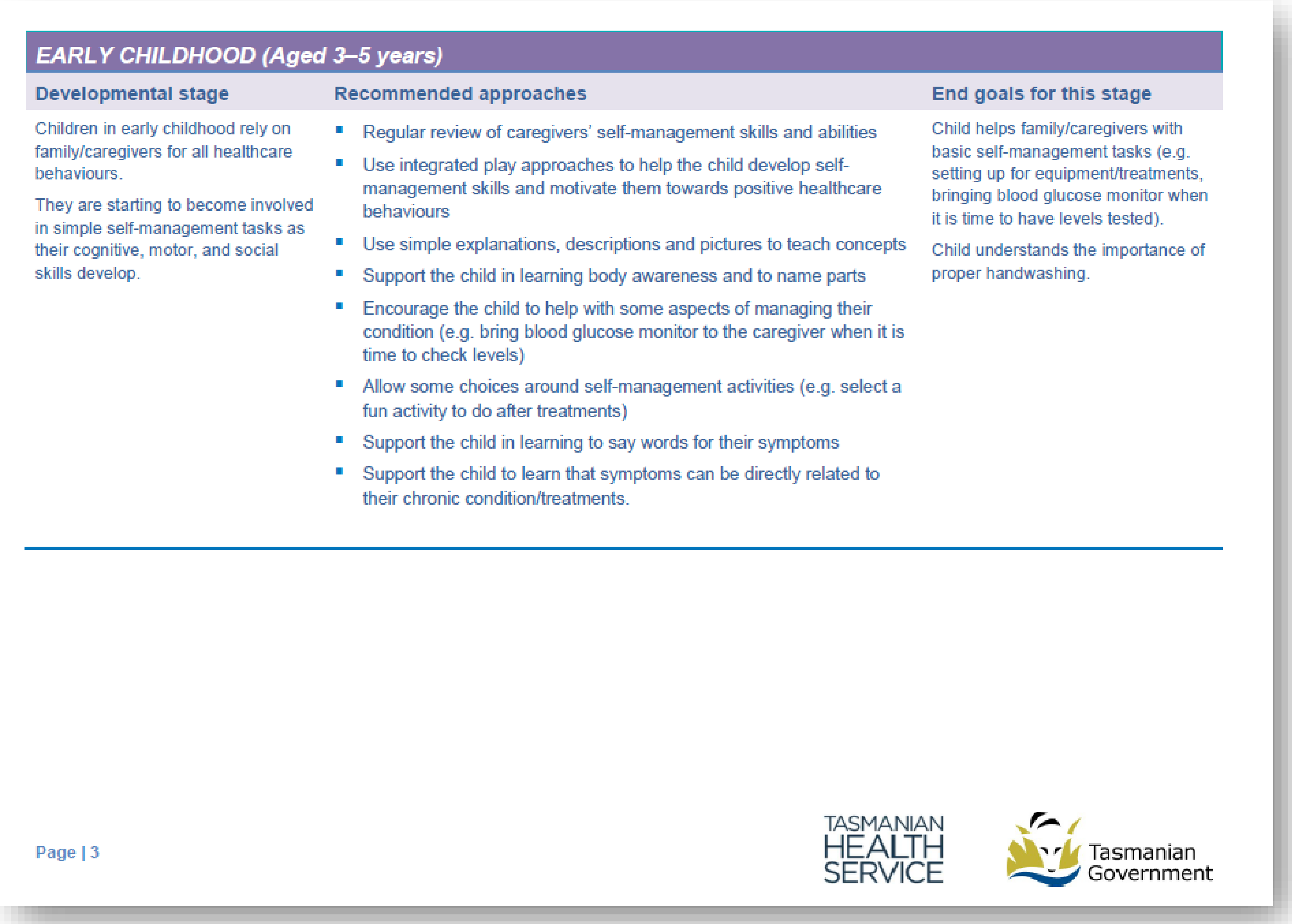


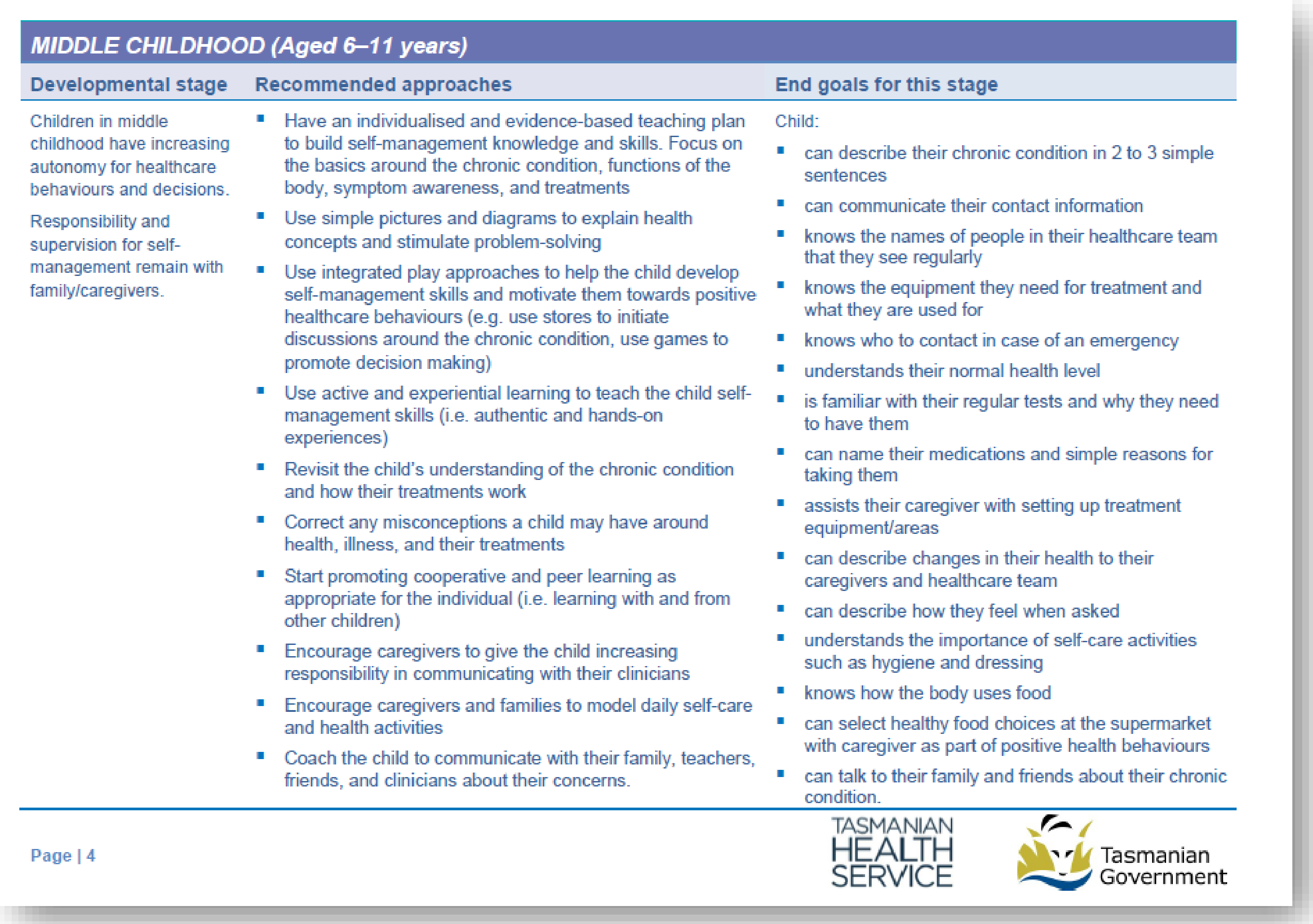
INFANCY (Aged under 2 years)

Developmental stage	Recommended approaches	End goal for this stage
Infants are dependent on family/caregivers for all healthcare behaviours.	▪ Regular review of caregivers' self-management skills and abilities ▪ Use integrated play approaches to help the child to develop self-management skills and motivate them towards positive healthcare behaviours (e.g. use of stories and characters in books to teach skills, modelling behaviours through the use of puppets) ▪ Have the child help with simple jobs associated with their condition (e.g. taking medications when asked) ▪ Encourage positive interactions around food (including exposures to food play, tastes, and different textures) for developing positive health behaviours ▪ Assist the child to actively wash their hands for developing positive health behaviours	Child is moderately accepting of daily treatments (e.g. take medications, participate in self-care related activities with limited resistance.



EARLY CHILDHOOD (Aged 3–5 years)

Developmental stage	Recommended approaches	End goals for this stage
Children in early childhood rely on family/caregivers for all healthcare behaviours. They are starting to become involved in simple self-management tasks as their cognitive, motor, and social skills develop.	▪ Regular review of caregivers' self-management skills and abilities ▪ Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviours ▪ Use simple explanations, descriptions and pictures to teach concepts ▪ Support the child in learning body awareness and to name parts ▪ Encourage the child to help with some aspects of managing their condition (e.g. bring blood glucose monitor to the caregiver when it is time to check levels) ▪ Allow some choices around self-management activities (e.g. select a fun activity to do after treatments) ▪ Support the child in learning to say words for their symptoms ▪ Support the child to learn that symptoms can be directly related to their chronic condition/treatments.	Child helps family/caregivers with basic self-management tasks (e.g. setting up for equipment/treatments, bringing blood glucose monitor when it is time to have levels tested). Child understands the importance of proper handwashing.



MIDDLE CHILDHOOD (Aged 6–11 years)

Developmental stage	Recommended approaches	End goals for this stage
Children in middle childhood have increasing autonomy for healthcare behaviours and decisions. Responsibility and supervision for self-management remain with family/caregivers.	▪ Have an individualised and evidence-based teaching plan to build self-management knowledge and skills. Focus on the basics around the chronic condition, functions of the body, symptom awareness, and treatments ▪ Use simple pictures and diagrams to explain health concepts and stimulate problem-solving ▪ Use integrated play approaches to help the child develop self-management skills and motivate them towards positive healthcare behaviours (e.g. use stores to initiate discussions around the chronic condition, use games to promote decision making) ▪ Use active and experiential learning to teach the child self-management skills (i.e. authentic and hands-on experiences) ▪ Revisit the child's understanding of the chronic condition and how their treatments work ▪ Correct any misconceptions a child may have around health, illness, and their treatments ▪ Start promoting cooperative and peer learning as appropriate for the individual (i.e. learning with and from other children) ▪ Encourage caregivers to give the child increasing responsibility in communicating with their clinicians ▪ Encourage caregivers and families to model daily self-care and health activities ▪ Coach the child to communicate with their family, teachers, friends, and clinicians about their concerns.	Child: ▪ can describe their chronic condition in 2 to 3 simple sentences ▪ can communicate their contact information ▪ knows the names of people in their healthcare team that they see regularly ▪ knows the equipment they need for treatment and what they are used for ▪ knows who to contact in case of an emergency ▪ understands their normal health level ▪ is familiar with their regular tests and why they need to have them ▪ can name their medications and simple reasons for taking them ▪ assists their caregiver with setting up treatment equipment/areas ▪ can describe changes in their health to their caregivers and healthcare team ▪ can describe how they feel when asked ▪ understands the importance of self-care activities such as hygiene and dressing ▪ knows how the body uses food ▪ can select healthy food choices at the supermarket with caregiver as part of positive health behaviours ▪ can talk to their family and friends about their chronic condition.

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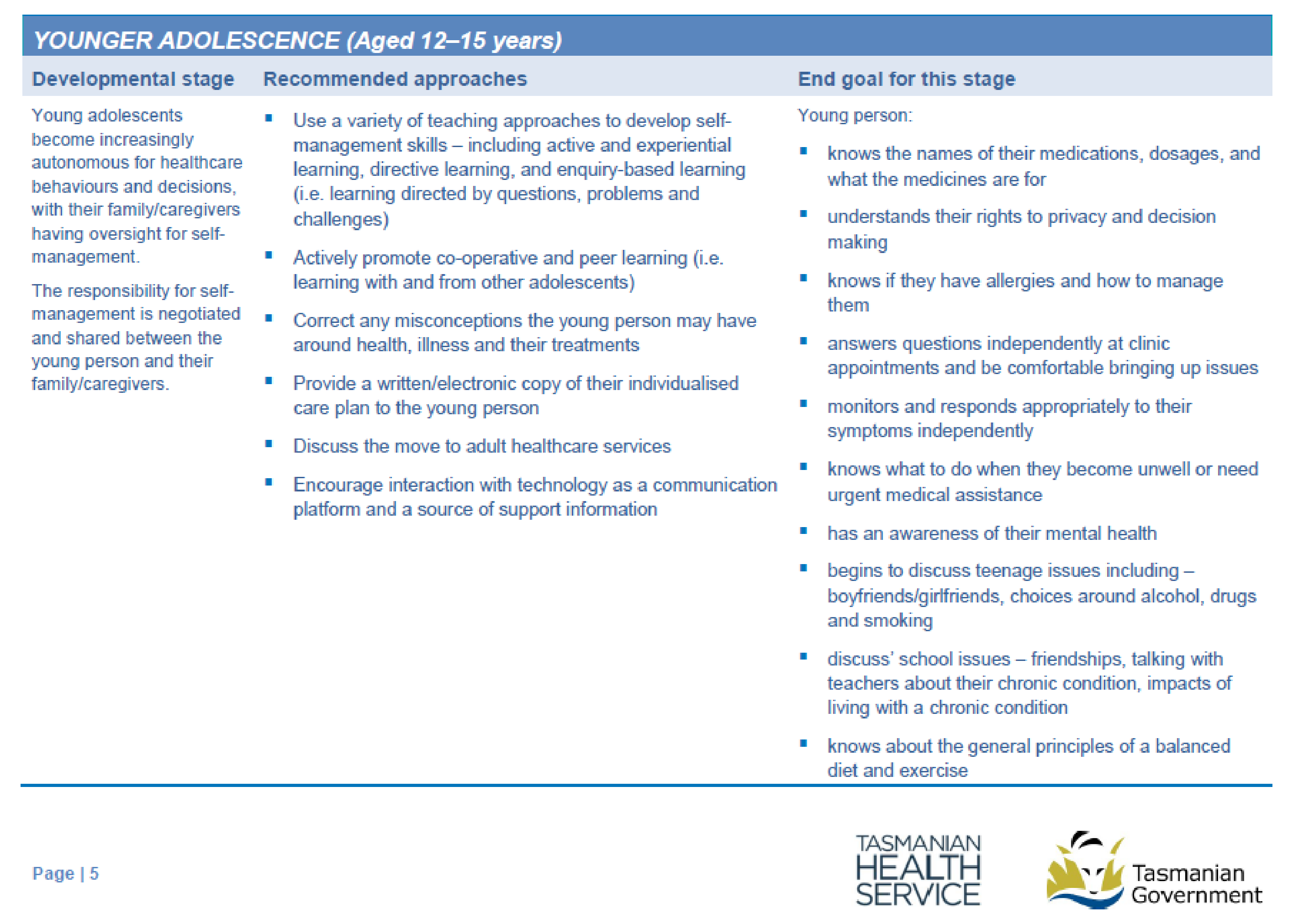

YOUNGER ADOLESCENCE (Aged 12–15 years)

Developmental stage	Recommended approaches	End goal for this stage
Young adolescents become increasingly autonomous for healthcare behaviours and decisions, with their family/caregivers having oversight for self-management. The responsibility for self-management is negotiated and shared between the young person and their family/caregivers.	▪ Use a variety of teaching approaches to develop self-management skills – including active and experiential learning, directive learning, and enquiry-based learning (i.e. learning directed by questions, problems and challenges) ▪ Actively promote co-operative and peer learning (i.e. learning with and from other adolescents) ▪ Correct any misconceptions the young person may have around health, illness and their treatments ▪ Provide a written/electronic copy of their individualised care plan to the young person ▪ Discuss the move to adult healthcare services ▪ Encourage interaction with technology as a communication platform and a source of support information	Young person: ▪ knows the names of their medications, dosages, and what the medicines are for ▪ understands their rights to privacy and decision making ▪ knows if they have allergies and how to manage them ▪ answers questions independently at clinic appointments and be comfortable bringing up issues ▪ monitors and responds appropriately to their symptoms independently ▪ knows what to do when they become unwell or need urgent medical assistance ▪ has an awareness of their mental health ▪ begins to discuss teenage issues including – boyfriends/girlfriends, choices around alcohol, drugs and smoking ▪ discuss' school issues – friendships, talking with teachers about their chronic condition, impacts of living with a chronic condition ▪ knows about the general principles of a balanced diet and exercise

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OLDER ADOLESCENCE (Aged 16–20 years)

Developmental stage	Recommended approaches	End goals for this stage
In older adolescence transition to self-management autonomy occurs for most people with chronic conditions. By the end of this period, the goal is that family/caregivers are acting as advocates, offering support and guidance as needed.	▪ Use a variety of teaching approaches to help the young person develop self-management skills, including active and experiential learning, directive learning, enquiry-based learning, and cooperative peer-based learning ▪ Encourage the young person to attend clinic appointments by themselves ▪ Encourage caregivers to step back into a self-management advocacy and support role ▪ Provide a written or electronic copy of their care plan to the young person ▪ Actively work with the young person to facilitate the transition to adult services ▪ Encourage interaction with technology as a communication platform and source of support information.	Young person: ▪ Has a comprehensive knowledge of their chronic condition ▪ Is aware of side effects and restrictions of the medications they take ▪ Knows how to reorder/arrange medications and other treatments ▪ Knows the names of their healthcare team and understands what they do ▪ Knows the basics around sexual and reproductive health ▪ Knows where to get more information about health topics from reputable sources ▪ Knows how to make or reschedule their appointments ▪ Understands implications associated with comorbidities of their condition ▪ Starts communicating directly with their healthcare team via phone/email ▪ Discusses their future employment options with the healthcare team ▪ Initiates discussions about their transfer to adult care ▪ Starts meeting members of the adult healthcare team

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