Early Dynamic Ultrasound in the Assessment and Management of Neonatal Instability of the Hip:

An intervention through health literacies to transform Rural and Regional Health

by

Susan Lyndsay Charlton

Thesis
Submitted to Flinders University
for the degree of

Doctor of Philosophy
College of Nursing and Health Sciences
November 2019

CONTENTS

ILLUSTRATIONS, TABLES AND FIGURES

ABSTRACT

Late diagnosis of developmental dysplasia of the hip in infants is reported to be an increasing problem in Australia, particularly in rural and remote areas (Azzopardi, Van Essen, Cundy, Tucker, & Chan, 2011; Studer K, 2016). Debate exists worldwide as to the value of selective or universal ultrasound screening as a diagnostic measure. Australian clinical guidelines advocate clinical assessment for all, with selective ultrasound screening for those at risk of the problem. Impacts for rural families with delayed diagnosis, access to treatment, and lifetime hip problems led to doctoral research into the use of universal screening in a regional centre in Australia. 'At risk' is a blunt policy implement. How it operates to understand and log regional injustice remains a key variable in this research.

Difficulties in conducting a controlled research experiment in two regional centres in South Australia were encountered, highlighting differences in health service between the two regions. These difficulties revealed much wider discrepancies in regional health service provision, which included recruitment and retention of allied health and medical practitioners, resistance to change, funding issues, consistency of service, and acceptance of innovation. Variations in health literacy, particularly in relation to infant hip problems, were a major factor. Geographic location may have had some influence on the outcome.

What commenced as a qualitative and empirical study developed into an interdisciplinary exploration, probing relationships between theories of health literacy and regional inequalities. Through this theoretical intervention, I demonstrated that the health service benefits from better collaboration and sharing of knowledge, scaffolded onto programmes of health literacy, included a more effective use of available expertise and a more open approach to the universal screening for neonatal instability of the hip. Developments in technology, particularly mobile screening devices, can now make a difference in overcoming some of the geographic difficulties of regional and rural access to services.

Universal early dynamic scanning of infant hips in one regional centre has demonstrated that early knowledge of hip status affects parental knowledge and may lead to improved management in the crucial period of early hip development. Regular assessment of infant hips must be part of child health visits at least until the development of normal walking and these examinations should be documented in the child's personal health record.

My original contribution to knowledge resulted from a challenging research project, and the challenges that jutted from it. When ascertaining the reasons for those challenges, the focus, priorities and research questions changed. The resultant doctorate demonstrates the value of theoretical interventions in empirical research. The theoretical explanation became more resonant and important in understanding the value of health literacy and why regional health is complex to study. Unexpected differences were found between two regional centres in South Australia and these contributed to the research difficulties, crystallising the need to advance hip development knowledge in parents. A consistent approach to knowledge about optimal hip development and neonatal care, combined with accessibility to accurate assessment of hip status, should be available to all and may go some way to improving the outcome and lifetime hip statistics for regional infants.

DECLARATION

"I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and

2. 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"

Sue Charlton.

ACKNOWLEDGEMENTS

I acknowledge the support received from my supervisors, Professor Adrian Schoo who introduced me to higher degree research methods, providing support and insight into accessing literature and encouraged dissemination of my findings and Professor Lucie Walters who supported me in the early gathering and reporting of evidence.

Without the enormous support, encouragement and advice I received from Professor Tara Brabazon during the difficult time when my research project failed, leading to the study assuming a different trajectory, this thesis would not have developed. I sincerely thank her for her generous support and remarkable ability to inspire further research and understanding of the problems encountered. My wonderful fellow researchers, members of the Write Bunch from around the world, who joined our writing group each week have become an important part of the completion of this thesis and will remain great friends through life.

My thanks go to the children who demonstrated ways to manage with hips which should have been better, sharing their joys and sorrows with me and the parents with whom we traversed the long and difficult journey through treatment and who inspired me to think we should be looking at infant hips differently.

The people who supported me in my study in Mount Gambier, the study participants, the assistants, the midwives and maternity staff. The GP's and obstetricians who were so supportive and interested in the work I was doing. Benson radiology, Lyn Muir and Kirste England the sonographers, the reception staff in Bensons. Sarah Ransom who has assisted me with data collection and backed me up during the research project.
Sally O'Connor who travelled with me, providing support and critical analysis of what I was doing.
Penny and Richard Cockington for accommodating me on my frequent trips to Flinders University in Adelaide and for putting up with my endless "chatter" about my activities.
My partners at 1 Stop Paediatrics for their patience, support and all the hard work they have done to allow me to research and write, read and research some more and to access the information I needed while they were working so tirelessly around me.
The Flinders University Rural Clinical School both in Mt. Gambier and the Riverland and particularly to Janet Richards, Rachel Hampshire and Lisa Long who tried to enlist support in the Riverland.
Professor John Kalnins who answered my earliest questions, gave me some training in Sweden and visited us in Mount Gambier and who taught me that there was great merit in identifying early neonatal instability in the hip, inspired me to read widely about the subject and has followed our progress along the way.

Perhaps the greatest thanks must go to my husband Peter who championed all that I was doing, gave me welcome advice in my studies and kept the home running smoothly, encouraging me to read and write as much as I could. My children and grandchildren have been extremely interested and helpful in my work, particularly with assistance with computer skills. Enormous thanks to Vicki Charlton who so willingly shared her skills in formatting and document production to bring this thesis to finality.

ABBREVIATIONS

ADUS	Anterior dynamic ultrasound
AMA	Australian Medical Association
APP	Application
AR	At Risk
ARIA	Accessibility Remoteness Index Australia
ASGCS	Australian Standard Geographical Classification System
ASGC-RA	Australian Standard Geographical Classification – Remoteness Areas
BMI	Body Mass Index
CaFHS	Child and Family Health Service
CALD	Culturally and Linguistically Different
CDH	Congenital Dislocation of Hip
CHL	Critical Health Literacy
CAT	Computed Axial Tomography
CASP	Critical Appraisal Skills Programme
CT	Capsular thickness
DB (hip splint)	Denis Browne Hip Splint
DDH	Developmental dysplasia of hip
DRG	Diagnostic Related Groups
eDUS	Early dynamic ultrasound
eADUS	Early Anterior Dynamic Ultrasound
FH	Family History
F/U	Follow up
FURCS	Flinders University Rural Clinical School
GP	General Practitioner
HBM	Health Belief Model
HL	Hip Laxity
IHDI	International Hip Dysplasia Institute
IMG	International Medical Graduate
KT	Knowledge Transfer
LC	Limestone Coast
LDUS	Lateral dynamic ultrasound
LSCS	Lower Segment Caesarian Section
MG	Mount Gambier
MGHS	Mount Gambier Health Service
Mm	Millimetres
MM	Maximum Movement

MRI	Magnetic Resonance Imaging
NDIS	National Disability Insurance Service
NIH	Neonatal Instability of Hip
PATS	Patient Assisted Transport Scheme
PHCRIS	Primary Health Care Research and Information Service
PIP	Practice Incentive Payments
PNG	Papua New Guinea
Q1	Questionnaire 1
Q2	Questionnaire 2
Q3	Questionnaire 3
RCH	Royal Children’s Hospital Melbourne
RFDS	Royal Flying Doctor Service
RGH	Riverland General Hospital
RL	Riverland
RRMA	Rural Remote Metropolitan Areas Classification
SEMA	South East Medical Association
SIDS	Sudden Infant Death Syndrome
SSA	Site Specific Agreement (ethics)
TPB	Theory of Planned Behaviour
UK	United Kingdom
UNESCO	United Nations Educational Scientific and Cultural Organization
UniSA	University of South Australia
USA	United States of America
WCH	Women’s and Children’s Hospital Adelaide
WHO	World Health Organization

PROLOGUE

The way in which we develop is influenced by our family and our environment and these influences have drawn me to the research in which I am currently engaged. As Director General of Public Health, my father instilled in us the view that prevention is better than cure, and this was his mantra throughout his life. He was against the melding of the public health department with the hospitals department as he believed that one dealt with wellness and one focused on illness. As a family, we were encouraged to join in discussions and contribute to debate, but woe betide those who made unfounded statements.

The combination of this background with my great interest in children and their development, led me to studying physiotherapy with the desire to become a paediatric physiotherapist. The powerful opportunity to follow the lifetime experiences of many families as they managed their children into adulthood and subsequently their own families, has given me a close understanding of what an impact disability and poor health can have on a family. Having worked in urban and rural settings in South Australia as well as remote areas of Papua New Guinea has provided a variety of experiences.

Completing my schooling with a year to fill in before I could commence my University studies, I worked at the Adelaide Children's Hospital as an aide in the physiotherapy department, where the job included assisting with exercise programmes for polio sufferers as well as splinting and plaster making. There I learned first-hand what difficulties were encountered by babies, children and their families who were touched by orthopaedic or developmental problems. The polio epidemic was still having an impact on many lives and the difficulties and distance for those who lived outside the metropolitan area were obvious both in family separation and access to services.

After completing the physiotherapy course, I returned to work at the Children's Hospital, completing two years before becoming a tutor in paediatrics at Adelaide University. During this time, I met and married Peter, a medical student. A few years were spent working at university, the hospital and in a private practice, where I held the positions of Director of Developmental Services and Director of Orthopaedics in the hospital physiotherapy department.

Marriage to a medical student with a passion for family medicine and genetics led to a change in direction in my career. After completing two and a half years of internship and six months in a metropolitan general practice, Peter applied to work in Papua New Guinea. We moved as a family with two small children, where he took up a role as a medical officer in

Wewak. Later, he became the only doctor in the West Sepik District, responsible for the health of 100,000 people, many of whom never saw a doctor but relied on Aid-Post orderlies and the Medicine Man. I was not employed in PNG but did voluntary work as a physiotherapist.

On our return to Australia from PNG, he chose to join a medical practice in regional South Australia to continue working where we both felt closer to our families but part of a rural community. We were able to continue to practice the type of family medicine we had enjoyed, in closer proximity to our extended families in Adelaide. Once established in regional South Australia, I commenced private physiotherapy practice, seeing some children I had previously seen in my practice in Adelaide and worked some hours at the regional hospital, providing a paediatric physiotherapy service which had not previously been available outside Metropolitan Adelaide.

My earlier interest in student training was rekindled when medical students were placed at the medical practice for training periods, usually for six to eight weeks. They were expected to live with the GP with whom they were placed and during this placement many of the students spent a few days in the physiotherapy practice to see what was involved and to create more of an awareness of the breadth of family medicine. This expanded over the years to placement for physiotherapy students and further developed my interest in student training.

A growing concern for children who suffered lifelong problems because of the difficulty of access to timely treatment for orthopaedic and developmental problems kindled a desire to promote early intervention both within the public and the private sector and strong outreach contacts were made through the Children's Hospital and various members of their specialist staff.

The discrepancy in outcome between early and late diagnosis of developmental dysplasia of the hip was of particular concern to me and it was clear that there were different outcomes reported with the variations in examination and treatment of this condition. I received an InFront Outback grant to further study methods of assessment of infant hips and any differences in outcome. This led me to probe and understand the research being undertaken in Sweden, where their statistics seemed to review better outcomes than our processes and results. Presentations on this study were delivered in Mount Gambier, Warrnambool and Adelaide, as well as at National Physiotherapy meetings, but seemed to gain only local impact. Most of the study was carried out through the Greater Green Triangle University Department of Rural Health, although the senior members of this team were interested as it was not aligned to their major work on diabetes, obesity and cardiac disease. No further grants were available, but an offer to apply for consideration as a post-graduate student was made. After some discussion with peers, family and staff at both Deakin and Flinders Universities, an application was made to Flinders University, where I was accepted through the Rural Clinical School to enrol in a PhD by research, with recognition being given to my work since graduation and my qualification through the Australian Physiotherapy Association as a Titled Paediatric Physiotherapist.

A trip to Sweden to visit our daughter led to discussions with surgeons and paediatricians about their examination and management of infant hips and meeting and working with Andersson heightened my interest in further researching world practices around neonatal instability of the hip and the development of dysplasia. The parental interest in the scans and the efficiency of the service impressed me.

I had embarked on my career under the medical model, where a physiotherapist provided services under the direction of the referring doctor, only instituting change after discussion and permission from the referrer. With a strong belief in collaborative teamwork with recognition of the individual skills of each member, it is satisfying to see this model more widely used today.

I hoped that my research would provide the evidence for the benefits of early screening and stimulate further discussion leading to changes in the management of infant hips. The development of the study has stimulated a much closer look at world developments in ultrasound. The recent development and availability of a small portable unit with a suitable transducer, may increase the use of early universal screening for more infants.

A study was proposed to understand how acceptable an early hip scan would be to parents and health workers in our regional centre. All mothers giving birth over a period of time at the regional hospital would be offered the opportunity to have an early assessment of their baby's hips using the anterior dynamic ultrasound method as adopted by Andersson. The research was directed at whether early knowledge of instability could alter the management and subsequently, the early development of the infant hip. It was recognised that the numbers and time involved in this study would not be great enough to show any statistically significant alteration in early diagnosis of DDH. Any alteration in early parental management could be measured against a control group which we planned to enlist at another regional centre in South Australia so that there was blinding of the differences in assessment between the two groups.

The problems encountered in carrying out such a controlled trial over the distances involved in regional South Australia were more diffuse and difficult than anticipated and led to a deeper analysis of rural and regional health and its impact on families. Health literacy – as a concept and trope – has been summoned to explain how to intervene and transform regional health. What commenced as a qualitative study with conventional methods, transformed into a provocative exploration of health literacy, regional injustice and strategies for intervention. Research offers surprises. These surprises are gifts which provide an alternative lens and insight to view a problem in a different way. That alternative lens emerges in the pages that follow.

INTRODUCTION

In 1960, in an article published in the *British Medical Journal*, Sir Denis Browne wrote:

> Where does the responsibility lie? If our profession were run as an efficient business with the object of diminishing suffering, every baby would be examined for orthopaedic defects very soon after birth (Browne D, 1960).

Browne worked with babies and young children who had congenital orthopaedic problems and deformities such as talipes equino-varus, dislocation of the hip and spina bifida. He attributed many of these deformities to “packaging problems” and intrauterine pressure on the developing foetus.

Since Browne made this strong statement, many changes have occurred in the assessment of infant hips and the diagnosis of problems. This article was published twenty years before the introduction of ultrasound examinations for hip problems in babies and about the time of the commencement of regular training and usage of the clinical assessment of hips as part of the neonatal examination of the newborn in Australia. The clinical assessment of infant hips was reported in Scandinavia using the method described by Palmen, about a decade earlier, but Barlow and Ortolani described the clinical tests which have been widely accepted around the world since 1969 (Barlow, 1966; Palmen, 1984). In the same year as the publication of Browne’s article, my career as a paediatric physiotherapist commenced when I began work as a physiotherapy aide at the Adelaide Children’s Hospital. My journey through physiotherapy in rural and regional South Australia, outlined in the prologue, has led to the research developed, actioned and presented in this thesis.

The overall aim of this doctoral research is to explore the role of early dynamic ultrasound in the assessment and conservative management of neonatal hip instability in human infants particularly in rural and regional South Australia. It seeks to examine current worldwide methods for assessing neonatal hips where, particularly in rural and regional Australia, late diagnosis of developmental dysplasia of the hip (DDH) is reported to be increasing (Studer K, 2016). What is known of developmental dysplasia of the hip and what is the relationship between neonatal instability of the hip and the development of dysplasia? Recognising that there is variation worldwide in methods to detect instability, can the early examination of hips demonstrate levels of instability that may lead to dysplasia? Will this then lead to improved management and better hip development? The role of early dynamic ultrasound in informing and influencing parental management of infant hips will be examined in one regional centre in South Australia, together with the influence this knowledge can have in that region.

Many physiotherapists have experienced the awful moment of having a parent question why their young baby is not starting to stand and walk, or why they are not crawling like their peers. Some families will notice that the nappy is difficult to change because the legs do not separate as well as one would expect. The immediate concern for the physiotherapist is that there may be something wrong with the baby's hip. Examination quickly reveals that this is likely the case and then the task begins of talking to the family and their doctor about having this further assessed. The physiotherapist immediately fears that there is a likelihood of the baby requiring surgery followed by a protracted time immobilised in plaster, with a prolonged rehabilitation time after the initial treatment is completed.

It is also documented that these children have a high chance of needing a total hip replacement in their third decade and subsequent replacement(s) later in life – a very daunting thought for any family. In a review of hip arthroplasty in adults who had been diagnosed late with DDH, it was found that 25 per cent of all total hip replacements in people under the age of 40 years were related to late diagnosed DDH (I. Engesaeter et al., 2011). Although in some cases there can be an indication of developmental dysplasia of the hip in the first few weeks after birth, there is much debate as to when the problem develops, what predisposing factors for the problem may exist and whether DDH can occur without any detectable signs in the first weeks after birth (A. Chan, McCaul, Cundy, Haan, & Byron-Scott, 1997; Dezateux, 2007).

Normal Hip Development

The hip joint is a ball and socket joint with the head of the femur fitting into the acetabulum, thus creating a strong weight-bearing joint in the adult. The acetabulum is formed by the ischium inferiorly and to the side, with the upper boundary being part of the ilium while the pubis forms the remainder, near the midline. The boundary is covered with the acetabular labrum superiorly. This serves to deepen the surface for the hip joint, producing overall a lunate surface that creates the joint with the head of the femur.

In infants, prior to ossification of these bones, a Y-shaped epiphyseal plate called the tri-radiate cartilage forms the surface (Lee & Eberson, 2006). Similarly, the head of the femur in infants is cartilaginous, generally showing signs of ossification from a few months after birth (Lee & Eberson, 2006). Thus, radiographic examination of the infant hip does not accurately assess the state of the developing joint, and prior to the use of ultrasound, problems with the development of a strong hip joint in children were therefore often not diagnosed until there were identified developmental difficulties such as delayed weight bearing or a Trendelenburg gait (Bracken, Tran, & Ditchfield, 2012). Late diagnosis causes serious problems, with poor mobility for these children and early onset of osteoarthritis (I. Engesaeter et al., 2011).

Neonatal Instability of the Hip

All neonatal hips demonstrate a level of instability immediately after birth, gradually becoming more stable over the first weeks after birth. The hips of newborns should be clinically assessed, with follow up assessment prior to discharge from the maternity unit. In the first six weeks after birth, the impact of increased or maintained instability can be dangerous to the developing hip. It can have an impact on the proper development of a strong relationship between the femoral head and the acetabulum (Gomes, Ouedraogo, Avisse, Lallemand, & Bakhache, 1998; Lee & Eberson, 2006). The failure of a firm relationship between the two cartilaginous structures has been shown by Gomes and also by Lee, to affect the proper development of the hip. Early understanding and management of the amount of movement in the joint has been shown by Andersson to be beneficial in promoting optimal hip development (J. E. Andersson, 1995).

Developmental Dysplasia of the Hip

Previously known as Congenital Dislocation of the Hip (CDH), from the mid-1990s this condition was renamed Developmental Dysplasia of the Hip (DDH) and included unstable, dislocatable or dislocated hips (Bracken et al., 2012). It involved poor acetabular development, neonatal instability of the hip (NIH), or a combination of both. If the hips are recognised as being dislocated, dislocatable or immature within the early weeks after birth, the condition can be satisfactorily treated, and the hips will usually develop well. If diagnosis is delayed until after three months of age, there is a strong likelihood that there will be ongoing problems leading to early joint replacement (Jacobsen & Sonner-Holm, 2005).

It has been recognized more recently by many researchers and clinicians, that instability of the hip exists in the neonate and that this can develop into dysplasia over time (Elbourne, 2002; Gardner & A., 2005; Rosendahl & Toma, 2007). Identification of neonatal instability is therefore important, although some suggest that this early identification may lead to unnecessary treatment in hips which could develop normally.

Variability exists in method of examination of the hip, timing of the initial examination and classification and reporting of those findings. This leads to different reported rates of incidence in the literature. Reported incidence of occurrence varies from 1.5 – 20 per 1000 live births and is influenced by diagnostic criteria, gender, genetics and racial differences (Shipman SA, 2006). This makes comparison of statistics between researchers and countries difficult. In this current study the term “neonatal hip instability” is used in the early weeks and “dysplasia” describes the morphological abnormalities which can be diagnosed on Graf ultrasound after 6 weeks of age. Some infant hips examined by Graf ultrasound prior to 40 weeks’ gestation plus 6 weeks’ post-partum (corrected age) are classified as “immature” in their development in the early weeks of life. It has been shown that hips considered to be normal on initial assessment have later developed dysplasia and some hips initially assessed as having too much movement have developed normally (N. M. Clarke, Clegg, & Al-Chalabi, 1989).

Severity of Developmental Dysplasia of the Hip (DDH)

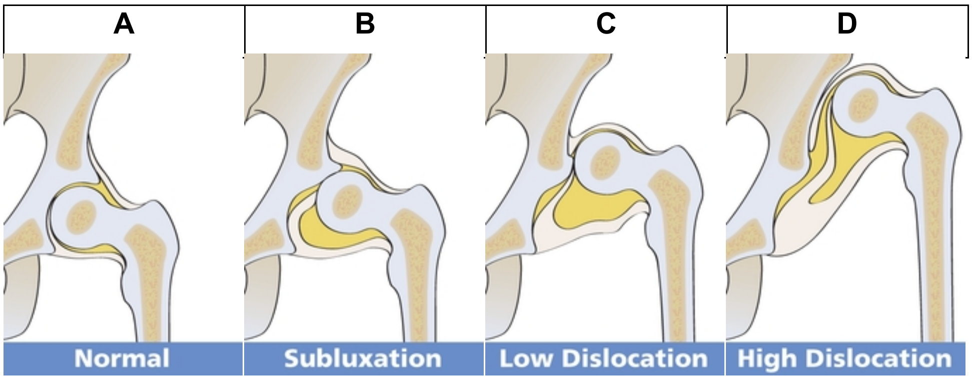


Figure 1 Schematic diagram of hip development

(Reproduced with permission Source: International Hip Dysplasia Institute)

A. A normal hip
B. A poorly developed acetabulum with the femoral not properly contained in the developing acetabulum
C. A subluxable femoral head which can be moved out of the joint on testing
D. Femoral head not enlocated at first examination, which may or may not be felt to return to the joint on testing

The causation of developmental dysplasia has been attributed to genetics, race, intrauterine and post-natal positioning (Palmen, 1984). The incidence of the problem varies from country to country and race to race. More than fifty years ago, it was observed that the incidence of hip problems was very high in the North American indigenous population but non-existent in the Chinese population (Carter C & Wilkinson J, 1964; Hoaglund F, Kalamachi A, & Poon R, 1986). Early work by Sir Denis Browne explained this by the positioning of the infant in utero and in the early weeks of life (Dunn, 2005).

The Inuit infants were strapped on sleds and strapped into cradles with straight legs, so that they could be transported easily over the snow (Bloch A, 1966), whilst the Chinese infants were placed in a position of wide hip abduction and strapped to the mother's back for transport. Browne used this knowledge to propose the use of "active" splints for hip dysplasia where the hips were held in a wide frog position, legs fully abducted, thus directing the head of the femur into the developing acetabulum, but at the same time promoting good controlled active movement of the legs during the transformational phase of the cartilaginous young hip joint into the bony joint of the adult hip. Browne developed a system of splinting which encouraged the movements with a tendency to correct the problem, while disallowing movements thought to cause or exacerbate the problem (Dunn, 2005).

There are some recognised increased risk factors for having DDH. The most common of these are family history, breech position at term, oligohydramnios, some foot deformities and equivocal clinical hip assessment. A study conducted by Lowry, reporting on 131 infants with DDH, found that 40 had family history, 68 were breech and 23 had a persistent click on clinical assessment (Lowry CA, 2005). This study examined 5485 hips in infants at risk of having developmental dysplasia of the hip. The researchers used the Graf ultrasound method at 3 days and again at 8 weeks after birth. One conclusion from this study was that the Graf ultrasound at 3 days was an unreliable test and the scan at 8 weeks provided a much more reliable indication of developmental problems in the hip.

Lowry then analysed which of the risk factors were consistently present in children found to have DDH. The risk factors found to be most reliable predicators for hip problems were family history, breech delivery or equivocal clinical assessment. It was found that clinical assessment alone was ineffective in diagnosing dysplastic or dislocated hips and concluded that this may be due to inexperienced operators or to limitations of the method. Eleven hips thought to be normal at 3 days were subsequently found to be dysplastic at 8 weeks. The overall incidence of DDH in this group was 3.2/1000.

Despite the variation in assessment and management seen in different parts of the world, there is consistent evidence of an increased rate of late diagnosis over the last ten years. This increased rate has been attributed to the increase in swaddling of infants as a way of encouraging settling (Williams, Foster, & Cundy, 2012).

Assessment and management of infant hips

Clinical Assessment

Clinical assessment is ideally performed on a relaxed, quiet baby, placed in a supine position with both hips flexed and symmetrically abducted. Using the techniques described by Barlow and Ortolani (Barlow, 1966; Ortolani, 1976), gentle pressure is exerted over the knee, in a backward movement with a small inward rotatory movement to assess the stability of the joint (Barlow). Using the fingers over the outer thigh, an attempt is then made to feel any relocation of the joint, felt as a "clunk" as the hip relocates if there is a problem (Ortolani). Clinical assessment identifies those hips which feel too mobile or which can be felt to "clunk" in and out of the joint on the Barlow and Ortolani tests.

Figure 2 Clinical Assessment – Hip

Images removed due to copyright restrictions. Available online from:
https://www.researchgate.net/publication/323747595_Developmental_Dysplasia_of_the_Hip/figures?lo=1

Figure 3 Barlow and Ortolani Tests

Routine clinical screening of neonatal hips has been reported in Sweden since the 1950s (Finnbogasan, 2008a), the United Kingdom since 1969 (Elbourne, 2002) and Australia since 1962 (Paterson, 1976). The examination relies on clinical assessment of movement or possible dislocation and relocation of the hip during provocation of the joint, using the techniques described by Barlow and Ortolani (Barlow, 1966; Ortolani, 1976).

Palmen in 1953 in Sweden, instituted routine hip examinations at the majority of hospitals where there was a paediatric consultant. His methods were similar to those described by Ortolani, in Italy, in 1937, although these tests were not routinely performed at that time. Ortolani reported, whilst examining a 6-month-old infant that he felt the hip move over the rim of the acetabulum and later, confirmed on x-ray that the hip was dislocated. Many Swedish studies therefore use and describe the Palmen-Barlow manoeuvre which became widely accepted in Sweden from 1957 (Finlay, 1967).

The use of ultrasound as a diagnostic technique was developed from 1980 and will be described in more detail in a separate chapter (chapter 2) in this thesis.

Current clinical guidelines for hip assessment

International Practices

The mode of assessment of infant hips varies from country to country and considerable studies have been undertaken to evaluate the efficacy of differing methods. There is universal acceptance of clinical assessment of all neonatal hips by the delivering doctor, a paediatrician or an orthopaedist in the first few days after delivery. In major centres the majority of reported articles are based on examination by a specialist, although it is recognised that this is not universally available. Population ultrasound screening of all neonates is practised in Austria and parts of Northern Europe and Scandinavia, while universal clinical assessment, followed by selective ultrasound examination for those with an equivocal clinical assessment or any of the common risk factors for DDH, is practised in most other parts of the world.

Australian Practices

In Australia, the current clinical practice guidelines recommend that all babies have a clinical assessment of their hips by the delivering doctor, with further assessments at medical appointments and when the infant and maternal nurses are consulted (Atrey, Gupte, & Corbett, 2010; South Australian Department for Health and Aging, 2014).

Clinical assessment of all neonatal hips is currently accepted as the most economic assessment of hips in Australia (Azzopardi et al., 2011). All infant hips are examined by the delivering doctor, midwife or attending paediatrician, using the method described by Barlow and Ortolani. The hips are described as being stable or unstable, dislocatable or dislocated, on clinical assessment when subjected to these tests. All hips felt to subluxate or dislocate on clinical examination will be referred for further examination by ultrasound and may be treated in a Denis Browne hip splint or a Pavlik harness. The standard ultrasound examination used in Australia is the Graf ultrasound. This examination will occur either at a large urban centre or a regional centre where the service is available, usually contingent on having a trained sonographer and radiologist.

Figure 4 Pavlik Harness

Reproduced with permission Source: International Hip Dysplasia Institute

Denis Browne Bar

© Royal Children's Hospital, Melbourne, Australia
Kids Health Info www.rch.org.au/kidsinfo

Figure 5 Denis Browne Hip Splint

Despite improvements in diagnosis augmenting the standard clinical assessment of infant hips, debate has continued about the most economical and effective way to assess hips. The number of children with late diagnosed hip dislocation in South Australia, is reported to be 0.77/1000 in a study of incidence between 2003 - 2009 and the number of those with dysplasia is reported to be higher (Studer et al., 2016). This figure represents a marked increase in the late-diagnosis rate from the low figure reported in studies between 1988 and 2003, when a rate of 0.22/1000 in South Australia. A study conducted in Western Australia with a cohort of infants born between 1 January and 31 December 2010 found a late-diagnosis rate of 0.57/1000 which the researcher stated was three times higher than the previously reported rate (Lisle R, 2012).

Furthermore, recent studies have suggested that birth in a rural or regional hospital is a risk factor for late-diagnosis of hip problems (Azzopardi et al., 2011). The increasing practice of early discharge from hospital (within the first day or two) is also a risk factor for late-diagnosis (Azzopardi et al., 2011), as these infants may leave hospital without a follow up hip assessment.

Operator inexperience in the assessment of infant hips has been claimed to be a contributing factor in the increased incidence of late diagnosed DDH in rural and regional South Australia (Azzopardi 2011). Differing experiential levels exist between clinicians in urban and rural areas, attributed to the birth rate of the area in which the baby is born and, consequently, the experience of the attending doctor. The work of Thornbury, where he distinguishes between efficacy and effectiveness - efficacy being a model that works with experienced operators, while effectiveness is a model which works in the customary clinical setting - demonstrates the basis for the urban/rural differences where rural clinicians have been stated to have less experience than their urban counterparts (Thornbury JR, 1994) (Dogruel, Atalar, Yavuz, & Sayli, 2008).

Consequences of late diagnosis

If diagnosis is delayed until after three months of age there is a strong likelihood that there will be ongoing problems leading to early joint replacement, as early as the third decade of life (Bracken & Ditchfield, 2012). As many as 8 per cent of all total hip replacements performed have been attributed to hip disorders in childhood (I. L. Engesaeter, T. Labore, L. Lie, S. Rosendahl, K. Engesaeter, L 2011) Such difficulties and the inactivity caused have been associated with an increased likelihood of developing disorders such as diabetes, obesity and heart disease (Marma & Lloyd-Jones, 2009). If the hips are recognised as being dislocated, dislocatable or immature within the early weeks after birth, the condition can usually be satisfactorily treated and managed and the hips will develop well. Early unexplained hip problems leading to early joint replacement may be the result of undiagnosed poor development of the hip (L. B. Engesaeter, Wilson, Nag, & Benson, 1990).

Clinical assessment alone under-diagnoses instability and is experience-dependent, with skilled, trained and experienced operators more reliably performing the procedure (Bloomfield, 2003; Sharpe, Mulpuri, Chan, & Cundy, 2006). As few as 31% of cases of DDH diagnosed have a history of recognised risk factors or positive findings on clinical examination (R. W. Paton, Hinduja, & Thomas, 2005; Shipman SA, 2006). Some infant hips reported as normal on clinical examination at birth, are later found to be dysplastic. Increased rates of late diagnosed dysplasia, after three months of age, were reported in Australia between 1988 and 2003 (Azzopardi et al., 2011) and again in a more recent paper (Studer et al., 2016).

Studies of the development of the hip in the embryonic stage have demonstrated the importance of a strong relationship between the developing head of the femur and the acetabulum, to promote good growth and stability (Gomes et al., 1998; Lee & Eberson, 2006). This is reinforced by Bracken who states that “concentric reduction of the hip is important for normal acetabular development” and underlines the importance of early diagnosis of hip problems (Bracken et al., 2012).

Some researchers have suggested that all hips should be examined by ultrasound to verify findings (Snyder M, 2016 #163; (Bache, Clegg, & Herron, 2002), but this is not considered to be best practice in many countries because of the cost of the procedure, difficulties with access to ultrasound services and fear of the occurrence of over-diagnosis and subsequent treatment of hips which may spontaneously improve without treatment (Shipman SA, 2006).

In a study of universal screening, Bache (2002) found that sixty per cent of the hips demonstrating instable in the first weeks, showed spontaneous resolution without treatment, with only 5% showing dysplasia on radiograph at 6 months. Questions remain as to whether early dynamic ultrasound enhances the detection of neonatal instability of the hip and whether such knowledge can be used to instigate and monitor conservative management of instability. If so, is there a place for conservative preventative care with parent education around ultrasound results, hip development and infant positioning and wrapping?

The literature reports that 0.1% of morphologically normal hips are dislocatable, 0.6% of reported immature hips are dislocatable and 60% of the hips which are reported as slightly dysplastic will be dislocatable (Dezateux, 2007). Since 2008, an increased incidence of late-diagnosed DDH has been noted worldwide (N. M. Clarke, Reading, Corbin, Taylor, & Bochmann, 2012). This increase has been attributed to the increasing culture of wrapping or swaddling of babies which has become more prevalent since the advice to sleep newborn babies in supine. Supine sleeping has occurred at the same time as an increase in unsettled babies and the use of firm wrapping or swaddling to settle babies has become widespread (Sleuwen, 2007).

Treatment of infant hips depends on age, severity and location. In Australia, hips that are diagnosed on clinical assessment as dislocated or dislocatable commence treatment immediately, usually under the direction of a paediatric orthopaedic surgeon or a paediatrician. A splint is generally applied, followed by an ultrasound examination after fitting of the splint to ensure that the hips are enlocated with the splint in place.

A hip found to have immature development at the six-week ultrasound examination, using the Graf technique, is usually splinted in abduction using either a Pavlik harness or a Denis-Browne abduction splint. A repeat ultrasound scan is performed to verify a satisfactory position in the splint. Splints are generally worn for eight to twelve weeks, until the ultrasound examination shows the head to be well covered and the α angle to be satisfactory. In some other countries, notably Scandinavia and some parts of Europe, splints such as Frejka pillows and von Rosen splints are used (J. Andersson, 2002). Hips that cannot be satisfactorily reduced may require surgical intervention and hips that do not develop satisfactory femoral head cover may also need surgery. Surgery can vary from an adductor release, a manual reduction or, later, a remodelling of the acetabulum (Bracken & Ditchfield, 2012).

An increase in the incidence of late diagnosis has been reported in Australia over the last decade (Azzopardi et al., 2011). The problem is reported to be greater in non-urban settings where the examination of infant hips may more likely be performed by operators with limited experience (Sharpe et al., 2006). Studies from regional Western Australia have highlighted this, as have studies from Victoria and South Australia (Goss, 2002; Lisle R, 2012; Studer K, 2016). The West Australian study reported a late diagnosis incidence of 0.57/1000 live births. Lisle (2012) also identified swaddling as the most consistent and significant common factor in the late diagnosis group, suggesting that a more detailed study of type and duration of swaddling is warranted.

A study conducted in South Australia has attributed the general increase in late diagnosis to the growth in supine sleeping, the effect of wrapping babies for improved settling and the subsequent move away from prone positioning (Studer et al., 2016). These alterations in baby management have all occurred at the same time, in an effort to lower the incidence of sudden death occurrences in infants (Studer et al., 2016). Supine sleeping of infants is part of the Safe Sleeping Programme conducted Australia-wide as a measure to lessen the incidence of Sudden Infant Death Syndrome (SIDS). Advice and diagrams to show supine sleeping positions and discourage prone or side-lying (Appendix A) have contributed to a drop in the incidence of SIDS (American Academy of Pediatrics, 2005). These techniques are taught and reinforced in maternity units and by maternal and child health workers. Although the benefits of this teaching have been shown in the reduction of sudden infant deaths, back sleeping coupled with a fear of placing infants in prone may be contributing to the increase in hip problems recorded universally.

There is no indication of instability occurring at a later stage in hips deemed to be stable on ultrasound examination in the first week after birth (J. Andersson, 2002) yet, on the other hand, hips that were considered to be sound on initial clinical examination have gone on to develop dysplasia (Rosendahl & Toma, 2007). Identifying hips that may be in danger of improper development is therefore a key issue. The higher incidence of late diagnosis in rural and regional South Australia noted by Azzopardi (2011), warrants deeper examination. It is suggested that lack of experience in those examining infant hips may be part of the problem and the statistics may not improve without targeted intervention that includes education.

The benefits of Early Detection

The consensus from those working with children with developmental dysplasia of the hip is that the earlier the problem is detected, the better the chance of a good outcome for the child and the family (Gardner & A., 2005). As a regional physiotherapist, concern was held over the research published by Azzopardi and Cundy showing that developmental dysplasia of the hip in infants was more likely to be diagnosed late in those born in rural and regional

South Australia than in those born in the metropolitan area. It was claimed that this was influenced by lack of experience in assessing infant hips in these regional areas (Azzopardi et al., 2011).

Influences in Rural and Regional Australia

Recognising that experience and training are important in skill development, consideration must be given as to how this may be achieved in the regions, where such issues as staff retention and access to ongoing education have been shown to be significant factors. The workforce in medicine and allied health in rural and regional Australia has been studied by many scholars over the last ten years. Studies have been conducted into availability and consistency of service across a range of medical and allied health services and many have reported inconsistencies in service provision. Allinson et al, in their study into allied health provision in neonatal intensive care units and special care facilities, found that there was widespread agreement on the value of neurodevelopmental assessments, but a lack of consistency in availability in Australia and New Zealand (Allinson, Doyle, Denehy, & Spittle, 2017).

A similar study looked at the provision of hand therapy services in rural and remote areas in a cross-sectional survey between metropolitan/regional and rural/remote areas(Kingston, Williams, Judd, & Gray, 2015). This study identified four main barriers to consistent provision of services: location, staff limitations, transport/travel time and lack of expert knowledge. These issues were examined under the themes of relationships, patient centred care, rural and remote practice and staff development and education. The researchers concluded that technology could be used across Australia in the support of rural and remote practitioners, to improve equity and inclusion. A shared care model was proposed where metro/regional practitioners could support and advise rural/remote therapists in sharing information, assessments and outcomes. Such an approach would enhance the understanding of rural and remote issues and promote a feeling of support for the therapists in these locations (Kingston et al., 2015).

The recruitment and retention of medical and allied health personnel in rural and regional Australia has come under much investigation with studies examining trends in employment in the workforce between 1990 and 2011 (K O'Toole, Schoo, Stagnitti, & Cuss, 2008). Carson et al (2017) have found that the numbers of physiotherapists in urban areas have risen above the national average between 2006 and 2011, while in rural and remote areas these numbers have fallen below the average since 2001. Similar findings were reported for the Australian general medical workforce (Carson, Punshon, Schoo, & Ryan, 2017).

A further study conducted by Buuljens et al (2017) examined public hospitals in the state of Victoria, Australia, with particular attention to the range of maternity models of care and access to allied health professionals. In their study, they found: "the service was dominated by obstetric models of care and little continuity of care and/or carer, despite best practice recommendations and consumer feedback regarding desirability of this." The authors found a discrepancy between information provided by the hospitals and that retrieved from Government sources (Buuljens, Robinson, Murphy, Milgrom, & University of Melbourne, 2017).

From a clinician's viewpoint, particularly in rural and regional Australia or for those learning the technique of clinical assessment of the hip, Goss (2002) found that constant and repeated training over a long period of time is necessary (as outlined above in section 1.1.3.4). In his training programme, Goss suggested that at least 100 examinations are necessary to develop the sensitivity and skill to perform the clinical test confidently. The ability to visualise and measure the movement on ultrasound examination of the hip may be useful in developing the skills of the clinician in performing the clinical assessment contemporaneously.

For many doctors working in areas where birth numbers are low, 100 assessments may take a very long time to achieve and the chances of feeling an abnormal hip even in 100 assessments is very low, considering the incidence of DDH may be 1 - 2 /1000 (Lisle R, 2012). Therefore, the expectation that inexperienced people are able to clinically assess the amount of movement in the hip may be inaccurate.

A comparison of current practices globally must recognize the clinical commitment undertaken in Scandinavia, where every infant is offered a dynamic ultrasound of their hips while still in the maternity hospital. The movement in the hip can be seen under guidance of anterior dynamic ultrasound and accurately measured during the standard clinical test. The results from this screening process have shown markedly better outcomes for these babies than those reported in Australia by Goss and Studer in their studies (J. Andersson, 2002; Goss, 2002; Studer K, 2016). No cases of late diagnosis of developmental dysplasia of the hip were reported by Andersson, with 0.18% of those examined being treated. Studer reported an increase in late diagnosis of DDH from 0.22/1000 in the years from 1988 - 2003 to 0.7/1000 from 2004 - 2009.

Andersson, in a cohort of 22,047 infants examined by ADUS in the first week after birth, found 175 infants in whom one or both hips were unstable (7.9/1000). He divided the hips into three categories:

- Dislocated, where the head of the femur was not visible in the acetabulum on ultrasound view. These hips showed > 7mm movement on testing
- Dislocatable, where the head of the femur could be moved 5 - 7mm on testing
- Stable, where the amount of movement was 4mm or less on testing

In this large cohort, Andersson noted a small variation in the measurements dependent on the birthweight of the infant. He reported that 1.1/1000 were dislocatable and 2.2/1000 received treatment. The treatment consisted of the wearing of a von Rosen splint with ultrasound checks to monitor the progress of the hip during treatment. The ratio of girls to boys was 3:1 and the left hip was involved in 64% of cases. There were no reported late diagnosed cases.

Goss advocates clinical assessment by well-trained clinicians and reports an incidence of neonatal instability in 6.4/10000 with a late diagnosis rate of 2/1000. This study was conducted in a regional centre in Victoria, while Studer in her South Australian study(J. Andersson, 2002; Goss, 2002; Studer K, 2016) found an overall incidence of DDH of 6.7/1000 with a late diagnosis rate of 0.7/1000 between 2003 and 2009. This late incidence rate represented 11.5% of all cases diagnosed and was a considerable increase on the late diagnosis figures prior to 2003.

Instability of the hip is known to be present to some degree in all newborn babies, gradually firming up over the first few weeks after birth in most infants. A firm relationship between the developing acetabulum and the head of the femur will provide the best opportunity for the development of a stable hip, as the cartilaginous joint transforms into the bony joint necessary for optimum weight-bearing throughout life. Early identification of those hips that remain unstable and poorly developed will lessen the chances of lifelong hip problems for this group of infants.

Late diagnosis of DDH is known to be a greater problem in rural than urban South Australia. This divergence is attributed to lack of experience in the assessment of infant hips, poor infant management of hips in danger and tight wrapping of babies to assist in settling. NIH has been blamed for these management problems having such an impact. Early management of NIH has been successfully instituted in some countries, where universal screening of all infant hips is conducted. Such universal scanning has been shown to be a useful adjunct to early management and improvements in portable ultrasound machines make this a reasonable expectation in rural Australia. A preliminary scan can identify those hips which require closer monitoring or referral for specialist management. This can not only expedite earlier awareness and prevention of long-term problems, but it can also increase parental awareness of good hip development. It may be useful in assisting the teaching of techniques of early clinical assessment for rural and regional clinicians who have been shown to have a lack of experience in evaluating the clinical assessment of infant hips (Goss, 2002).

After locating the problems, challenges, initiatives and research, this thesis set out to explore world trends in early diagnosis and management of neonatal instability and developmental dysplasia of the hip. From such international framing, late diagnosis has been shown to be a greater risk to infants born in rural and regional areas of South Australia. Parental knowledge and understanding of neonatal instability may contribute to improved management of the neonatal hip and lessen the chances of the development of dysplasia of the hip. Early identification of instability in the hip creates the opportunity for improved management and promote more consistent surveillance of those infant hips in danger of poor development, thereby lowering the incidence of late diagnosis of this potentially debilitating disorder. Late diagnosis of DDH is taken to be a diagnosis occurring after three months of age, when the chance of requiring a total hip replacement as early as the third decade of life as a result of early onset arthritis are greatly increased (Jacobsen & Sonner-Holm, 2005).

In attempting to evaluate the benefit of early identification of neonatal instability of the hip by the use of early anterior dynamic ultrasound, a doctoral study was commenced in two regional centres in South Australia, where one group was the experimental group and the other group was the control group. Two regional centres were selected because the difficulty of blinding the two groups was considered to be too difficult if they were both in the same region. The monumental failure of this research method was productive and confronting. The failure led to a deeper exploration of the differences between the two regions, the variation in interest and involvement in the study between the two regions and any differences in behaviour after the study.

Chapter one defines and describes the development of the infant hip, exploring neonatal instability, DDH, trends in assessment and management worldwide. Chapter two outlines the impact of hip dysplasia, exploring the case stories of children with early and late diagnosis of hip problems and some of the difficulties experienced by those families, emphasising the need for early identification of possible problems in hip development. The need for the proposed research study is demonstrated and outlined in the third chapter. Universal early scanning was offered to all babies born in one regional centre while standard care was offered to the control group, as outlined in the third chapter, with reference to the literature review underpinning the programme of research. Chapter four describes the continuing data being gathered in the group of infants considered to be at risk of having a developmental problem with their hips. The following two chapters examine the possible reasons for the differences in outcome between the two regions with an examination of the possible causes for the large discrepancy we found in uptake and the extreme difficulty encountered in conducting research with this vulnerable group of people. The final chapter examines changes in regional health services over the years of working in one region in South Australia and how these changes may have led to difficulties with recruitment and retention of experienced professionals in regional South Australia. Consideration is given to ways of improving the experience for health workers and health care users in regional areas in Australia.

Difficulties in obtaining, sustaining, maintaining and retaining medical and allied health workers in rural and regional Australia are widely reported. Some reasons for this are discussed, in conjunction with the difficulties experienced in accessing timely health care for families and children with identifiable health problems. Improvements in health education with particular reference to infant hip health, are proposed, with attention paid to earlier hip status identification and management, using advances in digital communication and education, coupled with developments in more portable battery powered ultrasound machines.

My original contribution to knowledge lies in the development of more accurate assessment of infant hips in regional South Australia with the availability of improved ultrasound opportunities. This measure of hip status will assist parental understanding and clinical ability of examiners to better manage early instability of the hip and may improve the outcome over a lifetime for those children who may otherwise have required later hip surgery.

The recognition of the multiplicity of rural and regional health service provision is explored throughout this doctoral research. Literature reviews have been integrated into the key chapters, rather than as a self-standing section. The interdisciplinarity required to answer, frame and develop this research has necessitated scholarship from allied health professions, regional scholars and literacy researchers. The goal of aligning this unusual and productive literature is to demonstrate the need to fully utilise professional expertise and tailor services to reflect availability and access to those services may increase incentive for retention of professional staff in regional Australia and encourage better interprofessional collaboration.

CHAPTER 1: THE IMPACT OF HIP DYSPLASIA

Introduction

Developmental dysplasia of the hip can occur in any child and the early diagnosis of this condition has been shown by the research to be important. Late diagnosis is blamed for lower success rates with treatment and higher surgery rates with an added cost burden to families. The number of late-diagnosed cases in South Australia has risen to 0.7/1000 in the last ten years (Studer K, 2016).

Neonatal instability of the hip (NIH), where the femoral head can move away from the acetabulum in the first weeks of life, may be an important risk factor for the development of dysplasia (Finnbogason, Jorulf, Soderman, & Rehnberg, 2008b). DDH is the most common notifiable musculoskeletal birth defect in Australia with an incidence of 7/1000 births in 2007 in South Australia (Gibson CS, 2007). Despite serious long-term consequences for children with late diagnosis of DDH best practice early screening techniques are debated with considerable variation in routine screening protocols internationally. A literature review was conducted to investigate the use of early dynamic ultrasound screening (eDUS) methods for the detection of NIH. What is the evidence for its use and the benefit of early knowledge of neonatal instability in infant hips? This literature review was published and a copy can be found in appendix C of this thesis (Charlton S, Schoo A, & L., 2017). The research literature required for this thesis transformed from this early published article and has been integrated in each chapter. This decision was made because the focus transformed through the recognition of regional inequalities and health literacy. Therefore, these research fields were aligned and conflated with the wider literature on instability in infant hips. The resultant research concentration and shape of this thesis is more precise and attendant to the research questions.

The consensus of those working with children with developmental dysplasia of the hip is that the earlier the problem is detected, the better the chance of a good outcome for the child and the family. Debate continues worldwide about the advantages and disadvantages of early population screening using ultrasound examination. In Australia, early universal clinical assessment of all infant hips is the recommended standard procedure, whereas in some other countries universal early ultrasound screening is practiced.

In order to understand neonatal hips in the first three months after birth and to better grasp the family impact of DDH in rural South Australia, it is useful to consider the stories of infants who have been diagnosed with hip problems at different ages. Those in the first group reported below, were not identified until several months after their birth, while those in the second group were diagnosed in the first few weeks following their birth. The studies are drawn from cases known to the author in her paediatric physiotherapy role in a regional centre where she has worked for many years. Records of all children seen in this practice are stored electronically in password protected files until the child reaches 25 years of age, as is the legal requirement. The case studies shared in this thesis have been drawn from records of children in whom active treatment was deployed over the period 2010 – 2019. The parents of these children have signed a consent for their stories to be used for educational purposes and the information has been de-identified to further protect their anonymity. All parents have access to their child's records within the practice and their stories presented in this thesis have been shared with the parents concerned. A previous study investigating parental acceptance of an infant ultrasound screening programme has informed the use of anterior dynamic ultrasound. (Charlton, Muir, Skinner, & Walters, 2012). The physiotherapy practice has been continuously providing service to children across the region for over forty years and is staffed by physiotherapists with both paediatric and teaching experience. It is unique in the provision of dedicated services to children in a regional area.

Clinical practice has highlighted the variation in assessment, diagnosis and management of early hip instability and developmental dysplasia of the hip in one regional centre in South Australia. Most expectant mothers in the regional centre are cared for ante-natally by their family GP with some midwife input. Their delivery is managed by GP obstetricians who are contracted by the hospital to provide a rostered service to the maternity ward. These GPs are "on call" to manage the delivery and care for the mother and new baby post-natally while they are in the maternity unit. Following the discharge of the mother and baby from the maternity unit they return to the care of their family doctor, with a midwife home visit during the first week after discharge and further follow up through CaFHS visits. It can be seen that continuity of care may be disrupted at several stages of the early post-partum period given the number of professionals who will contact the new family over the first busy weeks with this new baby. Some continuity could be gained from ensuring that all assessments are entered in the hand-held baby record by all who examine the baby.

The following clinical stories in this chapter, using fictitious names to protect the identity of the children, will demonstrate the variation, revealing differences in commencement and duration of treatment with varying outcomes. Over the years of practice, we have followed the path of many children who have been affected by late diagnosis of their developmental hip problems. The impact this has on their activity levels and social skills has been of concern over that time. Problems such as inability to take part in competitive sport, dancing classes or hiking exercises are common. Absence from school because of surgical intervention, coupled with loss of worktime for the parents, all contribute to the long-term cost of late or missed diagnosis of this problem, which if identified early can be fully corrected with minimal interruption to normal development or family life.

Experiences of late diagnosis and long-term intervention

Matilda

HISTORY: Born in a regional hospital, prolonged labour, difficult delivery. Post- delivery maternal complications. Hips reported as normal on clinical assessment.

Referred for physiotherapy assessment at 22 weeks of age, because of asymmetrical posturing.

EXAMINATION: Happy, responsive baby, asymmetrical posture, head rotated to the left, left leg flexed, right leg extended, marked loss of hip abduction in the right hip compared with left. Unhappy lying on her tummy.

Graf Ultrasound of hips: 25% femoral head coverage on the right (Graf Type III) and 45% on the left (Graf Type II).

INTERVENTION: Denis Browne hip splint applied, holding the hips in as much abduction as could be comfortably obtained, adjusted after a settling period. Referral to an orthopaedic surgeon in tertiary centre, where x-ray and ultrasound revealed poorly developed but enlocated hips. Matilda continued splinting for twelve weeks with an orthopaedic review at that point. The left hip was still unstable, and surgery was recommended followed by continuation of the brace.

At 10 months of age, further x-ray showed improvement and the brace was continued. Further x-ray at 16 months of age showed sufficient improvement to allow removal of the brace.

Case Discussion:

Matilda spent more than a year of her life in a brace without being able to enjoy a bath or other water play, having to adapt to moving with her legs constantly flexed and abducted at the hip, and being unable to crawl, roll and play like her peers. By the age of 2 years and 8 months, sixteen months after removal of her brace, she was able to run, climb steps and stand on one leg. She was physically performing similarly to her peers in a playgroup. Her social interaction and sensori-motor planning were lower than that of her peers and she relied heavily on parental help and encouragement. Her language and communication skills were well developed for her age. The family spent much of Matilda's infant life travelling for specialist care with frequent interruptions to work time. The impact for Matilda and her family was huge, with trips to specialist care once a month and multiple ultrasound and x-ray examinations. The cost of travel and accommodation added to loss of income can clearly be seen. Matilda's hips will need to be monitored over her lifetime and the chance of needing an early hip replacement is high.

Lucy

Age at first presentation: 3 years and 6 months.

HISTORY: Noticed at play group to walk with a limp and have difficulty sitting cross-legged on the floor, running and jumping. Unable to stand on one leg. Poor balance. She was born in a small country hospital. Uneventful neonatal period. No record of infant hip clinical assessment. Noticed to only roll one way and crawled with one leg tucked underneath her body. Walked at 14 months.

EXAMINATION: Walked with an uneven Trendelenburg gait and obvious shortening of her left leg. Difficulty sitting comfortably on the floor. Her left hip movement was extremely limited, fixed in 15-20 degrees of flexion and a tendency to a lumbar lordosis on attempts to straighten the leg. Her left hip abduction was limited. The hip was slightly adducted with a deep medial groin crease.

INTERVENTION: She was referred to an orthopaedic surgeon where a left dislocated hip was discovered. After surgery to the left hip she spent two months in a plaster hip spica, fixed in hip and knee flexion.

Case Discussion:

On removal of the plaster, Lucy was frightened of moving, unable to sit up and fearful of bathing and water. Her left leg was held in flexion at the hip and knee, and she was unable to lie in prone. Walking gradually resumed and at 4 years old, she was walking with a left limp and running with difficulty. Her hip remained stiff but had full extension range.

At four and a half, her hip was x-rayed showing the hip in situ with a misshapen head of femur and a rough acetabulum. She occasionally complained of pain and lacked adequate flexion and abduction in the hip. She was unable to sit on the floor with her legs out in front of her and still limped when walking. Usual classroom activities remained difficult for her.

Lucy continued to have mobility and coordination difficulties over the following years. Keen to keep up with her peers, she commenced a Little Athletics programme but developed back and leg pain following a fall, shown on later x-ray to be a crush fracture of a thoracic vertebra. At seven years and six months of age, her family reported that she had trouble keeping up with her peers when on school excursions although her hip x-ray was reported as satisfactory. Her inactivity had led to some gastrointestinal problems.

Problems over her lifetime as a result of the very late diagnosis of her DDH have included poor balance and coordination affecting her participation and confidence in interacting with her peers combined with delay in the attainment of her developmental milestones. She has suffered severe bouts of pain due to her immobility and tightness of muscles. The back injury could have been due in part to weakness of bones as a result of inactivity. The constipation and bowel motility were also related to a low activity level and inability to toilet in an optimal position whilst immobilised in a spica. Starting school in a pusher and encased in plaster had an effect on social acceptance by her peers. There were parts of the school programme in which she was unable to participate.

There was a protracted impact on her family as they lived on a farm in rural Australia and her father worked as a shearer and contract farmer but was unable to continue itinerant work because of his involvement in the increased care needs of the family. Relocation to a small rural town allowed him to find part time farm work. Trips to the capital city still involved a five-hour journey for the family. The special seating and mobility equipment necessitated the purchase of a station wagon as the family vehicle.

Lucy has had eight x-rays and spent almost three months of her life immobilised in plaster at a time when most of her peers were in a very active stage of their development, learning about their environment and developing their independence in different situations. This has had an impact on her confidence and ability to approach new situations. The family has made multiple trips to the capital city requiring overnight accommodation and absences from work.

Her hips will need constant monitoring throughout her life and it is likely that she will require an early total hip replacement in her second or third decade.

Rebecca

Age at first presentation: 8 weeks

HISTORY: Mother and Child and Youth Health workers worried about asymmetry and lack of hip abduction. Hips had been noted to be normal on clinical assessment in the neonatal period.

EXAMINATION: Happy baby lying with head to the right, body position curved convex to the left, able to actively turn head to the left 50 degrees beyond neutral to follow a dangling object. Very unhappy when placed prone. Graf ultrasound examination of hips was arranged.

RESULT: The ultrasound showed bilaterally immature hips with poor coverage and a low alpha angle indicating poor development of the acetabulum.

INTERVENTION: In consultation with an orthopaedic surgeon, a Denis Browne hip splint was applied holding the legs abducted and the hips in a good position. After 8 weeks the splint was removed. The hips were reported as having adequate femoral head coverage with 63% coverage on the right and 60% on the left. The alpha angles had improved to 71° on the right and 65° on the left.

FOLLOW UP: Annual imaging and reviews with the orthopaedic surgeon were conducted and at 6 years of age bilateral acetabular dysplasia with flattening of the femoral head was reported and a painful limp developed. At 7 years of age Perthe's disease of the left hip was diagnosed and treated in a Scottish Rite orthosis for 23 hours per day to alleviate continuing pain on activity. Treatment transferred interstate where she underwent a right femoral osteotomy and was non-weight-bearing for six weeks, followed by left hip surgery at age 8 years and 2 months with no weight-bearing for a further 10 weeks. She is now able to ride her bike, swim and to participate in athletics. Removal of her plates and screws will be carried out soon.

Case Discussion:

Subsequent family history highlights some significant facts. A younger sibling born 18 months after Rebecca had an early ADUS of her hips as she was considered to be in the "at risk" group for hip problems because of her family history. She was found to have an increased range of neonatal instability of the hip and was placed in a hip splint at two weeks. Her hips were enlocated on ultrasound views taken in the splint and she wore the splint for a further six weeks. On removal, her hips were reported to be stable in the joint with good coverage and a good alpha angle. Her hips have continued to be stable and pain free. At the time of her birth, her father shared his hip history which involved long standing bilateral subluxations of his hip discovered when he had his legs x-rayed after a motorcycle accident. It resulted in bilateral reconstructive surgery of both hips at that time and he will have further surgery in the future. He had played sport as a young man with no knowledge of any problem with his hips. This raises the possibility that an earlier ultrasound examination of the instability in Rebecca's hips could have led to earlier management of a familial development problem and may have led to better development of her hips, thus alleviating some later hip problems.

Evaluation of late diagnosis

The case histories of Matilda, Lucy and Rebecca illustrate the long-term problems children with late-diagnosed developmental dysplasia of the hips can face. They demonstrate the challenging position the family and the attending physiotherapist can find themselves in when confronted with such a profound problem that, when diagnosed earlier, can be relatively easy to treat. When occurring in one rural practice and drawing on a country region over a relatively short space of time, it raises the question of what steps could be undertaken in general to improve the early diagnosis and management of infants with hip problems in rural areas. The following reports of early diagnosis and management demonstrate a marked difference in duration of treatment and a minimisation of family disruption, emphasising the importance of investigating the overall benefits to rural and regional people. This second group of case stories will demonstrate the opportunity of assessing hip status earlier in the child's life, uncovering dislocation earlier and identifying instability which may have led to the development of dysplasia.

Experiences of early diagnosis and management

Jack

Age at first presentation: 2 days

HISTORY: Born by elective Caesarian Section, breech presentation with extended legs.

ASSESSMENT: In the post-natal ward hips were found to be clinically unstable and an ultrasound was arranged. Early anterior dynamic ultrasound was performed in the first week with a Graf Ultrasound at the same time, as this infant was in the "at risk" group of babies.

RESULT: ADUS revealed a subluxing hip with 5mm movement in the left on Palmen-Barlow test and 3mm movement in the right hip. Both hips were reported as immature on Graf examination.

INTERVENTION: A Denis Browne hip splint was applied. A further ultrasound was conducted one week later to check the position in the splint. Both hips were enlocated.

FOLLOW UP: Visits to adjust for growth and splint management were held. At 8 weeks, the splint was removed with a further ultrasound examination undertaken 2 days later. The ultrasound showed that both hips were well developed, enlocated and stable on stress testing. Both hips had 65% cover of the head in the acetabulum with an alpha angle of 78 degrees. The baby continued to have a typical milestone development and has had no further problems.

Case Discussion:

Although it is a traumatic experience for the parents to have their newborn infant in a hip splint and not be able to bath him in the usual way, with small adaptations the early weeks proceed as normal. The splint is removed before there is any interruption to normal milestone development. The infant is usually quite used to spending time in prone and is often advanced in head raising and propping skills. This infant had three early ultrasound examinations, five physiotherapy visits and one brace at a total cost of $530.00, some of which is compensable with medical benefits extra cover.

Louise

Age at first presentation: 2 days

HISTORY: Born by Caesarian section due to a prolonged labour. Noticed to have "clunky" hips on clinical assessment of hips and referred for an anterior dynamic ultrasound.

ASSESSMENT A subluxating right hip was seen on ADUS.

INTERVENTION: A Denis Browne hip splint was applied.

FOLLOW UP: The hip position was reviewed with a scan two days later. The hip was enlocated and, as the baby had settled well, she went home on day 7 to the family farm 250 kilometres away. The family returned for 2 review visits over the next 5 weeks and were instructed in the removal of the splint at 6 weeks. Two days after the splint was removed a review scan showed the hip to be enlocated and stable with 67% cover of the femoral head in the acetabulum, and an alpha angle of 70 degrees. A further visit at 10 months of age showed her development to be at an age appropriate level, with good sitting, crawling, pull to stand and her hips had a full range of movement.

Case Discussion:

Apart from the nuisance of having a baby in a hip splint and being unable to bath her, this family had two long trips to physiotherapy treatment and a further visit for a final review at 10 months. She had one ultrasound as an outpatient. In addition to the long road trips, their costs were $400.00 for the splint and the treatment, some of which was compensable with medical benefits.

Thomas

Age at first presentation: 8 weeks

HISTORY: Born in rural hospital, normal pregnancy and delivery. Noticed by GP at the 6-week review to have limited hip abduction.

ASSESSMENT: an ultrasound scan showed inadequate cover of both femoral heads. Subsequently, he was referred for treatment. At first visit to physiotherapist, it was noticed that he was tightly wrapped and, due to cultural custom, also had his legs tied together with a ribbon at the ankles. On untying ribbon, the hips were difficult to abduct allowing only 40 - 50° abduction of each hip.

INTERVENTION: A curved hip splint was applied in as much abduction as could be comfortably gained without any force and a return visit was requested in three days allowing for settling and some relaxation. On the third day in the splint the legs had relaxed and the splint was adjusted to a better position. A repeat scan was arranged to check the position of the hips in the splint.

FOLLOW UP: Four visits were conducted for adjustment and skin checks, and the splint was removed after 8 weeks (then aged sixteen weeks). The repeat ultrasound scan out of the splint showed the hip to be well developed and enlocated.

Case Discussion:

The practice of tying the ankles together, apparently a cultural custom, was previously unknown to the researcher. The problems this created for optimal hip development were discussed with the parents who were considered leaders in their community. Information was shared with them about optimal conditions for good hip development and best methods of wrapping were demonstrated. The later start of treatment had allowed the hips to become tight, making settling to a satisfactory position to be a slower process over more time and physiotherapy visits. The costs and end result were still much less than for those who did not commence treatment until much later. In this case the cost apart from travel, was approximately $600.00. Ideally, this child should have a follow up check with an x-ray at 2 – 3 years.

Evaluation of early diagnosis

The case histories of Jack, Louise and Thomas, all infants who were part of the “at risk” group reported on pages 35 - 37 of this thesis, demonstrate how earlier recognition of hip problems can shorten the treatment time and associated costs. Family history of hip problems is recognised as a risk factor for subsequent hip problems and usually arouses suspicion that early hip assessment of all children in that family should be rigorously undertaken. In the case of Thomas, it allowed the early identification of a positional problem which otherwise may not have been noticed until further damage had occurred to the hip development.

Discussion

There is universal agreement that the incidence of developmental dysplasia of the hip is more commonly found in the presence of the risk factors outlined earlier in this chapter. The effect of these risk factors is debated and viewed differently by different authors (R. W. Paton et al., 2005) (Bache et al., 2002). There are however, a significant number of children who will be diagnosed with dysplastic hips who have not been identified as being in this group. As many as 60% of late-diagnosed DDH cases will have no identified risk factors. Indeed, Sharpe, Mulpurri et al have described being breech at term as being protective for late diagnosis, as follow up with these babies is usually consistently carried out and documented(Sharpe et al., 2006).

The burden of DDH can be seen to affect health services, families and the individual with monetary and emotional costs at each level. Early diagnosis and monitoring of neonatal instability of the hip and the prevention of subsequent DDH may be of benefit at each level.

“Mummy, why can’t I play and run like my friends?”: The importance of knowing and accurate early identification:

The case reports outlined in this chapter (using fictitious names to protect the identity of those involved) illustrate the impact that late diagnosis and late commencement of treatment can have, not only on the child, but on the family and others dealing with the problem. By comparison, the shorter treatment time and much more satisfactory results in the early diagnosed group suggest that there may be benefit in a measurable method of evaluation of instability in infant hips to identify hips at risk of poor development. This earlier identification can lead to more targeted management and the promotion of optimal development.

The possibility of using the dynamic ultrasound as a teaching tool in the clinical assessment of infant hips should be further explored. Over the duration of the anterior dynamic study with the participant group enrolled in the universal scanning study, the assessors challenged their own ability to assess the amount of movement being felt on clinical assessment, against the actual movement measured. An increase in the accuracy of “predicting” the measurement was seen as the study progressed, indicating an improvement in ability to assess the movement whilst performing the Barlow manoeuvre. Further study in this area is warranted.

The varied outcomes of these cases prompted a greater literature search to understand the timing and methods being used around the world, to seek to improve the outcome for infants at risk of developing hip problems, particularly those in rural and regional Australia. A report of the literature considered in this study can be found in the appendices on page 198 of this thesis. The questions that guided my research were:

- What evidence is there about the benefits of early dynamic ultrasound in the assessment of NIH?
- What advantages and disadvantages are being reported?
- Could ADUS be reliably performed in a regional centre in South Australia?
- If so, is this true of other regional centres in Australia?
- What are the barriers and enablers for this?

From these early and late diagnosis stories there is a marked shortening of treatment time and family disruption with the earlier assessment. There are differences in what has been found between the two groups. In measuring the amount of instability in the very young hip, it has been possible to manage that and encourage better development of the hip. Parents have welcomed the opportunity of earlier intervention in those children who were found to have a dislocated hip, particularly in the case of the mother who had lived with a chronic stiff and painful hip as a result of late diagnosis in her own situation.

These life stories of early and late diagnosis highlight the benefit, indeed necessity, of timely identification of hip problems in babies. The personal impact on the child and the family can be clearly seen, together with the added cost to the health system. In examining individual family stories such as those outlined in this chapter, we are able to gain a clearer picture of the trajectory of concern, cost and disappointment these families have suffered.

These individual cases frame a discussion of the increased burden this can be for families living in regional South Australia where an increased risk of late diagnosis has been reported. They highlight the need to explore world trends in methods of earlier identification of hip problems in infants and to assess opportunities to improve identification in region South Australia. In the following chapter, the use of methods of ultrasound will be explored with discussion about varying techniques and timing of the use of ultrasound in diagnosis and management of infant hips.

CHAPTER 2: ULTRASOUND IN THE DIAGNOSIS AND MANAGEMENT OF INFANT HIPS

The type and timing of ultrasound examination of the infant hip is debated at length in the literature. The two most common methods discussed are the anterior dynamic ultrasound and the Graf ultrasound. It is clear from the literature that these are two entirely different examinations deployed for two distinct purposes. Clinical examination of all neonatal hips is currently accepted as the most economic assessment of hips in many European countries, UK, USA, Canada and Australia, with infants considered at risk of DDH, or with hips demonstrating subluxation then undergoing Graf ultrasound examination at 6 weeks of age.

Ultrasound techniques

Graf Ultrasound

In 1980, Graf described an ultrasound examination of the hip that allowed a morphological assessment of the structure and position of the components of the joint, making it possible to assess hip problems in infants at a much earlier age than previous x-ray examinations (Graf, 1983a). The ultrasound examination is conducted in a side-lying position, with the transducer over the lateral aspect of the hip joint. A view is obtained with the tri-radiate cartilage at the base of the joint and the bony acetabulum in view, with the cartilaginous labrum extending from that. Measurements of the angle of the roof of the acetabulum and percentage cover of the head are taken. Initially the hips were classified as normal, immature, dislocatable or dislocated, although these classifications were later further graded.

Type	Bony Roof	α Angle	Cartilaginous Roof	β Cover
Type 1	Good	>60°	Covers femoral head	1a <55° 1b >55°
Type IIa <3/12	Adequate	50 – 59	Covers femoral head	<77 Review 3/12
Type IIb >3/12	Deficient	50 -59	Covers femoral head	<77
Type IIc Stable/Unstable	Severely deficient	43 – 49	Still covers femoral head	With stress <77 With stress >77
Type D Decentering hip	Severely deficient	43-49	Displaced	>77
Type III Eccentric hip	Poor	< 43	Pressed upward	
Type IV Eccentric hip	Poor	< 43	Pressed downward	

Table 1 Ultrasound screening classifications according to Graf (De Pellegrin & Tessari, 1996)

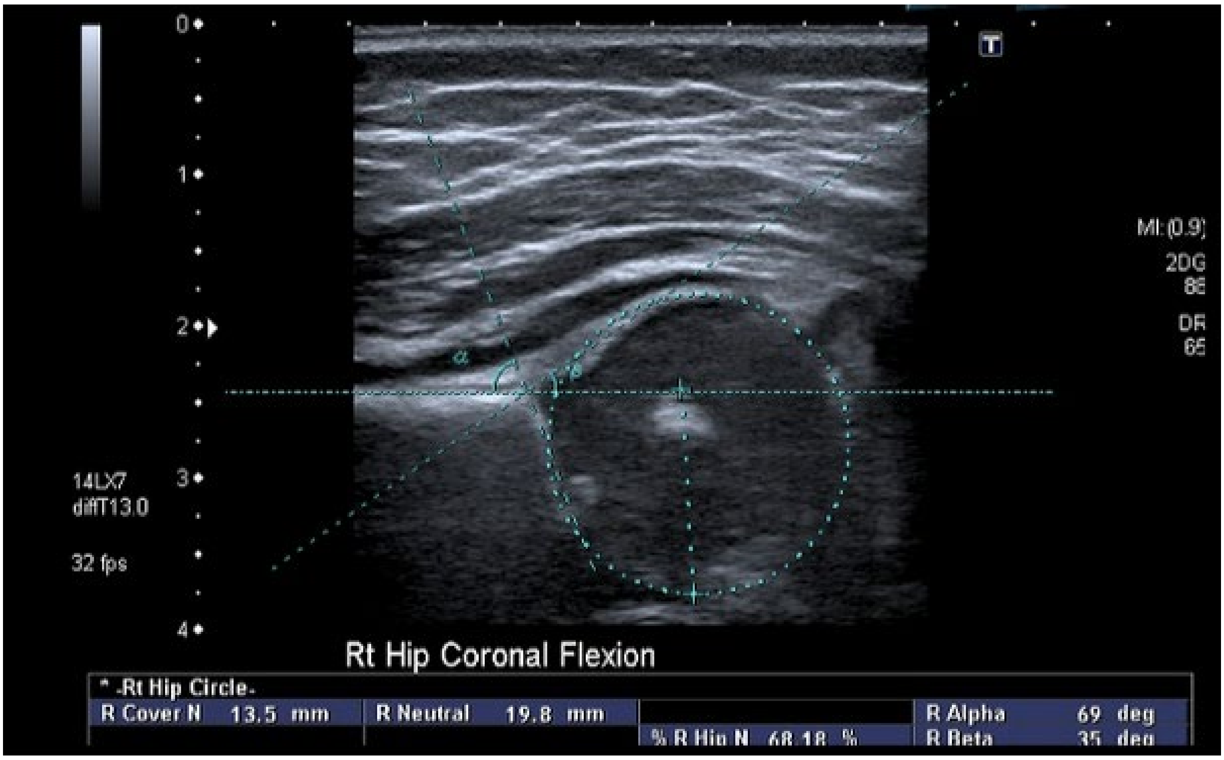


Figure 6 Graf ultrasound with measurements - normal hip with developing ossification centre

(Personal records – reproduced with permission Benson Radiology)

Ultrasound, as a diagnostic tool for hip problems in children, was modified by Harcke who, in 1984, devised a method of examining the hip dynamically using a lateral view while applying a backward pressure to the flexed hip (Harcke, Clarke, Lee, Borns, & MacEwen, 1984). This allowed a visual assessment of the movement of the head of the femur in relation to the acetabulum.

Dynamic ultrasound examination of the hip in Australia was reported as early as 1988, using a lateral approach over the greater trochanter of the femur (Saies, Foster, & Lequesne, 1988). A method of measuring the posterior movement under perturbation was devised; measurements were taken antero-posteriorly across the acetabulum in line with the femur. Harcke and Morin (2005) modified the lateral dynamic ultrasound (LDUS) with the baby supine, viewing the hip in flexion whilst performing a Barlow manoeuvre.

Terjesen added measurable assessment to this examination (Terjesen, Bredland, & Berg). In contrast, Dahlstrom (Dahlstrom, Oberg, & Friberg) instituted anterior dynamic ultrasound (ADUS) where the hip was examined in an antero-posterior direction, flexed to 90 degrees and in 60-70 degrees of abduction during the provocation tests of Palmen/Barlow (Finnbogasan, 2008a). The resultant movement of the femoral head backward in the acetabulum from a line across the top of the joint can be seen and measured in millimetres.

Other dynamic ultrasound techniques include those described by Novick and Gomes (Gomes et al., 1998; Novick, 1983). Novick used an anterior inguinal view with the hip flexed while performing a Barlow manoeuvre whereas Gomes used two types of ultrasound, a modified Graf lateral ultrasound applying pressure backward in a Barlow manoeuvre and the anterior technique described by Novick. The two contemporary ultrasound techniques that assess hip instability are lateral dynamic ultrasound (LDUS) and anterior dynamic ultrasound (ADUS).

Anterior Dynamic Ultrasound

The ADUS is an early screening test to measure the amount of movement in the hip during the Palmen-Barlow test. ADUS is a real time, dynamic scan measuring the maximum antero-posterior movement of the femoral head in relation to the acetabulum during hip abduction of 70 degrees (MM). As discussed, this measurement can be seen, measured and recorded. The ADUS becomes more difficult to measure accurately after six to eight weeks when the hip naturally has less movement and there is often more soft tissue covering in the area, increasing the difficulty of performing the Palmen-Barlow test and also making a clear picture more difficult to obtain. Early measurement of instability in the neonatal hip has been shown by Andersson and others to identify hips at risk of developing dysplasia.

A range of measurements of movement within the neonatal hip over the first six weeks has been developed (J. E. Andersson, 1995). Andersson describes the following measurements:

> In a view with the widest diameter of the femoral head, where the anterior and posterior acetabular edge could be identified, the measurement from the anterior acetabular edge to the femoral head without provocation is considered to be the capsular thickness (CT). A view of the greatest movement under provocation is taken, measuring the distance between the anterior edge of the acetabulum and the femoral head (MM) The difference between MM and CT is considered to be a measure of hip laxity (HL) (J. E. Andersson & Funnemark, 1995).

Andersson in his examination of over 100,000 hips, suggested that hips with less than 1 mm of movement measured with the leg flexed at the hip and in 70 degrees abduction were very stable, those with 2 - 4mm of movement were considered to be within the normal range. Those with greater than 4mm at the initial examination required careful management, keeping the leg frogged in abduction, and rescanning after four weeks to make sure the hips had become more stable. At this later second scan if there were greater than 2mm of movement, which Andersson described as the thickness of the joint capsule, the hip was considered to need further positional control to maintain a stable position of the head of the femur within the developing acetabulum.

Gomes described similar amounts of movement in his classification (Gomes et al., 1998), while Rosendahl (1994) calculated a percentage of head movement from a series of three lines drawn through the hip joint. Line a. was the baseline, parallel to the iliac border, line b. the bony roof line, tangential to the bony acetabular roof and line c. was the inclination line from the bony rim to the centre of the labrum. The angle between a. and b. was the measurement of the alpha angle.

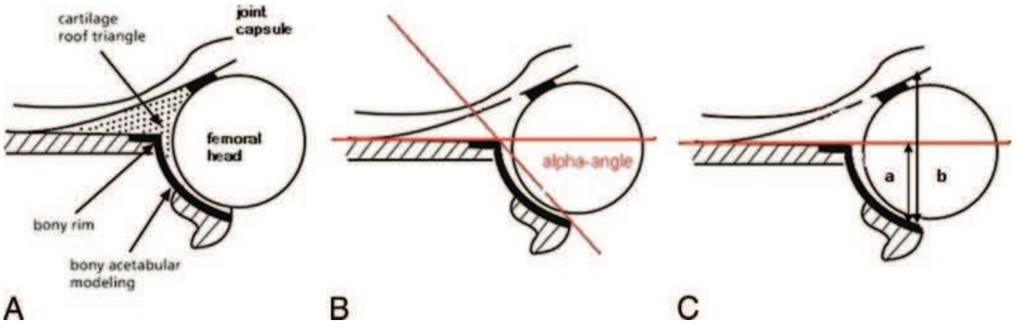


Figure 7 Alpha angle [Graf] (K. D. Rosendahl, C. et al, 2010)

Dahlstrom held the probe anteriorly on the hip joint, parallel to the femoral neck, viewing a section midway between sagittal and transverse and measured the postero-lateral displacement from there (Dahlstrom et al., 1986). Finnbogasan developed a single operator method using a specially designed table with an overhead support for the transducer and reported on this in his thesis (Finnbogasan, 2008a). Andersson uses a trained technician as the operator with a nurse to stabilise the pelvis. The Palmen/Barlow test was performed by one operator who gently abducted both hips 60-70 degrees thus stabilising the pelvis, before applying backward pressure to the abducted femur on the side being tested, whilst maintaining the other hip in 60-70 degrees abduction.

Figure 8 Anterior dynamic ultrasound showing 2.3mm of movement of femoral head in acetabulum

A review of the literature was conducted, to explore the role of early dynamic ultrasound (eDUS) in screening and early intervention of NIH. The primary outcome of the review was to describe the efficacy of eDUS with the secondary outcome of describing early interventions instigated as a result of eDUS findings. These results were then considered for the specific context of rural Australia.

Early interventions in the reviewed articles occurred prior to 6 weeks of age and was categorised into three groups: primary prevention, secondary prevention, and conservative management (Table 2).

Intervention Group	Intervention Method
Primary prevention	Advice and instructions on positioning to optimise hip flexion and abduction including avoiding swaddling with legs wrapped tightly together
Secondary prevention	Double nappy techniques, removable splints and Frejka pillows
Conservative management	Non-surgical splinting

Table 2 Early Interventions for DDH in first 6 weeks of life

The research considerations in response to the literature review.

ADUS can be used reliably up to 6–8 weeks after birth (Finnbogasan, 2008a; Finnbogason et al., 2008b; Holen et al., 1994). After that time, the increasing strength and weight of the baby make accurate performance of the Palmen Barlow test difficult. The amount of movement is higher immediately after birth and this has been attributed to infant uptake of the hormone relaxin in late pregnancy (Bache et al., 2002). Some researchers have proposed normal ranges of movement seen on ADUS of hips over weeks 1-6 of life, ranging from 1mm-6mm and progressively reducing with age (J. E. Andersson, 1995; Finnbogasan, 2008a). Andersson's robust study positions his normal range findings as most valid in contemporary western contexts (J. E. Andersson, 1995).

Early studies in this review period recognised that examination with eDUS improve the diagnostic value of static morphologic ultrasound examination (Elbourne, 2002; Gomes et al., 1998), particularly when performed by trained providers (Afaq, Stokes, Fareed, Zadeh, & Watson, 2011; A. Chan, Foster, & Cundy, 2001). Most studies recommended eDUS for infants with risk factors including: family history, breech position, foot deformity, and equivocal clinical assessment (Afaq et al., 2011; Bache et al., 2002; A. Chan et al., 2001; Finnbogason et al., 2008b). One small study expressed concern about the operator dependence of eADUS results (Kaijser, Larsson, Rosenberg, & Josephson, 2009). One study demonstrated that eADUS of infants with risk factors for DDH can lower the treatment rates (Finnbogason et al., 2008b). However, clinical examination and eDUS identify overlapping groups of newborns, with some infants having solely positive clinical examination findings and others having solely eDUS evidence of instability (Shipman SA, 2006). Some authors claimed that eDUS could result in additional hips being subjected to early intervention (Shorter, Hong, & A, 2011; Woolacott, Puhan, Steurer, & Kleijnen, 2005). At risk screening was recommended over universal screening by some, because of the low prevalence of NIH, its natural history to commonly improve spontaneously, and the cost of eDUS (Afaq et al., 2011; A. Chan et al., 2001; Finnbogasan, 2008a) .

As many infants diagnosed with DDH did not have a history of traditional risk factors, a number of authors proposed eDUS screening for additional groups including: all girls, units where neonatal clinical screening was not of high quality, and in geographical areas with high prevalence (Bache et al., 2002; Holen et al., 1994; Rosendahl & Toma, 2007; Shipman SA, 2006). The cost effectiveness of universal eDUS screening was recognised as dependent on national health system models (such as found in Scandinavia), however several studies recognised that this is changing, with increasingly litigious societies and lower cost scanning options being developed (J. Andersson, 2002; N. M. Clarke et al., 2012; Harcke, 2005).

There were inconsistent approaches to early interventions for unstable/subluxable hips between studies. A number of these research projects recognised that eADUS screening provided an opportunity for more frequent surveillance only (Afaq et al., 2011; Bache et al., 2002; N. M. Clarke et al., 2012; Elbourne, 2002; Finnbogasan, 2008a; Gomes et al., 1998; Harcke, 2005; Rosendahl K, Dezateux C, & Fosse K, 2010; Rosendahl & Toma, 2007) . Many of these studies advocate delaying splintage until after 6 weeks of age to allow for spontaneous improvement (Afaq et al., 2011; Bache et al., 2002; Finnbogasan, 2008a; Harcke, 2005). Only one paper, by a paediatrician mentioned primary prevention for unstable/subluxable hips (J. Andersson, 2002). This paper did not specifically discuss education of parents and carers about positioning and handling for optimal development of the infant hip. Six studies considered secondary prevention in the first 6 weeks including: double nappy techniques, removable splints and Frejka pillows (N. M. Clarke et al., 2012; Finnbogason et al., 2008b; Holen et al., 2002; Kaijser et al., 2009; Reikeras, 2002; Rosendahl & Toma, 2007) . Two studies described conservative management including non-surgical splinting with Pavlik harness or Denis Browne hip splint (A. Chan et al., 2001; N. M. Clarke et al., 2012). None of the studies in the literature review described baseline information about how infants with NIH were wrapped and positioned in the first months of life. Although it is commonly recognised that early intervention for DDH is frequently less invasive, only one small study (n = 41 hips with NIH Frejka pillows for 16 weeks compared with n = 44 hips with NIH in control group) considered the rates of infant hips needing management after 8 weeks of age following secondary prevention (Reikeras, 2002). Finally, only one study considered conservative management (Pavlik harness) soon after initial ultrasound, and although this study concluded that treatment rates were acceptable at 5-15 per 1000 births, it did not comment on avascular necrosis rates (N. M. Clarke et al., 2012). Of note is the discipline-specific preferences, with radiologists unlikely to consider early intervention other than surveillance, and orthopaedic surgeons having a greater focus on conservative management.

This literature review did not support universal eDUS screening of neonatal hips, however contemporary recommendations support eDUS for areas of high prevalence and reduced operator reliability of clinical screening. Rural Australia can be considered a geographical area with high prevalence of DDH where a concerning trend in increased late diagnosis has been found (Azzopardi et al., 2011; Cundy, 2004).

Discussion on choice of ultrasound type

The Graf ultrasound is unreliable in the first six to eight weeks after birth, as the measurements in the infant hip have a wide normative range in both the alpha angle and the percentage cover of the femoral head (Cundy, 2004). The Graf ultrasound records the morphology of the hip joint. An attempt to gauge the stability of the joint has been included, by applying a posterior force along the line of the femur to visually assess the movement of the head backward in the acetabulum. Attempts have been made to quantify this posterior movement across the acetabulum in line with the femur.

The ADUS and the Graf ultrasound are both extremely useful in the assessment of the infant hip. The ADUS is a simple test to perform and augments the clinical assessment which is standard procedure for every infant born in Australia. The clinical assessment gives an estimate of the amount of movement in the hip and is dependent on individual assessment, which has been shown to vary according to experience of the operator. Experienced paediatricians have been rated the most consistently reliable in their clinical assessment, while experienced physiotherapists and orthopaedic surgeons have been shown to be equally competent in one reported study (Bracken et al., 2012). The results can be more scientifically documented when the clinical test is verified on ADUS. In our trial, studies of 86 infants in one regional centre it has been seen that the test is repeatable and acceptable to parents and the most difficult thing has been to cease doing the ADUS for the general population.

Early understanding of the amount of movement in the joint has been shown by Andersson to be beneficial (J. E. Andersson, 1995). In a small pilot study conducted in Mount Gambier with the InFront Outback grant, information was sought about whether ADUS was acceptable to parents and could be used in a regional hospital to improve the understanding of their infant's hips. The ADUS was not seen as an alternative to the Graf which gives information about the morphology of the hip joint, it was used to measure the amount of movement in the infant hip in the first two weeks after birth. In our study Graf US was used to further examine hips in any infants where there was an excess of movement shown on ADUS. The Graf ultrasound was used to measure the alpha angle and demonstrate the position of the head of the femur in relation to the developing acetabulum. It is known that this is an unreliable test in this age group as there is wide variation in measurements. We used it to show any hips which were dislocatable or already dislocated.

Currently in Australia, infants considered at risk of DDH, or with hips demonstrating increased mobility or subluxation, undergo a hip ultrasound examination at six weeks of age using the method described by Graf, in accordance with the current clinical guidelines (South Australian Department for Health and Aging, 2014). The angle of the developing roof of the acetabulum and the percentage cover of the femoral head are measured and recorded. Early Graf ultrasound score, prior to six weeks of age, is reported to be unreliable at demonstrating the angle of the roof of the acetabulum (alpha angle) and the percentage cover of the femoral head (Azzopardi et al., 2011; Riad et al., 2005) due to the wide variation in measurements seen in this age group.

ADUS as a teaching tool

There may be a place for the ADUS as a teaching tool, reinforcing clinical judgement. It has been shown by Goss that at least 100 repetitions of clinical examination over a short period of time are necessary to develop competence in the clinical assessment of infant hips. As discussed earlier in this thesis, in areas where the birth rate is low, this may take a long time for individuals to achieve. The incidence of increased instability in the neonatal hip is reported at variable numbers in different studies, as there is some variation between studies as to what constitutes instability. The incidence of dislocation is 1:1000. This highlights the difficulty encountered when developing skill at assessing the amount of movement being felt on clinical assessment and has led to the recommendation by some that, ideally, all hips should be examined by an experienced paediatrician or paediatric orthopaedic specialist (Finnbogason et al., 2008b). This is not a realistic recommendation because of the lack of access to such specialists across outlying regions in Australia and therefore the cost to parents of attending such an appointment. An appointment with a specialist requires a referral from a GP. It follows that ideally an orthopaedic examination should be offered in every hospital where there is a birthing unit, but this is not practicable. Realistically such specialists are based in capital cities and some larger regional centres. In some instances, they may make infrequent visits to more remote areas.

Evaluation of the use of ADUS in the Limestone Coast region

Writing on congenital deformities of mechanical origin in Perinatal Lessons from the Past, Sir Denis Browne advocates inductive reasoning. Discussing the causes of the occurrence of some developmental abnormalities in infants, such as some foot deformities and infant hip problems he states:

> To prove the question one way or another by direct observation is at present impossible, and it appears likely ever to remain so. In consequence, I am reduced to a method that might possibly be used more in medicine than it is, the method of comparing what abstract argument shows to be the consequence of the granting of the hypothesis under test with what is actually found in real life. If the results of

> abstract inductive reasoning of this sort coincide with those of observation over a wide and complicated range, the truth of the hypothesis on which the reasoning was conducted is proved as nearly as absolutely as most things can be in this world.

With this statement in mind, it is pertinent to review the history of the use of ADUS in the assessment of infant hips in one regional centre in South Australia.

The recognition that morphological assessment of the hip did not provide the whole picture led to ways of making an assessment of the amount of movement which could be produced on testing, during the standard clinical test of infant hips. The earliest reports of dynamic screening in Australia were made by Saies in Adelaide when he viewed the hip laterally while applying a stress force posteriorly along the line of the femoral shaft. In this way he could see and assess the amount of movement, but it was not measured numerically. The stress view was included in Graf ultrasound examinations of the infant hip, after six weeks of age and demonstrated any tendency for the head of the femur to move posteriorly in the hip socket (Saies et al., 1988).

It was recognised that all neonatal hips had some level of instability immediately after birth, gradually decreasing over the first few days. This was attributed to the circulation of the hormone relaxin from the mother, during the later stage of pregnancy, although some dispute this (J. E. Andersson, Vogel, & Uldbjerg, 2002). It has been observed that female babies have a higher incidence of hip problems than males. Clinical assessment of newborn hips became universally accepted as the gold standard.

Clinical assessment of infant hips commenced nationally in 1960 in Australia and the techniques were taught in medical, nursing and allied health training. Evaluation of this teaching established that the test was experience dependent and quite subjective. Studies considered the variation in results with the clinical assessment, both between professions and with experience, and found this to be significant (Bloomfield, 2003).

The incidence of dislocation is low and varies with gender and race, so the experience of feeling a dislocating or mobile hip is as low as 3-7/1000 (Goss, 2002) whereas the incidence of some instability is higher, but quantifying this instability is a very subjective measure. Parental knowledge of the infant hip is also quite low, so it may be difficult for a parent to realise the importance of maintaining a good position for the developing hip.

Research in Sweden and Northern Europe developed an anterior dynamic ultrasound technique to assess the amount of movement during the Palmen-Barlow clinical assessment of the hip (Finnbogason et al., 2008b). This method was widely used in Scandinavia and became a part of the universal assessment of infant hips in that population. Critics of this method argued that it required two operators and was therefore too costly and that it led to overtreatment in the early weeks after birth.

The literature review undertaken shows articles from around the world debating these methods and arguing about the outcomes. Despite all research, there are still a worrying number of cases of late-diagnosed DDH and much debate as to what constitutes “late diagnosis”. In our region, in line with most current thinking, this is taken to be a diagnosis made after 3/12 of age, as the literature indicates that such a child has a high chance of requiring a total hip replacement in their third decade.

Every baby born at MGHS will have a clinical assessment of their hips made by the delivering doctor, midwife or paediatrician, both at the initial infant assessment and over the following few days. If any abnormality is detected a referral for further assessment will be made. This may be a referral to the paediatrician or to the paediatric physiotherapist. The paediatric physiotherapist acts in a consultant role to provide neonatal assessment and support for babies with orthopaedic problems born in MG. An study from the 1990s reports that well-trained allied health practitioners including physiotherapists have been reported to make hip clinical assessments at least as well as trained consultant physicians (Krikler, 1992) Together with the referring doctor the decision will be made as to what follow up is required. This may be referral to a tertiary centre, further examination such as early ultrasound, splinting or special management. The advice and support of WCH specialists may be obtained by telemedicine conferencing and transfer as indicated.

There is a reported worldwide increase in the use of diagnostic ultrasound and its use in remote areas of the world is increasing with ongoing research and evaluation. It has been found to be useful in developing countries where access to medical and surgical expertise can be very remote (World Health Organisation, 2013). It has been shown to lessen the need for travel for some patients and to speed up surgical and trauma treatment for others who have had their problem established before their transfer to tertiary centres.

In this chapter I have outlined the development of ultrasound examinations of the hip as a diagnostic measure. The use of static and dynamic ultrasound has been discussed, particularly the methods devised by Graf, using a lateral approach and the anterior dynamic ultrasound method developed by Harcke and modified by Morin, as used by Andersson in his studies. These two forms of hip ultrasound are shown to identify different attributes of the developing hip. The Graf ultrasound identifies the morphology of the joint while the ADUS measures the stability of the joint, which may be important differentiation in early development of the hip. Understanding the stability of the joint in the early weeks may be important in facilitating specific measures for handling and positioning of the infant hip and may alert clinicians to the need for increased surveillance over the neonatal period.

CHAPTER 3: THE INTERVENTION

THE INFLUENCE OF EARLY IDENTIFICATION OF HIP STATUS BY ANTERIOR DYNAMIC ULTRASOUND ON PARENT KNOWLEDGE AND MANAGEMENT OF INFANT HIPS

Introduction

Chapter 3 discusses the background to the intervention study, incorporating the literature review which formed the basis for the decision to further investigate early anterior dynamic ultrasound in a regional centre. The ontology and epistemology of the study will be outlined along with the methodology and methods used in the attempt to uncover any differences in parental action between two groups of new parents.

Historical perspectives

As discussed earlier in this thesis, in order to avoid developmental dysplasia of the hip (DDH), the metaphyseal growth and ossification of the neonatal cartilaginous acetabulum must occur around "a properly seated femoral head" (Gomes et al., 1998). Neonatal instability of the hip (NIH), where the femoral head can move away from the acetabulum, in the first weeks of life may therefore be an important risk factor for the development of dysplasia (Finnbogason et al., 2008b).

As a physiotherapist practicing in a regional centre in South Australia, concern was held over the research published by Azzopardi and Cundy showing that developmental dysplasia of the hip was more likely to be diagnosed late in infants born in rural and regional South Australia than those born in the metropolitan area. It was claimed that this was influenced by lack of experience in assessing infant hips in these regional areas (Azzopardi et al., 2011).

My research led to a closer examination of the anterior dynamic ultrasound techniques being used in Scandinavia and time spent in Sweden heightened my interest in this method of infant hip examination. The path would be to first assess our ability to trial the use of ADUS. This involved discussion with our local radiology department, local doctors, midwives and hospital administrators. Discussions were also held with radiologists from the WCH and with the orthopaedic department at WCH.

As a member of the Clinicians Advisory Group for the Greater Green Triangle University Department of Rural Health, a joint venture of Deakin and Flinders Universities I was awarded a PCRIS grant to undertake research into the ADUS method and its possible application in our region. Together with the senior sonographer from Benson Radiology we studied the technique and established a means of measuring the amount of movement we were seeing in each child's hip on real time scans. These videos were recorded and stored for later review. Professor John Andersson had established a range of measures in the infant hip and we took these as our standard measurements (J. E. Andersson, 1995). Thus, in the first week after birth, a movement less than 4mm is taken to be normal while any movement from 4-5mm indicates excess movement. A movement greater than 5mm indicates subluxation and some hips can be seen to be outside the acetabulum on initial examination. These measures were adopted in all my studies.

A further grant from Toowoomba through the InFront Outback research grant enabled a larger pilot study into parental interest and acceptance of this technique and allowed us to establish that our figures for the incidence of problems with infant hips correlated well with other reported studies. We found a statistically significant parental interest in the examination (Charlton S, Muir L, Skinner TC, & Walters L, 2012).

Discussion with Radiology

In discussion with the radiology department at WCH there was some interest in the pictures and videos of the scans, but there was criticism of the feasibility of performing the scan and the reliability of the result. Particularly, there was criticism of the need for two operators and the expertise required to perform the Palmen-Barlow test. Questions were asked about the reporting of the scans and the ability to measure improvement. All babies born at the WCH undergo a clinical assessment of their hips by the delivering doctor or a paediatrician. Infants with risk factors including equivocal clinical assessment, may be referred to the Hip Clinic conducted at the WCH. At this clinic, they are examined by an advanced scope physiotherapy practitioner using the standard clinical assessment and may be referred for further examination by an orthopaedic surgeon, to have a Graf ultrasound. The Graf ultrasound is normally carried out at six weeks, although it can be earlier in hips suspected of being dislocated.

The radiology department at the regional hospital was interested in trialling the use of dynamic ultrasound to assess the amount of instability in the neonatal hip, to assess reliability and how difficult the technique may be to learn and perform.

A visit to Trollhaten in Sweden to observe the neonatal hip assessment with anterior dynamic ultrasound and learn the technique from Andersson, demonstrated how the ultrasound was performed and the high acceptance by the Swedish parents to this assessment. Critics of Andersson and his work suggested that it may lead to overtreatment in hips which may spontaneously improve and that it caused unnecessary worry to parents (Gardner & A., 2005). The socialist-inflected health system in Sweden strongly supports universal ultrasound screening with nationally available health records for each individual, accessed through their individual personal identification number which follows them through life.

Training

Time was spent in training the sonographer in the performance of the Palmen-Barlow manoeuvre and the importance of starting with the hip in 60 degrees of abduction. This hip position and pelvic stability could be verified by the views seen on the screen. Two further sonographers have been trained to perform these scans and the principal sonographer has reported that it was not difficult to train the others. In reviewing the videos of 200 scans we found only one false positive, in which the pelvis could be seen to move. This scan was carried out in the first group of scans and since becoming aware of this, we have carefully assessed that there is no pelvic movement in any of our measured scans.

The Technique

The baby is placed across the table with the head towards the mother and the legs towards the operators. The baby is naked below the waist, with a nappy loosely in place, undone on the examination side. Operator one stabilises the pelvis by holding the hip in a stable amount of abduction, while the sonographer tests the contralateral hip. A view of the hip is seen, with the femur in a straight line across the femoral head, to the tip of the cartilaginous roof of the acetabulum. As the test is performed the head can be seen to move downward. The movement is repeated a few times and a measurement is taken from the original line to the centre of the femoral head, at the point of the anterior edge of the cartilaginous acetabulum. The ultrasound screen is positioned in such a way that both operators and the parents are able to see the picture and the results are discussed in real time. The amount of movement in each hip can be seen and measured. The record is stored at the view with maximum measurement of movement.

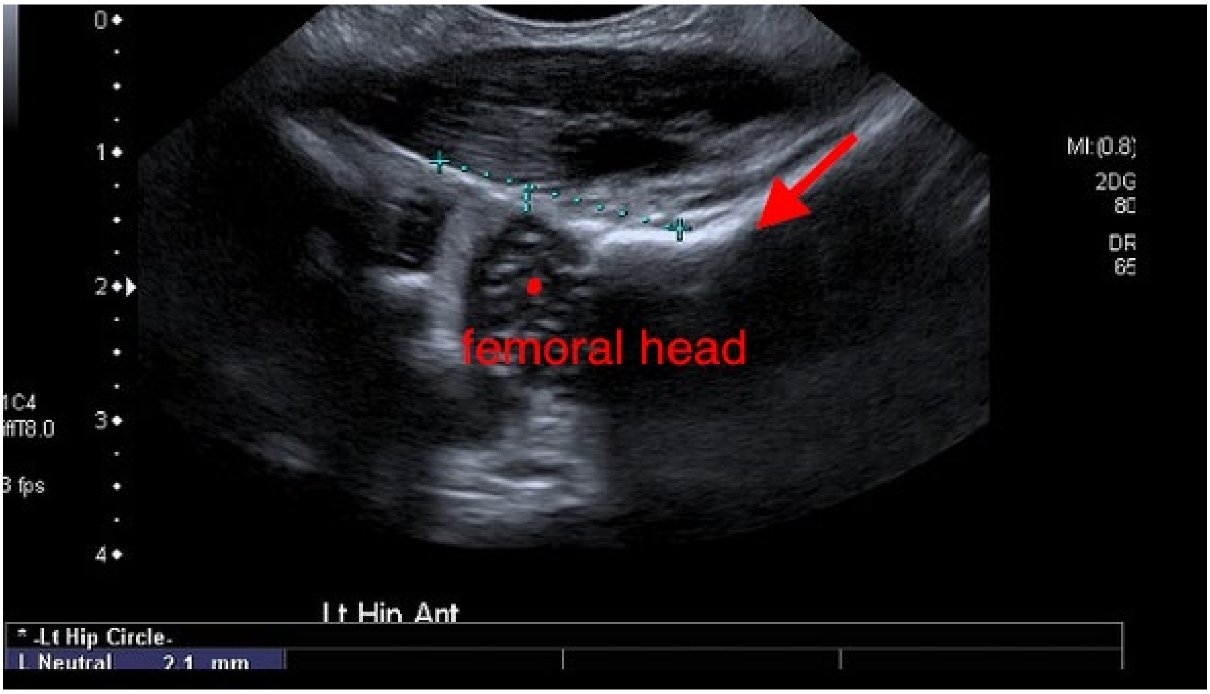


Figure 8 Measure of movement on ADUS

Pilot Study

This study examined the interest in, and acceptability of, universal dynamic ultrasound screening of infant hips. An anterior dynamic ultrasound scan of their baby's hips was offered to all parents fulfilling the inclusion criteria as approved by the Southern Adelaide Clinical Human Research Ethics Committee (Ethics 387.10).

The pilot study was conducted over a seventeen-week period in a regional centre in South Australia and reported in the Australian Journal of Rural Health (Charlton S et al., 2012). A copy of this article is included in the appendices (Appendix B) Parents of all babies born at a regional South Australian hospital were invited to participate in the study which offered an ultrasound examination of the baby's hips in the first week after birth. Infant hip scans were offered to 138 families in the first two weeks after the birth of their baby, using the anterior dynamic ultrasound technique as offered in some parts of Sweden (J. Andersson, 2002).

A total of 86 babies (172 hips) were scanned, representing 62% of all babies born over the period of the study. All scans were performed by the same sonographer who reported that the ultrasound technique was easy to teach a clinician. A significant number of parents (90%) reported that they were pleased to see the results of their infant's ultrasound and did not find it difficult to attend for the ultrasound screening session. This study was a small implementation pilot study in one regional centre in South Australia. It showed ADUS screening of newborn hips to be an accessible study and demonstrated the feasibility of a larger scale study of ADUS in rural hospitals. The scanning techniques used in this study were confirmed by a visit from John Andersson whose assessment methods we followed. He observed several scans and verified the process and reporting of the scans.

Learning from the pilot study

Stability of the pelvis during the Palmen-Barlow test is very important. This is usually achieved by maintaining the hips in bilaterally equal abduction with one leg held still while the other is tested. This is then a two-handed test. When combined with an ADUS it has been found that the transducer is more accurately maintained over the joint if the operator performing the test is also holding the transducer. A second person is then required to stabilise the pelvis during the examination. This has led to criticism of the ADUS because of the need for two operators for the examination.

In our study, the sonographer performed the test manoeuvre while maintaining the correct alignment of the transducer and the researcher ensured the stability of the pelvis and ensured that any movement seen on the screen was true hip movement with no pelvic element to that movement. The ADUS was not seen as an alternative to the Graf which gives information about the morphology of the hip joint, but rather to make an assessment of the amount of neonatal instability in the early weeks after birth. In our pilot study Graf US was used in infants where there was an excess of movement shown on ADUS, to measure the alpha angle and demonstrate the position of the head of the femur in relation to the developing acetabulum. It is known that this is an unreliable test in this age group as there is wide variation in measurements considered to be normal (Cundy, 2004). We therefore see that the Graf and the ADUS are not either/or in this age group but may be used in conjunction to give a clearer picture both initially and over time, for those hips which have been shown to have increased instability at the first examination.

Discussion – Rural benefits of ADUS

Rural Australia is a context where few babies are examined by paediatricians. Operator reliability of clinical screening, using the Barlow and Ortolani tests, requires constant practice, continued education and accurate follow up (Goss, 2002). In Australian rural settings, low birthing numbers may limit clinician experience and distance limits paediatric examination and feedback. It is therefore proposed that eDUS could assist clinical judgement, improve the quality of screening, and prevent missed diagnoses of NIH in rural Australia. Our pilot study has shown that ADUS can be performed and measured in a regional centre and has clearly demonstrated parental satisfaction with seeing the scan.

Austria and some other parts of Europe, including parts of Scandinavia, advise universal eDUS (Holen et al., 2002). The United States Task Force on hip recommendations prefers universal screening, recognising both LDUS and ADUS have been used for early screening, although this cannot be implemented nationally, due to ultrasound not being available everywhere in the United States and due also to a shortage of suitably trained sonographers. The Task Force therefore advises universal clinical assessment plus selective ultrasound examination for those infants with risk factors or equivocal clinical assessment (Afaq et al., 2011). Although Andersson's robust quantitative values for normal hips and NIH suggest early ADUS may be more consistently applied in rural Australia. The pilot study in rural Australia has demonstrated the feasibility and acceptability of early ADUS screening (Charlton S et al., 2012). Routine screening with eDUS may be more economically viable as portable ultrasound machines become more affordable and are further incorporated into contemporary clinical practice in rural Australia and internationally.

The reported increasing rates of late diagnosis of DDH in rural and regional Australia are concerning and may be in part attributable to changes in infant management. The successful education program about prevention of Sudden Infant Death Syndrome, advocating placing babies in the supine position for sleeping, has led to many babies never being placed in prone in their early weeks. The reported increase in baby settling difficulties (N. Clarke, 2014) and resurgence of swaddling to settle babies leads to increased extension and adduction of the infant hip (Williams et al., 2012). Wrapping occurred simultaneously with a move away from bulky cloth nappies that better maintained infant hips in abduction and flexion. Secondary prevention, with double nappy techniques, removable splints and Frejka pillows, as outlined in chapter 2 of this thesis, could theoretically reduce DDH in rural Australia. Although evidence for early secondary prevention in human studies remains thin, studies with animals show the effect of position on hip development is much more marked in the immediate weeks after birth (Wang, 2012).

Secondary mode of prevention may be particularly attractive for parents in rural Australia where these interventions can be arranged locally, preventing referral and travel to distant specialist services. Primary prevention measures in the first 6 weeks of life, with advice and instructions on positioning to optimise hip flexion and abduction, including avoidance of swaddling with the legs wrapped tightly together, could easily be instigated as routine practice in rural Australia.

Certainly, an early educational program in Japan, highlighting the dangers of traditional swaddling, demonstrated improvement in hip development with significantly lower numbers of infants with late occurring DDH (Wang, 2012), showing that early education can enhance optimal infant hip development. The prone position, with hips flexed and abducted, promotes good hip development. Protective turning of the head, a primitive neonatal reflex seen in newborns, diminishes over the first few months and many babies are not happy on their tummies if they have not experienced the position during their first weeks (Twitchell, 1965; Williams et al., 2012). Placing the infant in the prone position in the first few days, for short supervised times such as after a bath, will elicit the protective turning reflex and the head will be turned to one side to clear the face for breathing. Repeated positioning like this will cause the movement to become a learned response when the infant is placed in prone. Supervised awake tummy time should be encouraged from the earliest weeks.

In the context of increased DDH in rural Australia, contemporary evidence suggests that introduction of eDUS could provide rural infants with more effective screening than clinical examination alone. Targeted early interventions such as improved postural management for optimal hip development, and simple removable supports to abduct infant hips could prevent some cases of DDH. The literature review confirms that hips at risk of developing dysplasia may be identified and tailored management may minimise the damage to developing hips in the early weeks of life. The relationship between the amount of neonatal instability and the development of dysplasia is unclear, in particular, which hips will spontaneously improve, and which will go on to later DDH.

Novick stated that dynamic ultrasound during the first two weeks showed 5-6% of hips with measurable instability while Graf's morphological studies demonstrated 25-50% of hips were immature in their development (Novick, 1983) (Graf, 1983b). This finding suggests that the risk of unnecessary treatment may be higher in the Graf population than in the ADUS population. All neonatal hips have some level of instability in the first few days after birth, gradually lessening in most cases over the first 24 to 36 hours (Keller, Weltin, Rattner, Taylor, & Rosenfield, 1988). Some hips will continue to demonstrate excess movement that leads to poor development of the acetabulum and subsequent displacement of the femoral head (N. M. Clarke, 1986).

Research questions

A research study was proposed to further explore the use of universal early anterior dynamic ultrasound in the management of infant hips in a regional centre in South Australia. The aim was to gauge whether parent understanding of their baby's hips, when viewed on dynamic ultrasound, influenced their subsequent care of the hips. The hypothesis was that those parents who viewed the hips on ultrasound would have an improved understanding of the importance of positioning and wrapping for the ongoing development of the infant hip.

Lee (2006) in his paper, “Growth and Development of the Child’s Hip”, has stated that: “A located femoral head is necessary for acetabular development and also for correct femoral head development.” In consideration of this premise, my research sought to demonstrate any change in infant hip management following targeted education about hip status and development.

The key questions addressed when ADUS was universally offered to new parents were:

- Could ADUS be reliably performed and measured in the regional centre? (Pilot study). The pilot study demonstrated that it was possible to reliably carry out these scans in our regional centre.
- How did parents react when offered the opportunity to see their baby’s hips on ultrasound? (Pilot study). The answers to this question were seen in the pilot-study which demonstrated significantly that parents were pleased to see their infant’s hips on ultrasound.
- How did the results of eADUS in our region compare with other results reported in the literature? Although the numbers in our study were small, the study results aligned well with larger studies conducted elsewhere in the world.
- Did parental visualisation of the infant hips on eADUS influence parental care and management? The study was designed to demonstrate any differences in parental understanding and management between an intervention and the control group.
- Were there any significant differences in infant management between the experimental and the control group? There were significant differences between the two groups but not in the way we had expected.

Theoretical perspectives

In undertaking this research study, the Theory of Planned Behaviour as described by Icek Ajzen (Ajzen, 2011) and the Health Belief Model described by Hochbaum, Rosenstock and Kegel 1952) were considered. A constructivist approach to the study was taken allowing the following considerations to be explored.

The Theory of Planned Behaviour (TBP) starts with the development of knowledge, which may cause changes in attitude and in what one perceives as normal. This may lead to behavioural adjustments which in turn, may affect intention and influence subsequent behaviour. Planned behaviour models have been shown to be very helpful in facilitating health improvement, particularly in helping people to stop smoking, exercise more or alter their life style. TBP has been shown by Ajzen (2005) to be more effective in interventions targeted at specific beliefs about behaviour rather than core beliefs or basic assumptions. Mashi et al in their paper*, "*How expert advice influences decision making" state that it is the comparison between how highly the advice is valued, coupled with the assessment of the beneficial effect, will affect compliance (Mashi, 2012). The experiences which an individual has may impact on knowledge about a subject and attitudes to the information being offered.

Therefore, when targeting the posturing and wrapping of young babies, will the understanding of normal hip development change parental intentions and subsequently behaviour? In what ways should this information be provided? Does the education process have any effect on the outcome, as suggested (Strecher, 1997)? There will be variation in the impact of new ideas, influenced by the manner in which the ideas are presented. The impact can be affected by prior learning, cultural beliefs, family views, time constraints, habit and willingness to change.

The Health Belief Model

The Health Belief Model (HBM) is a behaviour model which examines what influences the modification of one's attitudes and beliefs towards health. It has been frequently used in research and health education, particularly in relation to illness prevention, such as in some cancer screening programmes, health lifestyle changes and vaccination programmes. It is based on perceived susceptibility, perceived benefit, what modifying behaviours one could adopt and the likelihood of being able to achieve any change. The individual's perception is influenced by how importance the issue is to them, how likely they believe they are to have the problem and their understanding of the severity of the condition (Connor, 1994). Any behaviour modification can be influenced by demographic variables such as environment and culture. Behaviour modification may also be influenced by the perception of the general likelihood of the occurrence of the problem. The participant's willingness to act can be influenced by what prompts the action and this may also be influenced by variations in culture and the environment. Cultural and behavioural differences are seen in many facets of child rearing and can impact heavily in the early weeks of a new baby's life. In situations where there is a large extended family all living together it can be difficult for a new mother to make changes which are seen to be the opposite of the methods adopted by the extended family.

The HBM is influenced by the general health beliefs of the population, the specific health beliefs of the individual, as well as the impact any changes will have on the action of the individual and the subsequent result (Cummings, 1980). Behaviour can be impacted upon by special influences, cultural factors, socio-economic status and previous experience. Action can be encouraged by presenting a clear course of action to be taken at an acceptable cost, together with an increased feeling of competency and empowerment to undertake the action required (Strecher, 1997).

Parental Knowledge

Knowledge of normal infant development and the influence of leg position on the development of the hip, could help parents understand more about infant hip care. Parental visualisation and understanding of the developing hip may give a clearer picture of the potential value of appropriate posturing and wrapping. Seeing the hip on ultrasound image may have a place in the reinforcement of conservative management of early hip instability in the first few weeks of life without increasing the incidence of unnecessary splinting.

Learning

Learning is achieved in different ways by different people. Merriam in her book, “Learning in Adulthood” describes it as “a subjective experience tied to a place environmentally, socially or spiritually” (Merriam, Cafarella, & Baumgartner, 2012). Some learn by listening to others, some by experiencing situations and noting the consequences, some by visualisation and some by feeling. There is therefore, benefit in attempting to use as many learning modalities as possible to reinforce messages about hip care in babies. Von Glasenfeld (1987) has written of the responsibility for learning, where the learners are actively involved in the learning process and not just passively observing the instruction.

Thus, our experiment was designed to offer a range of learning experiences involving reading, discussion and practice. Information was provided in written, pictorial and electronic video format in the control group, with the added vision and explanation of the hip for the experimental group.

In this expanding digital environment, many parents rely on the information received from the worldwide web and peer group discussions on their screens rather than information gained from extended family traditions (Khoo, Bolt, Babl, Jury, & Goldman, 2008). The majority of parents use the internet for information seeking or social contact reasons (Plantin & Daneback, 2009; Roberts, Callahan, & O’Leary, 2017). In research of the literature about internet usage in parents, Plantin found that middle class, first time mothers aged between 30 and 35, when using the internet, were most likely to seek health and parenting information (Plantin & Daneback, 2009). The parents interviewed in this study reported weakened support from their parents or close family, sometimes due to distance from the family. The same study found that professionals used the internet more for information and support and stated that being able to access the information at any time made it a good option. Barnes (2008) in her study found that, “increasingly, woman referred to printed material and internet resources as well as ante-natal classes, to learn about mothering” (Barnes et al., 2008).

There has been a marked change from the “village learning” when tradition and family values were of greater importance in baby management, with many parents now raising their children without support from their wider family. Information from the Australian Bureau of Statistics (accessed June 2018 online at: www.gov.au), states that one out of every four Australians was born overseas. When this is considered along with the increasingly early return to work of young mothers following the birth of their baby, plus the fact that women are continuing to work for longer, this can be seen to contribute to the breakdown of traditional social support networks.

Cultural Differences

A differing rate of occurrence of hip problems in babies has been observed between differing races, as recognised by Sir Denis Browne (Introduction) with diverse traditions for managing young babies. This has been further observed with the Japanese population and the lowering of the incidence of hip problems following an education programme on safe wrapping and carrying of babies (Yamamuro, 1984).

The awareness of problems in infant hips may not be widespread. Many parents on finding that their child may have a poorly developing hip are surprised to find other parents who have experienced or heard of the problem, but in the general population the knowledge may not be very prevalent. In those with some history of hip problems there is a strong desire to check that their baby’s hips are not affected, but if there is no family history there is often no thought that this could be a problem. It is noticeable that those families who have experienced an infant with a hip problem will demand attention to making sure that the hips are enlocated and will look after the hips more consistently.

Effect of Swaddling

The increased use of swaddling or wrapping babies for ease of settling, has been blamed for the increased rate of hip problems over the last decade (Williams et al., 2012). The effect that tight wrapping has on the developing hip has been discussed earlier in this thesis. Two seasonal incidence studies conducted in Birmingham and Australia (Charlton PJ, 1966 ; Edwards, 1961), suggested that increased tight wrapping may be a cause of hip problems in young babies. The Australian study was conducted as part of an honours research programme through the Genetics Department of Adelaide University and involved a retrospective search of the records held at the Adelaide Children's Hospital for all children with congenital dislocation of the hip (CDH). The author was the research assistant on this project. Information was collected about the child's birthdate and gender. The data was analysed to note any peaks and troughs in the incidence of CDH, according to birthdate. This information was then correlated with data collected from a similar project conducted in Birmingham over a similar seasonal period of time. The results of these two studies showed an increase in the incidence of CDH in the winter months in both centres. Both studies were conducted prior to the commencement of diagnostic ultrasound as a tool in the assessment of children's hips, at a time when the condition was known as congenital dislocation of the hip. Both studies were retrospective studies of children treated for congenital dislocation of the hip at major centres in each location. The seasonal incidence which was apparent in each centre was postulated to be related to the need for tighter clothing and more wrapping in the winter months as opposed to the lighter clothing and covering required in the summer. Similarly, with the current increase in firm wrapping to settle young babies, we are seeing another upsurge in incidence of hip dysplasia. Thus, the influence of special health beliefs and consequences of action can clearly be seen.

The Barriers to Modification of Behaviours

Changes in behaviour can be truncated or inhibited by inconvenience, expense, or the fear of unpleasant experiences. Incentives to act can be provided by clear and concise outlines of the courses of action at an acceptable cost, thus enhancing the feeling of competency of the individual to take action. Advice from a known and trusted individual is more likely to be acted upon. These behaviour modification experiences can be affected by individual influences, cultural and socio-economic factors as well as previous experience.

The influenced of cultural and ethnic beliefs on motherhood in migrant woman has been studied by Liamputton and Naksook (2003), who found that migrant woman expressed "hardship in being a mother while having to adjust to a different lifestyle." They asserted that difficulties with language made the role of motherhood more difficult and limited the mother's access to many things. They claimed, "without English, many women were not able to access health and social services provided for a new mother and baby" (Liamputton, Lim, & Bagley, 2003).

Isolation from larger communities can also affect behaviour and any modification to patterns of parenting behaviour. Feelings of isolation are commonly expressed by new mothers in the early months of motherhood, where feelings social isolation and personal disconnect are commonly described. These feelings have the potential to be increased in rural and regional areas where the distance to towns and health services may be great. The increased feeling of isolation may be exacerbated in migrant women who are also experiencing cultural change at the same time. The need for affirmation, validation and consistency with practical and emotional assistance is important with this group of new mothers (Paris & Dubus, 2005).

The need to travel over large distances to join in parent groups of access health advice can have an isolating effect on new parents. Travel with a young baby is never easy and many new mothers report a feeling of isolation simply because of the difficulty of getting out. For mothers in rural and regional areas, the difficulty of travelling many kilometres with a young baby can be a major exercise often involving hours away from home and increasing the difficulty of infant management, plus adding to the dangers of travel for a possibly sleep-deprived mother.

In rural and regional Australia, continuity of care can be very difficult. Services are often provided by visiting specialists or locum doctors because of difficulties with recruitment and retention of staff. Travel to a maternity unit a long distance away from home may mean that follow up care and ongoing management will be carried out by the family doctor closer to home rather than the doctor responsible for the birth and early management of the mother and baby. The infant health record can be a help in transmitting important features of care but may not always be maintained or used by all professionals having contact with the family.

Many parents rely on a neighbour or family friend for advice or they may post a question on a parent website or group page on the internet (Madge C & O'Connor H, 2006). Groups such as the "Inner West Mums and Bubs", which can be accessed on Facebook and describes itself as, "a support and networking group for mums – a kids' market, job-share and info forum for all things mums, bubs, toddlers and even bigger kids", boasts 4,122 members and claims to have increased its membership by 280 in one week.

Mothers will visit the family doctor with their new baby, for a six-week check-up following the birth. The doctor should examine the baby at this appointment and make a further clinical assessment of the hips. The ratio of patients to doctors is higher in rural and regional areas than in metropolitan areas and obtaining a timely appointment with the family doctor for a follow-up appointment may be difficult. Figures obtained from the Department of Health and Aging state that there are 392 full time equivalent doctors per 100,000 population in the metropolitan area, while there are 206 per 100,000 in rural and remote Australia. This difference is even greater when considering General Practitioners and Obstetrics and Gynaecology specialists, where the numbers are 142/100,000 in the metropolitan area compared with 24/100,000 in rural and remote areas (www.aphra.aph.gov.au).

The early period with a newborn baby is often a “time poor” period with much of the time devoted to feeding and growth of the infant and sleep deprivation of the family. In a small study conducted with a group of mothers three months after the birth of their babies, almost a quarter of the mothers reported difficulties with sleep deprivation and little preparedness for how this would affect them. Thirty five percent of mothers in the study reported feeling unprepared for the physical experience after their birth and twenty percent were not prepared for the emotional effects of having a baby (Barnes et al., 2008).

Methodology for the Research Project

A multimodal study design with two arms was proposed, where the first arm was quantitative and compared any change in parents’ management of positioning and wrapping of their baby before and after different forms of education about the development of infant hips.

The second arm was both quantitative and qualitative, measuring any change in knowledge about infant hips before and after two paths of education, leading to increased tummy time and more appropriate wrapping. The study was conducted in a cluster cohort control trial with the experimental group in one regional centre (Limestone Coast LC) and the control group in another regional centre (Riverland RL) in South Australia. This design was chosen to blind the control group to the difference in education of the two groups where both groups were to receive identical educational training except for the ultrasound scan, which only the experimental group would receive. It was considered that even in reasonable sized regional communities there would be danger of contamination between the groups if they resided in the same region, as it would be difficult to keep the control group unaware of the experimental procedure being tested. There are strong parent groups among mothers who attend the same pre-natal classes and are often in the maternity unit at the same time. It was felt too difficult to randomise mothers giving birth in the same hospital in a confined community to either the experimental or the control group without some awareness on their part. As a preliminary measure staff in both post-natal wards were instructed in correct infant wrapping techniques and encouraged to assist new mothers with these techniques.

Sample justification and data analysis

It was estimated that 100 babies were needed in each cohort. The project began in Mount Gambier before it was started in the Riverland. The two sites did not necessarily need to run concurrently, but there was some overlap. The numbers needed were calculated on the basis of the previous pilot study conducted in Mount Gambier and published in the Rural and Remote Health Journal. This study found that parents liked seeing their baby's hips on the ultrasound monitor and did not find it difficult to come in for the ultrasound scan. In this pilot study we found 3 babies who needed to have their hips rescanned in a total of 86 infants. Given that the incidence of dislocation is stated as 1:1000 but more hips are reported as being unstable or inadequately covered, we conservatively took this incidence to be 1:60. Using the power analysis table, we estimated that 100 babies would be needed in each group to see any difference in adherence, motivation or understanding.

The calculated estimation of improvement in positioning of the baby was based on the author's paediatric practice experience since the commencement of the Safe Sleeping programme. It was estimated that most mothers were discouraged from putting their babies in prone as a result of the SIDS training. In the first six weeks babies were realistically only placed in prone for no more than 10 minutes per day or less than 1.5 hours per week. An improvement to a total of 30 minutes over the space of each day was sought. It was considered that prone time could incorporate time spent in prone on a parent's arm or chest in addition to tummy lying when awake following feeding, bathing or dressing.

Outcome Measures

Data collected from this research was both quantitative and qualitative. Questionnaires measured knowledge before and after education, parental motivation, plans for positioning and any alteration to management.

Survey and diary quantitative data was to be analysed using descriptive statistics (frequencies, means, range and variance). Statistical associations between education method and frequencies of wrapping and positioning would use Spearman's rank-order (non-parametric) correlations. Differences in adherence between the two groups would be analysed using the Mann-Whitney U test and a 2 tailed analysis.

In planning the research experiment the following possible reasons for differences between the two sites and any other deterrents to participation were considered:

- Fear of SIDS. This may deter some mothers from taking part in the study as they may not be confident of placing their baby in the prone position at any time.
- Variation in climate between one regional centre and the other may lead to more wrapping in the cooler climate in one site. The daily temperature variation is

much greater in the LC than that experienced in the RL which could lead to increased tendency to wrap an infant for longer periods in the LC.

- Variation in number of babies diagnosed with DDH between regions, where access to US is not available at one site and diagnosis is made on clinical assessment alone. Referral to a specialist centre in a capital city is then made for an ultrasound scan, thus tending to lower community awareness of the incidence of this problem.
- Cultural differences in the population, involving different traditions of wrapping and nursing babies. It is recognised that there is seasonal work in both regions and this will lead to an influx of itinerant workers often overseas travellers or migrants. Both areas have also provided refugee accommodation from other countries. These two variables, while recognised, were not evaluated in the study.

No interruption to existing standard protocols for the assessment and management of infant hips for either research group was anticipated, as the study would be completed for each participant in the first six weeks after birth, which then allowed for current standard clinical guidelines to be followed in a timely manner.

Study Design

Control Group (Standard Advice)	**Experimental Group (ADUS)**
Clinical assessment of hips	Clinical assessment of hips
Consent to be involved in research and initial demographic data collection	Consent to be involved in research and initial demographic data collection
A preliminary questionnaire will be given to all parents to gauge their understanding of the hip joint in a baby and to ascertain any family history of hip problems	A preliminary questionnaire will be given to all parents to gauge their understanding of the hip joint in a baby and to ascertain any family history of hip problems
Handout on hip development	Handout on hip development
Video on safe wrapping	Video on safe wrapping
Measure understanding and motivation	Measure understanding and motivation
Exploring possible barriers and enablers that may impact on optimal care (and link with handout and video)	ADUS Routine ADUS protocol w or w/o F/U as indicated explanation of ADUS findings Exploring possible barriers and enablers that may impact on optimal care (and link ADUS with handout and video)

Measure understanding and motivation	Measure understanding and motivation
Diary of positioning of baby and method of carrying	Diary of positioning of baby and method of carrying
F/U 8/52 with Interview re possible barriers and what elements increased motivation and influenced behaviour	F/U 8/52 with Interview re possible barriers and what elements increased motivation and influenced behaviour

Table 3 Study Design

Two single page handouts were prepared, one outlining pictorially the development of the hip (appendix E) and the other showing pictures step by step of wrapping techniques (appendix E). A suitable video outlining hip development and good wrapping techniques could be accessed on the website of the Royal Children's Hospital, Melbourne (https://www.rch.org.au/kidsinfo/video). Permission was gained to use this in the education programme and a link was provided to the website. It was planned to direct parents to the website to view the video during their hospital stay.

The qualitative data were designed to demonstrate any changes in knowledge about infant hips before and after two paths of education about hip development. Both groups were to be asked to answer a short questionnaire before and after education about infant hips. These questionnaires were structured to gain insight into knowledge and intended behaviour and thus provided information for both the qualitative and quantitative aspects of the study.

Method

Recruitment

At each site a regular perinatal meeting involving obstetricians, GP obstetricians, midwives and nurses is routinely held. The monthly meetings discuss delivery numbers and outcomes and review practices within the maternity unit. The principle researcher addressed the perinatal groups at each site to outline the research programme and to seek assistance with the recruitment of participants.

An introductory leaflet was provided for distribution to obstetric patients in their ante-natal packs at or after the 30-week ante-natal visit to their doctor or midwife. The leaflet was also provided through ante-natal classes and where possible, reinforced through pre-natal visits to the doctor. The General Practice clinics and CAYHS personnel in each region were visited to outline the research and to familiarise personnel with the material. The obstetricians and paediatricians were also informed of the study, as were the physiotherapy staff involved with post-natal care at each site.

Enrolment of participants

All parents giving birth in either regional hospital were invited to participate in the research. Ethics approval was obtained from the Southern Adelaide Human Research Ethics Committee with Site Specific Applications to both sites (appendix C). The researcher visited the principal maternity site at the Riverland General Hospital (RGH) and met with midwives and doctors who agreed to speak to their patients and invite them to participate. A visit was made to the physiotherapy unit attached to the RL hospital, where the research was outlined to the physiotherapists, particularly those working with maternity patients. A midwife familiar with the ADUS study in the LC was now working in the RL site and agreed to discuss the project with new mothers during their post-natal stay in the RGH. The principle researcher was resident in the LC and after meeting with the GPs and obstetric staff in the area, undertook to visit the maternity unit daily, to invite families to participate.

Each family in both areas was offered a detailed explanation of the research in written form and upon agreeing to participate they were asked to sign a consent form. A research assistant visited the maternity unit in Mount Gambier when the principal researcher was unable to do so. The new parents in the RL were invited, in the maternity unit, to be part of the study, given a similar outline of the research project and invited to sign a consent form to be part of the research. This was to be done by the attending midwife or nurse over the days immediately after the birth.

In both groups, those who agreed to participate by signing a consent form, were then asked to complete questionnaire 1 which sought information on the demographics of the family, the birth history of the baby and some questions seeking knowledge of parental awareness of baby hip development. Information was also sought on parental intention to wrap and position their baby. At each site participants were given two handouts, one on infant hip development, the other on tummy time. A link was provided to a short video freely available on the Royal Children’s Hospital Melbourne website with permission granted by RCH for its use. This video clearly explains hip development and safe baby wrapping techniques. It was planned to have parents watch this video while in the maternity unit.

Interventions in the Study

Interventions in the study included an educational component in each group with an ADUS added in the research group. Three questionnaires were proposed in each group with an added diary and telephone interview over the period of keeping the diary. The questionnaires were constructed jointly with the principle researcher and the supervisors, as we were unable to find any tested, readily available, suitable questionnaires. In studying the advice of Steiner and others in the development of questionnaires we devised our own set of questions (Steiner D L, 2015). The information sought was both demographic and as a baseline to existing parental knowledge about infants and their hip development. They were set to show differences in areas of knowledge and intention in early hip management. The questionnaires were tested in a small group of mothers to ensure ease of understanding of language used and reliability of similarity between questions.

Recognising that there may be some parents for whom language was a barrier, it was suggested that a supporter may attend with them to act as a translator if they wished to participate. All mothers who did not wish to participate were reassured that this would not alter their management or affect their ongoing care and assistance.

Participants in the LC were asked to bring their baby to the radiology department within the hospital, either while still an inpatient, or within the first two weeks after the birth, to have an anterior dynamic ultrasound scan of the baby's hips. The researcher or her assistant were present at each of these scans and the scans were performed by one of two sonographers familiar with the technique of ADUS. The scan results were discussed with the parents at the time and they could clearly see the outline of the hip and the amount of movement in the joint when the Palmen-Barlow manoeuvre was carried out.

The measurements were recorded and saved to computer so that the pictures could be reviewed later. A letter to the family doctor of the parent's choice was completed, advising that the baby had taken part in the research project and stating the findings of the scan and any recommendations for follow up if required.

Questionnaire 2 was then to be completed by both groups. This questionnaire contained similar questions to Q1 and was designed to show any alteration in understanding of either neonatal hip development or best wrapping techniques and to give some indication of baby positioning.

Both groups were given a small diary which they were asked to fill out once per day, outlining the position their baby had been in for sleeping and awake times and whether the baby had been wrapped or not. The parents were contacted by telephone once during the course of keeping the diary. This was designed to encourage the keeping of the diary and to discuss any difficulties the participants were having. This contact allowed the making of arrangements to collect the diaries and Q2, if not already received. On return of the diaries the parents were asked to complete the exit questions in Q3. The entire process was designed to be completed by the start of the baby's seventh week and thus did not alter any adherence to standard clinical guidelines for any infant.

Structure of Questionnaires

Questionnaire 1

This was divided into three sections with a score in each section. The first section included questions on demographic background of the family, seeking answers to age, educational level of parent, home situation, position in family, previous knowledge of hip problems and any knowledge of wrapping and tummy time. Scores in this section were collated in an overall "informed score" designed to give the researcher an understanding of what was already known before the educational component of the research was undertaken. The second section of questions sought information on parental plans with wrapping and positioning of the baby. Answers in this section were collated under an "intention score".

Section 3 looked at birth history particularly asking questions about the delivery and any relevant family history and information on parental knowledge of wrapping techniques and infant positioning, for each group. In the research group this questionnaire also recorded the scan result.

Questionnaire 2

Answers to these questions were intended to reveal any reaction to the educational component in each group, with the first section providing a score for the value parents placed on the information they received. The second section was designed to show any change in knowledge about hip condition and the effect of wrapping and positioning, giving a total informed score. Section three again provided an intention score for positioning and wrapping which could be compared with the score in Q1.

Diary

The diary was provided to each family, following completion of Q2, to record activities with the baby once per day, over a six-week period. Parents were asked to tick boxes indicating how the baby was wrapped for sleeping, if the baby spent some time on the tummy, was feeding and sleeping well. The diary was designed to fit in the pocket of the Blue Baby Handbook, which most mothers keep in their baby bag. It was felt that this should only take a few minutes to fill in once each day.

During the keeping of the diary, a telephone interview was conducted. An attempt was made to contact each participant to gain information on current position of the baby and to discover if there were any problems in the keeping of the diary.

Questionnaire 3

A simple questionnaire was asked of each parent, either when they returned the diary to the researcher or when they were ‘phoned to ask for the return of the diary. There were nine questions seeking information about knowledge, baby’s sleeping and waking times and mother’s well-being. A 3-point Likert scale was used, with parents asked to say whether statements were true, false or unknown.

The Experimental group

The ultrasound examinations in the experimental group were conducted each Wednesday in Benson’s radiology department at the regional hospital, with the ultrasound scans carried out by one of the trained sonographers. The anterior dynamic ultrasound (ADUS) was performed using the technique developed by Dahlstrom (1986) and further enhanced by Andersson (1995) who described a range of values of measurement of movement with this technique.

The standard technique of anterior dynamic ultrasound using a Toshiba Aplio XG US SSA – 790 11 -4 MHz 7 mtle curved linear probe was proposed. Management of the infant hips following the examination was focused according to the findings of the ADUS.

Using the method and measurements described by Andersson, the femoral head was visualised in the acetabulum in the resting position and again as the hip joint was provoked with a Barlow test. The position of the head of the femur in the joint could be seen and the movement under provocation could be measured. Where the maximum movement (MM) was < 3mm, the parents were reassured that the hips were stable and enlocated. Advice about posturing and care of hips was provided to those parents whose babies had an MM of ≥ 3mm and follow up screening was arranged for 4 weeks later. The limit of 3 mm was used as a conservative measure in our study, although Andersson had stated that up to 4 mm of movement in the first week was acceptable as stable. This adjustment was made in consideration of the fact that we were carrying out the initial scans any time in the first two weeks after birth since the scans were only available on one day per week.

At the time of the original ADUS scan, the parents were shown the developing hip with an explanation of the picture. Normal development of the joint was explained, including the need for good opposition of the head and the acetabulum for optimal development. Positioning and wrapping were explained, with an indication of the changes according to position. A record of the results of the scan, addressed to the family doctor was given to each parent, with the suggestion that it be placed in the “Blue Book” given to each baby born in South Australia, and shared with the family doctor at the next appointment. This then ensured that the standard clinical guidelines for the management of infant hips could be followed within the recommended time frame. Thus, the family doctor could make the decision as to whether further studies of a particular hip may be required. This may be a Graf ultrasound at 8 weeks or the need for an x-ray assessment at 5-6 months.

Since the advice given at the first scan involved management of positioning and perhaps a follow up second scan only, it was considered that using the lower measurement would not create any undue stress for the parents. Any infant with dislocatable hips was immediately referred for treatment under the supervision of a paediatric orthopaedic surgeon, who had access to the ultrasound pictures taken in our study.

The test used to provoke the hip was the same as the clinical test that all babies would undergo, but with the ADUS the amount of movement could be measured and compared over time. The researcher or her assistant attended all ultrasound examinations with advice about the results of the ultrasound forwarded to the delivering doctor and given to the parents to share with their family doctor. Records of each ultrasound were stored on the researcher's password protected computer and recorded on the research data sheet.

An explanation of the requirements for the further part of the research was given to each family at the time of their ultrasound scan and they were advised that the research assistant would ring them over the period of keeping the diary to discuss any difficulties they were having with the diary, or any queries they may have about the research.

Control Group

For the control group, the researcher visited the regional hospital and talked to the nursing, physiotherapy and medical staff about the programme. It was decided that the midwives and the post-natal physiotherapists would manage the research at this site. A representative from the rural clinical school would assist with the collection of completed questionnaires and arrange their dispatch to the principle researcher. The midwife would talk to the mothers after the birth of their babies and outline the research, inviting them to participate. After reading the explanation of the research and agreeing to participate, parents were asked to sign a consent form and complete Q1. Following completion of Q1 they were given the same educational material as the experimental group and invited to watch the RCH video on wrapping. In either group, any infant thought to have a dislocating hip was to be immediately referred for specialist care.

Von Glasenfeld has written of the responsibility for learning, where the learners are actively involved in the learning process and not just passively observing the instruction (von

Glasenfeld, 2002). Thus, my experiment was designed to offer a range of learning experiences involving reading, discussion and practice. Information was provided in written, pictorial and electronic video format in the control group, with the added vision and explanation of the hip for the experimental group.

The written information was contained in printed form outlining hip development and optimum positioning, wrapping diagrams and pictures of tummy time. Participants were asked to access a video of wrapping techniques for infants and were instructed in safe wrapping by the nursing staff and the CaFHS workers.

For the experimental group, the educational component consisted of:

1. Printed handouts on hip development and infant wrapping, (appendix D)
2. Access to a video outlining hip development and safe wrapping techniques (http://www.rch.org.au/kidsinfo/fact_sheets/Wrapping_ your_baby_safely-to_prevent_developmental_dysplasia_of_the_hip_VIDEO/).
3. A real time anterior dynamic ultrasound of their baby's hips with an explanation of the picture and a measurement of any movement seen on ADUS.

The control group in their educational component received:

1. Printed handouts on hip development and infant wrapping identical to the experimental group.
2. Access to the RCH video outlining hip development and safe wrapping techniques.

Following the educational component of this trial, both groups were asked to answer a further questionnaire (Q2) aimed at showing any difference in understanding of hip development and management. These questionnaires were constructed so that the results could be coded and compared. Quantitative data were collected through the questionnaires and the keeping of a diary over the first six weeks of each infant's life. The responses to the questions and the diary entries were then stored in coded form on a spreadsheet.

At the completion of the keeping of the diary, the LC participants were asked to deliver their diaries and questionnaires to a central location and to answer the eight "true/false/don't know questions contained in Q3. The RL participants were asked to return their completed diaries and Q2 to the front office of the RGH where they would be placed in stamped and addressed envelope for return to the Flinders University site in Mount Gambier. They were to be contacted by telephone to complete Q3.

Rationale for coding for data in questionnaires

Questionnaire 1

Constructed in four groups of questions, this questionnaire was designed to establish parental background knowledge, experience and intentions for baby care prior to the educational component of the research study. Parental thoughts on intended methods of baby care were established through answers outlined in this questionnaire.

The first group of questions sought information on family history, pregnancy and birth history, including birthweight and method of delivery and position in the family. Responses in this section can indicate presence of any known risk factors for hip problems.

Any previous experience of hip problems within the family, friends or workplace may increase parental knowledge of infant hip problems. Therefore, knowledge was sought about any factors which may have led to previous awareness of hip problems in infants and level of experience with infants in general. It was assumed that any parent who indicated that they already had experience with hip problems in babies or who were familiar with baby care may have more knowledge about care and management of infant hips. Scores of 1 or 2 were allocated, where 2 = more informed and 1 = less informed.

The next group of questions identified current knowledge, to establish the base score of awareness. There were 7 questions giving a maximum score of 13 on a 3-point Likert Scale. In this group scores ranged from 0 – 2, where 0 = no knowledge, 1 = some knowledge and 2 = good knowledge.

In the final group of questions, answers were sought to questions of intent in the areas of positioning and wrapping over the following 4 weeks. A “well directed intention score” was obtained for this group where the best intentions would give a maximum score of 16. Scores in this section ranged from 0 – 4 where 0 indicated that there was no understanding of correct positioning or wrapping or no intention to adopt good methods in these areas. A score of 1 indicated poor intent, 2 suggested some interest in position and wrapping, 3 showed better understanding of the importance of positioning and wrapping, while a score of 4 indicated the best intentions.

Questionnaire 2

This questionnaire sought to evaluate the perceived worth of the information and advice presented about the care of infant hips. Changes in knowledge since Q1. Could be calculated and any change in behaviour from the intention score could be measured by the reported management behaviour in the second questionnaire.

The first series of questions created a “Valued Information Score” where questions were framed around the advice given, with added questions about the ADUS examination for the experimental group. Answers were scored from 0 – 4 where 4 indicated very good interest and understanding, 3 = moderate understanding, 2 = uncertainty about the benefit, those who scored 1 did not find it of any use and a score of 0 indicated no interest at all.

The second group of questions related to current knowledge and allowed the comparison of knowledge before and after the intervention. The scores were identical in their rating with the current knowledge scores in Q1, with a range from 0 – 2 where 0 indicated no knowledge, 1, some knowledge and 2, good knowledge.

The third group allowed a “taking ownership score” and when compared with the intent score in Q1, enabled the evaluation of any change from initial intent to future planning with increased knowledge. The final section of this questionnaire sought intentions for the following four weeks and was used to gauge success when correlated with the diary information.

Diary

The diary was intended to be a once daily record of the infant’s activities in regard to sleeping and awake positioning and wrapping, the general health of the baby and the well-being of the mother. Parents were asked to make entries in a simple diary once per day, simply placing a tick in the most appropriate boxes for that day. This information outlined the amount and number of events of “tummy time” per day, an indication of wrapping techniques and an assessment of settled state.

Leading up to the development of the diary, the graphic designer held an informal discussion with a new mother’s group, to gauge opinion as to the ease of keeping this documentation. There was a general consensus that mothers would find it more palatable to use a telephone app to provide the information about their baby’s position and wrapping, although some said they would like the permanent record of the information. Most felt that they would take time to get accustomed to filling in the diary. The design and construction of an app suitable for all mobile telephones was considered but the costing proved far too high for our project and thus the written diary was proposed.

Discussion was held about contacting participants at a non-scheduled time to enquire about the baby’s progress and invite them to message a photograph of their baby’s position at that time. This was however, considered likely to be ethically unacceptable, given the dangers of photographing minors and putting these images on the internet.

After considering these options, the small diary was designed with a week to each opening, requiring a tick or a number in six areas, once per day. These areas outlined the position of the baby when asleep and awake, the general well-being of the baby, the minutes and number of times spent in prone per day and the style of wrapping of the baby.

All participants in both the experimental and the control group were to take home the small diary designed to fit into their blue baby book. The diary contained a week to each opening for six weeks. Parents were requested to fill it in once per day, by placing ticks or numbers in one box in each of six categories. These categories were designed to gather information about the general well-being of the baby, the usual sleeping position, the wrapping and tummy time.

The blue baby book is designed to be an infant health record, given to every mother after the birth of their baby and contains information about the baby from birth throughout their childhood. It is intended to be a record of the child from birth to at least kindergarten age and contains information of birth procedures, feeding, inoculation, and general health record for each individual child. Mothers take the “blue book” to visits to the doctor, infant nurse, health professionals who may see the child and all are asked to report in it. It also contains a record of the infant’s growth and development.

During the period of keeping the diary each family was contacted by telephone to ascertain how they were managing the diary and whether they had encountered any problems. Information was also sought on whether there had been any contact with a CaFHS nurse over this period. At the completion of the six-week diary, the parents were asked to submit the diary and to complete a short exit questionnaire seeking information about their experience with the research (Q3).

Questionnaire 3

This short questionnaire was designed to show any change over the six weeks of the study in behaviour, knowledge about infant hips, wrapping or positioning, with a 3-point Likert Scale with a maximum score of 10 indicating good knowledge and success with regime.

The entire process was designed to be completed for each child by the start of their seventh week and thus did not alter any adherence to standard clinical guidelines for any infant.

Results

Any infant with a hip having greater than 3mm of movement is required to return at six weeks for a further scan and at this time both an ADUS and a Graf ultrasound are carried out. At this subsequent examination the amount of movement on ADUS should be less than 2mm of movement. It has been observed that the Graf ultrasound at six weeks will often be reported as immature as the acetabular development will not be complete and the alpha angle will be less than the recommended level, particularly in infants born before full term. For this reason, we tend to schedule the second appointment at six weeks corrected age, rather than six weeks chronological age.

The Mount Gambier group recruited to the required number in three and a half months, with 66% of all mothers birthing over that time enrolling in the study. One hundred and four people signed a consent form and agreed to participate. One mother attended for the ADUS but did not fill out Q1 or participate in any other part of the study. Three of those agreeing to participate did not fill out any questionnaires or attend for an ADUS. This was due to early discharge from hospital and an inability to come back for the ultrasound or in one case because of an unwell mother who was unable to bring her baby to Bensons for the examination. Apart from those four, all mothers completed Q1 and returned it. All attended for the ADUS and results of that examination were collected, and the family doctor was notified of the result. In the 101 subjects scanned, three required a follow-up scan because of increased movement in the hip on ADUS.

Parents were generally keen to see their baby's hips on ultrasound and 99% of those who enrolled completed Q 1 prior to the examination. After the scan, the parents took Q2 to complete and return either while still in the hospital or after discharge when they would return the questionnaire to the FURHS MG site or the physiotherapy clinic and tummy time.

Over the period of the keeping of the diary, each family was contacted once by phone to gauge how they were managing with the diary and to encourage them to continue. Arrangements were made at that time, for collection of the diary and when this happened they were asked to answer questions for Q3.

Twenty-three participants completed all parts of the study and although the numbers are too small to be significant, I note some consistency between other published statistics and the results from our study. Half of those who completed the whole study stated that they had a relative or friend who had a child with hip problems. Six babies were born by caesarean section, fifteen were born before their due date, eight of these were two weeks early.

The response to Q1 was very pleasing with almost all participants completing this. Q2 was not so successfully completed and several attempts were made to encourage participants to either send the completed questionnaire to the researcher or to drop it in to either of the requested places. This follow up yielded several more responses, but the return rate was only about 30%. The diary was the most difficult to get compliance with accurate usage and it is almost impossible to estimate how many of the responses we received to this were accurate. This will be a significant point explored in the second half of this thesis. This ‘failure’ was a trigger for a movement in my research mode and form of analysis.

The data entries in the study have been audited randomly by a third person to gauge accuracy of the entries. An assistant randomly selected every fifth questionnaire and checked the coding, comparing her results with the entered results. A research assistant conducted Q3 either on return of the diary or when telephoning to request return of Q2 and the diary. The response rate to Q3 was therefore higher than either Q2 or the diary, giving the possibility of some limited data which could be correlated between Q1 and Q3.

During the first month of the project it became clear that there were problems with enrolling participants in RL. The midwife familiar with the project was not always on the ward and most of the maternity patients were not aware of the research before their admission. In discussion with the staff on the ward, it was decided that the post-natal physiotherapist may be the most constant contact. A further approach was made to the physiotherapy staff to seek their assistance with enrolling participants. Despite several visits to the physiotherapy department and discussion with the therapists concerned, there were still no participants enrolled in this arm of the research. Over the period of the study there were several staff changes in the physiotherapy unit and the researcher was unable to locate the same physiotherapist on any of her visits.

On advice that each family is visited by the CaFHS nurse in the first week after their discharge, a variation on the ethics approval was sought, to allow the CaFHS nurse in the RL to enrol participants from this group. The researcher met with CAFHS supervisors in both Adelaide and the RL, to explain the research and to seek their help. An SSA ethics form was signed and the research papers were provided along with some posters explaining the importance of tummy time and correct wrapping procedures. A step by step outline of the process of taking part was also displayed. Despite these measures and adjustments, not one participant was enrolled in the study from the RL.

Attempts to expand the area of recruitment

When it became clear that recruitment was a problem in RL and that birthing numbers were not as high as expected, I visited the Loxton hospital as there are about 90 births there per year. Loxton hospital has a modern birthing unit with a delivery suite including the availability of a water birth, and a family unit where the entire family may be present for the birth and stay with the mother and baby while they are in hospital. This hospital is covered under our current ethics approval and comes under the jurisdiction of the same medical director as RGH. The supervisory midwife was familiarised with the research project and invited to enlist participants from the parents birthing in the Loxton unit. Research papers were provided for distribution through this site. No participants were enlisted over the sixteen months of seeking support.

The unexpected differences in interest and response between the two regions, despite our original thinking that they were similar, highlighted that generalising statistics about health cannot be categorised into only urban or regional figures but must give consideration to a variety of other confounders which warrant further investigation. This research reinforced the difficulties with conducting research with this population and encouraged further thinking about simplifying data collection. It heightened the need to examine the unexpected difficulties in more detail.

CHAPTER 4: WHAT WENT WRONG?

In the light of the challenges experienced with the research in two regional centres in South Australia, Chapter 4 will explore possible explanations for these unexpected difficulties and how the direction of this exploration of regional health expanded. In considering the research and the variations in response to this study, all confounders must be explored. The importance of gaining evidence in early infancy can be seen, but the difficulty of research with this vulnerable population must be further outlined with a view to finding simpler methods of eliciting their collaboration in uncovering important markers which may assist in the early recognition of the importance of NIH, to improve hip care for infants in rural and regional Australia.

While arguments for and against the methodology had been considered, unforeseen difficulties within and between the groups were encountered throughout the research project. There was clearly not enough consideration given to the fragile emotional state of the families at this very sensitive time, or to the sleep deprivation and time management adjustments that participants may be experiencing. Reasons for the poor results from the research project warrant further investigation, but the results yield some significant commentaries about research with this group of people. It is clear that to gather the information required in establishing any awareness of the occurrence and management of neonatal hip instability, this research must be undertaken in these early weeks of an infant's life, but more thought needs to be given to simpler ways of gathering this data and measuring the results of any intervention.

The first six weeks of a new baby's life are a time of great change for any family (Baumann M & Berlio A, 2017). Much of the preparation for the arrival of a new baby is directed at the "how" of the delivery and a great deal of emphasis is placed on the establishment of feeding and sleeping patterns (Barnes et al., 2008). It is a time of huge change to the sleeping routines of the whole family and a major alteration in household responsibility (Gay C, Lee K, & Lee S-Y, 2004). There is often some inter-generational jostling and many mothers experience differing advice from many quarters. The new feelings and emotions experienced in early motherhood require much adjustment (Paris & Dubus, 2005). Any extra activities over this period, in either experimental or control group, should be as simple as possible. We may have had a better response rate if we had relied on telephone interviews to complete Q2 and any questions about positioning and wrapping. In discussing a telephone approach method in the preparation of the project, it had been felt that picking a suitable time which would not disturb either feeding or sleeping for the mother or baby might be difficult. We considered that the written questionnaires allowed the opportunity for responses to be entered at a time to suit the family. The pressures of the care and attention to the baby and the family may have meant that the filling in of extra things such as the Q2 and the diary were put off and ultimately forgotten. There are many documents involving registration of the birth, changes to Medicare cards, social security forms and others to be filled in and acted upon at this time and it became clear that this was just another thing for a busy family to fit into their routine.

In observing many new mothers in the first weeks of their baby's life, it is clear that most seem to feel more connected to the "outside world" when using electronic media to keep in touch with others or for seeking information (Paris & Dubus, 2005). It is my view that using the mobile telephone or internet connections would have been a more satisfactory way to encourage participants although difficulty can be encountered with connectivity. The work of Plantin & Daneback (2009) where they have shown that the majority of parents use the internet for information and social contact highlights this increasing tendency (Plantin & Daneback, 2009).

Although there was awareness of the variable reliability of mobile and internet coverage across the regions, we had a lack of knowledge about the extent of this difficulty or how unreliable this may be. Unreliable connectivity increases the problem of research in rural and regional health. We encountered repeated difficulty in contacting participants via telephone, which may indicate that results relying on the ability to telephone participants may not have been consistently easier.

Health

A paper recently published in the *Rural and Remote Health Journal* (Thomas SL, 2017) discusses the inequities of primary health care service provision in rural and remote health communities focussing on the cost of these services, but there are several other factors which can impact on this expenditure. Degree of remoteness, the proximity of services, the provision of transport and the loss of family support must also be considered. Farmer and Munoz assert that there are other overlapping factors such as history, economics, politics, weather variations and natural assets which can affect behaviour in any area and must be given consideration as possible confounders in any research (Jane Farmer, Munoz, & Clare Daly, 2012) In the Thomas study, numbers from the Australian Bureau of Statistics were used and populations considered ranged from small communities with 100 people to those with 5000.

In my recent study conducted in two regional centres in South Australia, marked differences were revealed between the two groups. We were looking at larger regional centres servicing populations of 30.000 to 40.000 people. Here we found that distance from the nearest capital city seemed to make a large difference. This prompted us to consider the reasons which may impact on this.

The regions under consideration were two South Australian regional centres, the Riverland and the Limestone Coast. Each of these regions is serviced by a regional hospital, the Riverland General Hospital and the Mount Gambier and District Hospital, details of which may be found on the SA Health website: (www.sahealth.sa.gov.au). Each hospital provides accident and emergency services, medical, obstetric and surgical services, as well as mental health and community health services. There are strong general practices serving each area. Both areas rely heavily on primary production income, including viticulture, wine and forestry as well as cattle and sheep. There is some manufacturing and value adding in each area.

Education

Education facilities in each region must be considered, as these are often cited as a reason for people staying in an area or moving away for the education of their children (Gardiner M, Sexton R, Durbridge M, & Garrard K, 2005). Both areas are well serviced by primary and secondary facilities, as well as some tertiary opportunities. There is more opportunity for University studies in the Limestone Coast region, with the expansion of University courses on offer through UniSA as well as Flinders University and many young people are now choosing to complete their study in the region.

Distance

One of the major differences between the two regions is the distance from Adelaide, which impacts on the ability of the population to travel to the capital city to access services. The Riverland is 1.5 to 3.00 hours by road from Adelaide while the Limestone Coast is 2 – 5 hours from Adelaide. The regional health service in the Riverland is situated at the Riverland General Hospital, 238 kilometres from Adelaide, whereas in the Limestone Coast the regional hospital is 450 kilometres from Adelaide. Both centres are close to the Victorian border and it is interesting to note that there are major health facilities in large Victorian centres quite close to the state border, with Mildura close to the Riverland and Hamilton, Portland and Warrnambool close to the Limestone Coast region. These Victorian facilities are very well staffed with specialist and ancillary services, highlighting the State differences in health service provision. In light of the services offered and the distance of travel, many people in the Limestone Coast would prefer to travel a short distance over the border to another country town, to consult a specialist, rather than making the lengthy trip to Adelaide. Such is the recognition of this phenomenon, a formula exists for the interchange of attendance numbers and funding arrangements between the two states.

The difference in uptake between the two sites provoked a closer look at any unforeseen differences between the sites which may have contributed to the disappointing outcome. The meta-commentary about the flaws in the research is significant. Incomplete data sets are part of qualitative analyses and the interpretation of this information must be robust and transparent, ensuring improvements for subsequent iterations of research and researchers. The section that follows probes the major differences in the populations, offering thoughts for future research projects but also the foundation for the theoretical discussions emerging in the remainder of this doctoral thesis.

Parent knowledge

Familiarity with early ultrasound examination of instability in infant hips was more common in the Limestone Coast than in the Riverland and this difference had not been adequately considered. More time should have been spent in discussion with health professionals in the Riverland to gain their confidence in understanding what we were studying. This may have encouraged greater enthusiasm in explaining the research to the potential participants. Further knowledge in this population about the long-term repercussions of late diagnosis of infant hip problems may have made recruitment easier.

The impact of not being able to have an infant hip ultrasound in the Riverland may have had an effect on the expectation of the parents, as there may have been less awareness of infant hip problems. Any such problems were usually managed by specialists in Adelaide. It may also have affected the number of infants being referred to specialist centres, as a result of doubtful clinical assessment of neonatal stability. A clearer understanding of the protocol followed in the case of a doubtful neonatal examination, would have assisted in the preparation for the research project. This could perhaps have been gained from some discussion with parents who had been sent to Adelaide for investigation of their infant's hips. Developmental dysplasia of the hip is a notifiable condition, reported to the peri-natal statistics unit at the Women's and Children's Hospital. Notification can be made on the SABDR form, a copy of which is included in the annual report 2012 (Gibson CS, 2007) It is difficult to gather figures on the numbers of children referred for specialist assessment of their hip status, unless the referral is reported as a disability on the prescribed form. Further study on the referral pattern for hip ultrasound may be useful to establish the pattern of management of infant hips in RL.

Differences in peri-natal environments between the two sites

There were some differences in the admission and post-natal stay of the mothers. In LC, resident specialist obstetricians and GP obstetricians are rostered to provide twenty-four-hour cover to the labour and post-natal wards. There are at least two midwives rostered on each shift as well as general nurses. There are three delivery suites and a ten bed post-natal ward with one nursery room.

Women receive their ante-natal care from their General Practitioner, through “shared care” arrangements, or they may choose to be cared for ante-natally by the specialist obstetric practice. Both the GP and the specialists encourage midwife visits ante-natally as well. There is an ante-natal education programme and a pre-admission clinic run by the midwives which all parents are encouraged to attend. All mothers birthing at the MGH are required to spend at least four hours in the maternity unit after the birth of their baby. It is a much-discussed feature of ante-natal classes by those who conduct them, that the major interest of the attendees at such classes are primarily concerned with the impending birthing of their baby (Weiner A & Rogers C, 2008). Attempts to discuss infant management seem far insignificant compared to matters of latter stages of pregnancy and the birthing process.

Most mothers transfer to the post-natal ward after birthing, where their continued care is managed by the attending doctor and the nursing and midwifery staff. There are staff paediatricians who may be called if necessary. On discharge, mother and baby are referred to their family doctor or usual medical clinic. In the first weeks after discharge, they may be visited at home by the midwife and the CAFHS nurse.

In the Riverland, pre-natal care is the responsibility of the GP and midwives. There are 8 – 10 midwives in the area. Most mothers attend a pre-admission clinic, which is run by the midwives in the hospital. Posters about the research project, tummy time and optimal wrapping of babies were put up in the room used for the midwife visits. There was uncertainty about who was responsible for antenatal classes or if they were offered in the Riverland. Attempts were made to meet the GPs to discuss the research project with them, but we were unable to discover if there were any meeting times which we could attend to address the group. On visits to the ward, the researcher was able to meet with one of the GP obstetricians, but this meeting was very brief and gave little opportunity to discuss the research in much detail. Further attempts were fruitless, but dissemination of the material provided was promised. A regular daily meeting of staff involved in the maternity area of the RGH is held but attempts to meet and speak to this group were not successful and raised questions about any local importance attached to this research and the interprofessional collaboration in this environment. The supervising midwife who had agreed to oversee the project in the ward arranged a meeting with all the midwives including the domiciliary midwives, to familiarise them with the research and to seek their help in the enrolment process. The principal researcher attended this meeting where interest was expressed in the research.

On admission to the delivery suite in the Riverland, mothers are attended by one midwife each shift until birthing. The midwife stays continuously with that patient until the baby is born. After the birth, mother and baby are returned to a general ward and cared for by general nurses, which may include the midwife if there are no other women in labour (personal communication Lisa Long Midwife. see appendix F).

There is a visiting obstetrician who provides specialist cover on week-days. There are strict regulations about patients who must be referred to a major centre before delivery and this includes all multiple births or complicated deliveries. The average post-natal hospital stay is three days. Discharge from hospital before four days post-partum has been cited as a risk for missed diagnosis due to loss of follow up assessment (Azzopardi et al., 2011). A community midwife visits the mother and baby in the first week after discharge and then they are followed up by CaFHS nurses.

Differences in participant enrolment

In the experimental (LC) group, we found that 66% of all mothers birthing over the trial period enrolled in the study. There was interest in hearing about the study from 98% of mothers birthing during this time. The remaining 2% were those mothers we were unable to talk to while they were in the ward. Some were immediately post-op having had a Caesarian-section and some were non-English speaking and did not want any visitors. A few mothers left hospital several hours after the birth of their baby and we were not able to speak with them. Some mothers returned to their local hospital as soon after the birth as they were allowed to do so. This group were likely to miss the post-natal visit and had also not had any introductory explanation of the research.

Video viewing in hospital

Although there had been administrative agreement at both sites to encouraging viewing of the RCH video while the mothers were in the ward, this did not occur. It was later discovered that the hospitals would not allow use of the internet to do so, unless parents had arranged to buy internet time. Mobile telephone coverage from within the hospital was not consistent or readily available and there was no suitable video player on the ward sitting room television, so parents were unable to access this video in the ward or on their mobile telephones while still an inpatient. A small number of families viewed it on their iPad while still in hospital and others said that they would view it at home.

Diary

The diary proved difficult for many parents to complete. They were too busy/tired in the first week to commence entering responses into the diary and for some, this meant that they did not ever start. Others only started entering data in the second or third week. For some it appeared that they may have filled the diary out all at one time, with the same writing implement and a very similar pattern of entries, perhaps when contacted by the research assistant to ask for its return. It is difficult to decide in which cases this may have occurred and therefore impossible to estimate how many of the responses we received to this were accurate. This therefore raises doubts about the validity of any information gathered from the diaries but some indication of intent to observe the recommendations of early infant care can be gathered. The difficulty and suspicion of lack of accuracy in the reporting in the diary demonstrates that this is not a reliable method of data gathering in this group of people. It is challenging to place any value on data received in this way as it lacks validity and repeatability. Rogers and Caruso report that sleep diaries used in their study had a sensitivity of 92.3% and a specificity of 95.6% but the parameters on recording the data were more clearly defined and the data was more subjective, perhaps leading to more timely and accurate entries (Rogers A, Caruso C, & Aldrich M, 1993)

In considering the outcomes after the study, it seems that the keeping of a diary was a much more difficult task to ask a new mother to do than had initially been thought. Of particular interest would be further analysis of the responses gained in the demographic data, in determining whether the position of the baby in the family made any difference to the keeping of the diary, or whether it more closely correlated to sleep deprivation as learned from the answer to the Q3 question asking whether feeding and sleeping had taken up most of the time in the day.

Only a quarter of participants completed and returned Q2, a very disappointing result. There were several explanations for this, but the extreme busyness and tiredness of a new mother was obviously a large part of this poor response rate. Part way through the experimental phase of the study, the principal researcher was unavailable for health reasons and the ADUS study was supervised by the research assistant who had been trained in the process. This break in the continuity of the study may have had some effect on follow up, and subsequently the outcome, although attendance at the ultrasound examinations was still maintained at the same rate.

An App for a mobile device had been considered as an alternative to the diary but was rejected because of the cost involved in producing such an App, needing to be compatible with the variety of mobile phones one could encounter in the population. There may be some useful data we can extract from the diary in regard to amount of tummy time and wrapping techniques, but the numbers are small.

Some parents, when contacted, were unable to locate either their diaries or Q2 but completed Q3 on the phone. This provided information on differences between Q1 and Q3 but much of the interim information is not available. There were some participants who completed Q1 and attended for the scan, but we were unable to contact them further as their telephones were no longer active. Some did not respond to the calls or the messages that were left on their message bank.

Regional differences in health literacy in regard to infant hips

In discussion with nurses and allied health professionals, on subsequent visits to the Riverland, it became clear that there was little understanding of the occurrence and management of DDH within the hospital and community health setting. The physiotherapists were not responsible for the treatment of any infants undergoing management of infant hip problems and advised that these children were treated in Adelaide.

Perhaps there is less awareness of infant hip problems in the RL community as a result of diagnosis and treatment being carried out in Adelaide. At one of the screening days in the LC a mother remarked that she was aware of the problem of DDH as her first baby had been treated for the condition. This made her eligible to be part of the at-risk screening programme. She stated that when other people became aware that she had a baby with hip problems, many other people acknowledged that they knew someone else who had the same problem. Perhaps in an area where the diagnosis and treatment are carried out elsewhere, there is less opportunity for these conversations to occur. If so, does this lack of awareness alter the importance that new parents put on the early positioning and wrapping of their babies? It was hoped that the responses to the questionnaires would help answer some of these questions.

In considering this information, it became clear that amongst health professionals in the Riverland, there was lower emphasis attached to infant hip assessment and management, because it was a condition which was not locally managed. Awareness amongst parents may also have been lower than in the Limestone Coast region. An opportunity exists to examine in greater detail, any differences in diagnosis and management between the two regions, in terms of any differences in occurrence and length of treatment for DDH, in a further study. From a physiotherapy viewpoint, paediatrics is a small part of the basic physiotherapy undergraduate training with variations nationally within undergraduate courses. Clinical paediatric training is most often obtained in tertiary centres in the metropolitan area. It is difficult to comprehend the whole family impact of such conditions as DDH when the involved families are seen out of their home context, where the consultation may be conducted with a specialist team. For these reasons, although it has been stated that ‘rural credentials are transferable across settings” (Jane Farmer et al., 2012) perhaps in this research it was a confounder. Inter-regional competition and loyalty may have had an adverse effect on the outcome of research where one region was the participant group and the other was the control group, when the researcher was based in the participant area. This tendency for regional competition is encouraged by the central funding and management of rural and regional services which can at times appear to be politically influenced.

Methods of increasing rural knowledge of infant hip development and care must be explored. National and State clinical guidelines advocate clinical assessment of all infant hips (SA Maternal & Neonatal Clinical Network, 2010). Research demonstrates that operator experience is a vital part of the clinical assessment (Goss, 2002). A further exploration of assessment techniques is therefore warranted to optimise early examination of infant hips in rural and regional South Australia.

There are many parts and many problems emerging when assessing timely parental involvement in the research study. The unexpected difficulties warranted further investigation. Following the high interest in early ultrasound seen in the Limestone Coast, a decision was made to continue to offer an ADUS to any baby considered to be in danger of having a hip problem as a result of equivocal clinical assessment, family history of hip problems or breech positioning at term. More discussion is required into the unexpectedly major differences in involvement in the research study between the two chosen sites. Further unexpected results occurred in the experimental group which had a very high drop-out rate once the status of the infant hip was established. The reasons for this warrant further investigation. A solid finding of the research with the experimental group in the LC was the strong desire from parents and health workers to have a measured assessment of the infant hip and to follow up with ongoing care and surveillance.

Conclusion

The difficulties encountered in this early infant study leads to a deeper discussion of regional health services and the possibility of further study of this topic. The parental acceptance of the early examination suggests that a further trial is warranted.

CHAPTER 5: THE "AT RISK" STUDY

Introduction

The reported research study and the preceding pilot study have shown strong parental acceptance of an ultrasound screening programme in the early weeks after birth in one regional centre in South Australia. Late diagnosis of developmental dysplasia of the hip is known to be a greater risk in regional Australia than in metropolitan areas (Studer et al., 2016). National clinical guidelines and therefore Medicare funding, applies to those infants referred by their doctor for early screening because of being considered at risk of having a problem hip (South Australian Department for Health and Aging, 2014). In accepting the commonly stated risk factors for developing dysplasia of the hip (as outlined in the introduction to this thesis) and thereby warranting early ultrasound examination, it is likely that many problem hips will be missed (Bache et al., 2002). Birth in a regional centre in South Australia could, on the face of the reported evidence, be included in these risk factors, but this is not standard procedure yet.

When the enrolment of participants reached the required number for the universal scan study, and the funding was exhausted, there were ongoing requests from doctors, allied health professionals, parents of new babies and CaFHS nurses, to continue to provide neonatal ultrasound hip scans. This can be taken as confirmation that the process was acceptable to all these groups concerned with the well-being of young babies, as well as the parents involved in the experimental study.

In the questionnaires returned by the parents in both the pilot and the research studies, there was solid support for attending the ADUS and seeing their baby's hips on the ultrasound monitor. Most parents expressed relief at seeing an enlocated hip and understanding more about hip development. The scan provided a good opportunity to discuss the safe use of prone positioning over the early weeks after birth. Tummy time is known to be optimal for the development of neck and back strength in the early weeks, as well as encouraging good hip positioning (Twitchell, 1965). The opportunity to discuss wrapping techniques was also appreciated and this was done during the dressing and undressing phase of the examination. The scanning of each baby was completed in ten minutes or less and in this time a copy of the scan with measurements could be stored and transmitted to both the referring doctor and our records. It would therefore be possible to scan at least 5 babies in one hour if they were prepared for the scan by undressing and wrapping loosely in a rug in their cot before coming into the examination room.

As knowledge of the scans spread amongst the parent groups, requests for the examination increased. Discussion was held with Benson Radiology to consider ways in which the scans could be continued. The universal ADUS scans had been funded through the research study. There was however, an identifiable funding problem in continuing to offer the scans to all babies, as there was no Medicare funding for the examination if it were not medically authorised, in line with current clinical guidelines. A return to the accepted protocol of conducting an early ultrasound examination in the first six-week period was therefore offered to any child who was considered to have any of the recognized risk factors for having a hip problem. These children had historically been examined using the Graf ultrasound method prior to 6 weeks of age if the hip were thought to be dislocated or dislocatable. In those infants presenting as breech at term, the Graf ultrasound was usually performed at six weeks of age. If an earlier Graf examination were carried out in the weeks after birth, most hips were reported as being immature in their development. This finding is consistent with the literature which states that the Graf is an unreliable test under the age of 6 weeks due to the wide range of measurements seen in this group (Cundy, 2004).

In consideration of the universal early ultrasound experiment we had conducted, it was decided to examine this group of infants with both the Graf and the ADUS examination, in order to gain an indication of any instability in the joint which may lead to poor development as reported by Lee (Lee & Eberson, 2006). The results of these scans were transmitted to the referring doctors and the scans were stored in the infant's records, enabling further reports to be compared with the originals. Over the period of this protocol for examination, there has been an increasing number of babies referred with a range of risk factors for having hip problems, the two most common being breech position at term and family history. Many parents are asking for the ADUS examination and expressing interest and relief on viewing the hips on ultrasound.

Research question 2. Are there differences in measurement of hips in the AR group and does knowing that your baby is in the AR group alter parental attention to advice about wrapping and positioning?

Following a further amendment to Ethics 388.15, approval was granted to continue to collect data on the hips of all babies considered to be at risk of hip problems, in the first two weeks after birth. The ADUS was used to identify those hips which had an increased range of movement on the Barlow test, which would give a measurement of neonatal instability of the hip. In doing this it was recognised from the literature that there was a chance that a number of later developing DDH cases may be missed and Bache confirms this, showing that up to 66% of late developing DDH cases were not in the “at risk” group of infants (Bache et al., 2002). Discussion was had with the obstetric doctors and General Practitioners, as well as Benson Radiology and it was agreed that any infant considered to be at risk of DDH could be assessed by ultrasound examination in the early weeks, in accordance with the existing clinical practice guidelines, thus qualifying for the scan covered by Medicare. After consideration, it was decided to include in this “at risk” group:

- Any infant in whom the early clinical assessment indicated excess movement on the standard Barlow/Ortolani test
- Those with a family history of hip problems, either first or second degree relative
- All breech babies, whether they were born by Caesarian section or vaginally.

This protocol was widely accepted by the delivering doctors. There were however, many parents whose babies did not qualify for an early ADUS when using this protocol, but who were keen to have their baby’s hips scanned, particularly those families already familiar with the ADUS. This was most noticeable in the group of mothers having their second or subsequent baby, when their previous baby had been included in one of the earlier studies. These parents were keen to have the hip position confirmed by early ADUS performed on their subsequent infants.

As previously discussed, birth in regional South Australia has been cited as a risk factor for late-diagnosis of DDH (Azzopardi et al., 2011). This raises the concern that there may be increased claims for litigation in late diagnosed cases in the regional areas of the State. Perhaps all regional births could therefore present an increased risk, thereby warranting early assessment and a strong case for their inclusion as a risk factor requiring early ultrasound assessment can be made. The reasons given for this increased risk include the inexperience of clinicians in carrying out the clinical assessment, isolation and distance of travel to a suitably experienced assessor, shorter hospital stays at the time of birthing and movement from small rural hospitals to larger regional hospitals. Inter-hospital transfer often includes an early return to the local facility in the immediate post-partum days, thus interrupting continuity of care in early hip examinations (Goss, 2002). Frequent professional development in the art of assessing infant hips clinically has been recommended by Goss and others, but this creates the added problem of increased clinical practitioner time away from often under-staffed facilities to engage in such training.

Increasing fear of failing to identify dysplasia of the hip early, may have contributed the number of infants in our region being referred for assessment of their hips and undergoing hip ultrasounds between six weeks and four months. One of the common reasons for referral has been the appearance of unequal skin creases on the thighs of infants. This finding is described in the literature as an unreliable pointer (Roposch, Liu, & Hefti, 2011). It seems to be a more frequent finding in examinations conducted by child health nurses and some doctors and is a positive indication that hip surveillance is continuing. At the same time, it suggests a level of uncertainty about interpreting the findings of the examination or perhaps fear of mis-diagnosis

The most reliable signs in this age group are a diminished or unequal range of abduction of the hip, or a positive Galeazzi sign (Roposch et al., 2011). The Galeazzi sign is measured with the infant lying supine with both knees flexed and heels close to the buttocks on the supporting surface. A positive Galeazzi sign is noted when the knees are not at the same level during this test, indicating shortening of the affected leg due to the hip displacement. Clearly this sign will only identify those hips which are dislocated but will not indicate those enlocated hips which are shown to have sub-optimal acetabular development when undergoing ultrasound examination using the Graf method.

Image removed due to copyright restrictions. Available online from:

https://www.researchgate.net/publication/323747595_Developmental_Dysplasia_of_the_Hip/figures?lo=1

Figure 9 Positive Galeazzi (Priyanka Kumari)

The uneven creases on the thighs of young babies may be increased by the tight inner elastic bands in disposable nappies which make them more secure, but invariably sit asymmetrically much as knicker elastic can do. A distinction should be made when assessing skin creases, between thigh and gluteal creases and this assessment can be more adequately assessed when made with the child in the prone position.

Amongst doctors and child health nurses, there has been an increase of referrals for ultrasound checks of infant hips when doubts are raised. Choudry and Paton (2018) have noted an increase in litigation for late diagnosis of infant hips and believe that this is due to changes in culture and changes in the way that such litigation is funded rather than an increase in negligence. They also remark on the increase in numbers of infants being referred for ultrasound examination and suggest that there are increasing rates of surgery as well (Choudry & Paton, 2018). In recognition of the fact that mis-diagnosis of developmental dysplasia of the hip is the third most common cause of litigation in paediatric orthopaedics in the United Kingdom and is reported to be in a similar position in the United States of

America, the suggestion is made that clinical assessment may not be sufficient. Some lawyers are questioning whether other diagnostic measures are available. McAbee, Donn et al (2008) purport that increasing use of ultrasound has been responsible for a lowering in numbers of litigation for mis-diagnosed DDH over the last few years (McAbee, Donn, & Mendelson, 2008). They identify an expanded range of risk factors as warranting early ultrasound, including being firstborn, belonging to some nationalities with a higher tendency to DDH and in the presence of some foot deformities.

The ADUS was a useful tool for earlier examination to assess and measure the amount of instability in the hip, in the belief that this instability may be a pre-cursor to later development of dysplasia. Increased instability at this early developmental stage can affect the development of a good fit between the developing head of the femur and the acetabulum (Gomes et al., 1998). Measuring and monitoring this instability with ADUS in the early weeks, prior to the examination at six weeks using the Graf ultrasound, can allow advice about management which may assist better development and avoid later treatment.

Andersson's work, suggesting the range of standards of movement in the neonatal hip, may influence those who are using the clinical assessment of movement felt on examination. His figures show that there is a difference in outcome between hips with 2 or 4 mm of movement on assessment in the first weeks (J. E. Andersson, 1995). Such a difference can be difficult to judge clinically, especially where numbers being assessed may be low. It has been noted in the literature, that the incidence of reported DDH is much higher in the clinically assessed population than in the ultrasound population (Finnbogason et al., 2008b). This will therefore lead to increased treatment rates amongst the clinically identified hips.

There may be an effect on the confidence of the examiner, knowing that it is possible to get an accurate measurement of movement in the hip, using dynamic ultrasound. This may contribute to an explanation of the increased referral for ultrasound examination. It is difficult to separate this factor from the increased requests coming from the parents to see the hip on ultrasound.

Methods of AR study

Any infant found to have any of the commonly acceptable risk factors at birth or over the following days, was referred by either the doctor present at the birth or their family doctor and asked to make an early ultrasound scan appointment. The scans were conducted at the same time every week in Benson Radiology at the Mount Gambier Hospital. The principle researcher or the research assistant were present at all scans, which were conducted by one of three sonographers trained in the process.

In the first 36 weeks of the AR study parents were asked to provide some demographic data about their baby and the birth. They were asked to complete an enrolment form and given the same questionnaires and hand-outs as the participants in the universal study. It was decided not to provide the diary, as the response to that part of the previous study had been so poor.

The parents of a further 24 infants were enrolled in this part of the study, but again we encountered extreme difficulty in continuing to engage these families in further study once it was established that the status of the hip was within normal limits. One of this group of 24 infants was discovered to have bilaterally dislocated hips, which had been undetected on clinical examination and he was subsequently referred for orthopaedic management. It was decided to continue to offer the AR screening to all referred families but to cease asking the parents to complete the questionnaires. The parents were then asked to provide birth and demographic information to allow comparison of our statistics with other AR groups reported in the literature. A further 115 infants have been scanned in this group up to 30/09/2018.

Results of our AR study.

One further infant scanned in the larger group, had dislocated hips on the first scan and was referred for immediate treatment in a DB hip splint. The hips were difficult to reduce and maintain in the splints and were treated at WCH Adelaide. One infant commenced treatment in DB hip splint on review at six weeks, when despite advice about management, she still had increased instability in her hip and Graf US confirmed poor acetabular development. Two further infants who had not had an early ADUS because they did not fall into the AR group at birth, were referred for a Graf ultrasound at 8 weeks, found to have poorly developed hips and were placed in DB hip splints.

Difficulties with AR study

Similar difficulties of engagement, as had been found with the previous universal study, were encountered with the AR study, with diminished participant follow up. It became clear that most parents were keen to see the pictures of their infant’s hips and returned for follow up scans as required, but there was no commitment to completing follow up questionnaires once the results were known. How much this related to the busyness and tiredness of new parents is hard to know. It is clear however, that parents are keen to know the status of their child’s hips and interested in viewing the scan and learning about hip development. To gain definitive knowledge about what changes this early knowledge may make to parental understanding and ongoing management, methods of reporting and recording information must be simplified. A larger study would allow closer comparison with the statistics reported in the Scandinavian studies.

To correlate results with hip development through the growing years and into adulthood would provide better evidence about any long-term effect on costs of hip problems over a lifetime (I. L. Engesaeter, T. Labore, L. Lie, S. Rosendahl, K. Engesaeter, L 2011). A more conclusive analysis of the benefit of early ADUS will require a much larger scale investigation over a greater population mass, with several years of follow up cycles. This research study has demonstrated that it is possible to offer early dynamic ultrasound screening to all infants in the first weeks after birth, but more convenient ways of doing this need to be investigated, with further funding assistance to families through better funding arrangements, to enable equity in the uptake of the opportunity to have an early hip scan.

CHAPTER 6: MANAGING THE INSTABILITY

IS IT JUST THE HIPS? WHAT RESEARCHERS LEARN FROM THE RESEARCH PROCESS AND RESULTS

Support for early dynamic ultrasound examination of infant hips has been demonstrated in a regional centre in South Australia. A deeper understanding of how valuable this is will require a larger study over several regions, to determine the benefit it may offer to early diagnosis and prevention of further hip problems in young children. This chapter examines some of the reasons for the loss to follow up results in the research and the failure to enrol a control group in a separate region.

Over the period of the combined studies in our region, there is a growing interest in hip health in infants. We have identified a range of measurements of neonatal instability and seen natural improvement in many of these hips. Instability has persisted in some cases and has led to follow up treatment. The incidence of babies over the age of three months requiring splinting has been higher in the periods when “at risk” ultrasounds were being done rather than universal screening. The measurement and management of NIH in any infant hip may be important in lowering the incidence of late diagnosis of DDH in regional South Australia.

Our research record of ultrasound examinations gives a history of 242 babies, 101 in the universal scanning research study and a further 141 in the “at risk” group, together a total of 484 hips examined in the first six weeks of life. The birth rate at the Mount Gambier hospital is between 400 – 450 babies per year, so this represents more than 60% of births over both time periods, each spanning close to six months in the year in which they were conducted.

Further records of hip status in some infants born in the region, between and since the universal studies, are available through the paediatric physiotherapy practice in the region. It would be of value to compare these statistics with records from WCH, using postcodes, as some infants may have been followed up at that facility. Our records have shown that during the period of universal screening there was only one case of diagnosis after three months of age. During the time of “at risk” scans, 6 babies who were not considered to be “at risk” and therefore were not eligible to have an early scan, have been diagnosed with immature or dysplastic hips after 3 months of age. Unfortunately, a further 3 children over the age of 2 years have also been diagnosed with poorly developed hips. None of these children was in the early scan group, but all of them are likely to have ongoing hip problems and may require early hip replacements as a result.

A heightened regional awareness of hip problems in infancy has been noted generally in the Limestone Coast population, amongst parents, midwives, child and youth health workers, doctors and allied health professionals. This is evidenced by parents requesting hip assessments as well as health professionals requesting education sessions about assessment and management of hips (address to LC regional meeting CaFHS 27/09/2017). Two sessions have been held at CaFHS in Mount Gambier, one of which was a regional education seminar at which statistics from the two studies were presented. A demonstration of the use of the portable ultrasound device was held with the maternity staff at the MGDHS and two local medical clinics in the region have sought further advice about the scanning process. A note of the result of each individual examination is given to the accompanying parent to be given to the family doctor at the next visit. A presentation was made to the Mount Gambier District Health Service perinatal meeting on 18/10/2018, demonstrating the portable machine and outlining the research data to date.

From the research

Data collection

It is clear that to gather the information required to demonstrate any changes in the early management of neonatal hip instability, this research must be undertaken in the very early weeks of an infant's life. More thought must be given to simpler ways of gathering data to measure the results of such research. It seems likely that interviews carried out in concurrence with CaFHS or midwife visits may produce more reliable information.

A photographic record of infant positioning and wrapping would have been a more accurate reporting measure, but this was considered unlikely to satisfy ethical requirements because of the need to photograph, and store, pictures of young children. Perhaps we would have had more success with week by week data sheets which could be emailed or posted to the researcher at the end of each week. This would have allowed for more timely information about participation and may have yielded more complete and accurate results.

In support of the involvement of CaFHS nurses in some data collection, we found that 100% (n29) of parents who were contactable by telephone for an interview over the period of keeping the diary, gave a positive response to the question of whether they had seen a CaFHS nurse since their return home from hospital. Despite several attempts, the remaining 69 parents were not able to be contacted, either because they failed to answer their telephone on repeated attempts, or advice was received that their phones were no longer connected. Mobile telephone connectivity is recognised as a serious issue throughout the region, with much attention being directed to “black spot” remediation, but the impact poor connectivity may have caused on the study had not been given enough consideration.

A proposed Life Study commenced in the UK and intended to follow a cohort of 80,000 newborns throughout their lifetime, was cancelled after the first eight months because of poor recruitment (Pearson, 2015). The researchers in the Pearson study observed that in the gathering of information there was a need to, “find ways that pose the least burden possible to parents.” A similar Norwegian study suggested that it was useful to have systems through which information can easily be extracted but data collection was difficult for that study too.

What further could have been done in the control group to improve feedback and data gathering at this time?

With the wisdom of hindsight, I should have enlisted earlier help and assurance from those who had signed off on the SSA in the Riverland, agreeing to support the research. Arranging the necessary meetings with those involved was extremely difficult. The different geographic locations with the research supervisor in Bendigo, the chief medical officer in Mannum, the principle researcher in Mount Gambier and the Director of Nursing in Riverland General Hospital, made any hope of a physical meeting a huge task. The benefits of having everyone together at the developmental stage of the research may have made an impact. The importance of having a more senior champion of the study cannot be overlooked and I believe would have made a remarkable difference to the results. At no point was a joint meeting of all involved in signing off on the research ever held. There was never a feeling of any ownership or interest in the research in the Riverland site, apart from the midwife who was attempting to drive it at that site, and the FURCS assistant who also clearly understood the whole project. Attempts by the researcher to contact the Chief Medical Officer by telephone took several weeks, culminating in one successful phone call and there were only two successful, brief meetings with the Director of Nursing. The importance of collaboration in both the setting up and the rolling out of the research is reinforced in this regional research. The difficulties experienced in holding preliminary meetings should have been probed more deeply to understand whether competitiveness between the regions may have affected willing engagement.

I visited the Riverland sites on four occasions, with overnight stays on two occasions. On the first occasion, the plan was to stay for three days at the start of the programme, to talk to the assistants in the region and to commence inviting participation. During this pre-arranged visit, there were no obstetric patients admitted and therefore there was no chance to demonstrate the approach as it was being carried out in the Limestone Coast. There was no dedicated area for the researcher to set up. Most meetings were held informally, standing in corridors or in empty rooms in the ward. The difficulty of carrying out research as a physiotherapist with little recognition in the area and no infrastructure back up can be seen.

Over this period, further meetings were held with clinicians working at the Flinders Rural Clinical School at Renmark, to finalise arrangements for collection of the questionnaires and their return to Mount Gambier. The staff at the Flinders University Renmark site were familiar with the research through regular research video meetings with all rural clinical schools. The research proposal had been presented via video conference from Renmark, across all rural clinical school sites during an earlier visit to the area. A Flinders University clinical supervisor who also worked in the radiology department at the Riverland General Hospital, agreed to assist in the collection of the completed questionnaires and to return them in the reply-paid envelopes, to the rural clinical School in Mount Gambier. No questionnaires were ever completed or returned, as there were no participants recruited.

Lack of continuity in experimental group

There was considerable interest in the research within the experimental group, where most families birthing over the period were keen to hear about the project and agreed to participate. If the ultrasound examination were held on a day that the families were still in hospital, they were happy to attend. Once discharged, if the initial scan had not already been completed, the parents were required to attend with their baby in the first two weeks after birth during scanning time on a Wednesday. For some families this proved very hard. A system of screening with a portable machine, in closer proximity to the maternity unit and offered more frequently during the week, as seen in Trollhaten, may make this more easily accessible.

Many mothers were discharged from hospital with good intentions to continue the study but found returning after discharge too difficult. Maintaining contact with the families except in those instances where follow up scans were recommended, and the family doctor became more involved, also proved difficult. Although contact telephone numbers had been collected the call was often diverted to message bank or the number rang out. In some instances, the telephone service no longer existed, or the telephone was out of a service area.

The difficulties with data collection across the experimental group combined with the absence of data from the control group led to there being no data collected for comparison despite multiple attempts to gain data from each group. This led to an in-depth examination of some possible reasons for the disappointing result.

Familiarity with the programme

Familiarity with the hip study was clearly a strong confounder of the differing results in the two sites. The pilot study to measure parental approval of the ADUS had been carried out in the Limestone Coast several years earlier and the doctors and nursing staff had previously been involved in that research. This may have had a community effect as well. Some of the mothers giving birth during the research experiment may have had a previous child participating in the pilot study or been aware of others who had been involved.

The strong working relationship between both the researcher, the assistant researcher and the nursing and medical staff must also be considered a positive confounder in this experiment. Much more time needed to be spent on community engagement and professional understanding of the process of the research in the Riverland and this proved difficult to arrange.

The Riverland people were blinded to the fact that all parents in the Limestone Coast were being offered an ultrasound examination of their baby's hips. They may have been unable to see any reason to commit to extra activities at a very busy time of their life. It had been considered that the time required to answer the questionnaires and fill in the diary would not amount to very much for the parents, but it became obvious that it was very hard to find the motivation to commit to doing any more, on a regular basis, at a time when there was a disturbed household routine and great potential for sleep deprivation.   Perhaps with a little friendly encouragement, parents may have been ready to assist, particularly if they had understood more about the reasons for the study. The Riverland participation may have been better if the project had been more clearly explained in broad terms of what we were researching. A simple explanation that another group of mothers in a different area were being provided with the same questionnaires after an education programme, may have developed a greater interest and inter-regional competition which could have encouraged participation.

The reasons for differences between the two regions

- Inequality of knowledge about the research and neonatal instability of the hip may have affected the outcome. Differences in this knowledge between the two regions may have led to a lack of interest in what we were trying to do. Perhaps more time in familiarising health professionals with the reasons for the research and the benefits of early management, prior to the commencement of the research, may have improved participant enrolment by promoting greater support in encouraging interest in the research.

- Differences in professional knowledge and familiarity with the project and neonatal instability of the hip perhaps changed motivation to participate. The years of previous study in the LC had heightened awareness of the status of infant hips. The long-term paediatric physiotherapy practice in the region had led to cooperation with infant welfare nurses and GPs in the assessment of infant hips.
- Differences in hospital environment and post-natal management became more obvious and may have impacted the outcome. The dedicated post-natal ward in the LC may have increased awareness of assessment of infant hips and post-natal care generally. Differences in availability of local care and proximity to a tertiary centre may have had an impact on early referral for specialist assessment and care in RL
- Differences in awareness of CaFHS staff to the research and the problems of neonatal instability of the hip, plus the close professional association of the researcher to CaFHS staff in the Limestone Coast area as a result of the long-standing association of paediatric physiotherapy and CaFHS in LC could have confounded the enrolment of participants.

Demographic differences between regions which may have contributed

Sir Michael Marmot has written about the impact of geographic/locality differences on health problems, particularly looking at the major health issues such as diabetes, heart disease and obesity. He talks about this as a global issue and demonstrates vastly differing survival statistics according to where we live and our access to services (Marmot, 2005).

These differences impact on areas of Australia, where the major population is situated along the East coast of the continent, with other major capital cities around the remaining coast. These capital cities are well serviced with specialist as well as general medical and ancillary services, but there are inequities between all of them. Some of these issues arise because of the division of responsibility of provision of services, between the Federal and State governments, with some small part being played by local government services and some private facilities. To illustrate just how difficult this cross-border problem can be in terms of medical and allied health service provision, some State based services will not provide services and equipment across the border, even if the client attends the service at their nearest regional facility, if this happens to be in another State. The differences in the State-by-State roll out of the National Disability Insurance Scheme (NDIS) highlighted some of these difficulties. My physiotherapy practice is situated close to the State border and some children travel from Victoria for their treatment but are ineligible to register and receive services under the NDIS because their residential postcode was not in an area included in the early roll-out, although they attended school in South Australia.

Transport within and between States, major centres and outback regions is varied, costly particularly when considering regional transport, unreliable and sometimes non-existent. This can impact not only on patients and families but also causes difficulties for visiting specialists who agree to visit the area. Recently the visiting paediatric orthopaedic surgeon had a two-and-a-half-hour delay waiting for a plane in Adelaide, to conduct a full day of consulting in Mount Gambier. His start time for appointments was delayed by three hours on arrival in the consulting rooms and the only return flight was on schedule at the normal time at the end of the day – a frustrating day for specialist, parents and families with appointments and staff in the consulting rooms. Occurrences such as this dampen the enthusiasm for visiting specialists to make the trip for the benefit of regional patients.

Radiology services

There is a privately contracted radiology service provided at the Mount Gambier hospital, with a resident radiologist. Services provided include x-ray, ultrasound, CAT scans and MRI scans. Bensons provide community ultrasound and x-ray services at a community site as well. In 2010, Bensons moved away from printed films to electronically distributed films and all the local clinics and allied health services use this service. This service can be simultaneously extended to specialists in the capital city as well, so a specialist opinion can be obtained on any examination undertaken in Mount Gambier by allowing access for that specialist to view the pictures electronically.

An infant with a doubtful hip on clinical assessment, can have an ultrasound performed locally on referral from the delivering doctor, with follow up treatment carried out by the local physiotherapist. An opinion can be sought from the specialist in Adelaide, who can view the films and offer advice about the treatment recommended. The ability to video link in this way can be used in other situations, particularly with children with developmental difficulties there can be a video link with the specialist in Adelaide to enable a viewing of gait and joint range. This can be of great benefit to the family, saving them a long trip to the capital city, with all the difficulties of transport, equipment, accommodation, traffic and parking. The collaborative discussion between consultant, parent and local service provider is an added benefit. There is some government assistance with transport costs for families who may need to travel, but this is extremely limited and requires authorisation from the local GP, together with endorsement from the specialist consulted in Adelaide.

This scheme is the Patient Assisted Transport Scheme (SA Government (Health), 2018). It becomes clear that people living in the LC region are used to having services provide in the region and not having to travel the long distances to a major centre. Accessing the PATS website, I find that I would be eligible for $141 for the two-way trip which would require an overnight stay and either a lengthy car journey or an expensive aeroplane flight, neither of which are easily managed with a very young infant. This financial assistance must be applied for online and is paid retrospectively which can create difficulties for many country people.

The ability to provide the professional services outlined above, at a local level depends on many factors:

- Availability of suitably qualified personnel.
  This has been shown to be increasingly difficult with the churning effect of medical and allied health services in the regions. Maintaining contemporary standards in health care requires frequent professional development opportunities which can be difficult if there are no replacement professionals during times of absence.

- Good reliable internet coverage.
  Despite the continuing roll-out of the national broadband network across Australia, reliable internet coverage remains unreliable or on-existent in many areas, with a great number of “black spots” in unpredictable areas. Internet is an ongoing difficulty for people in rural and remote areas when communication generally is moving to electronic contact.

- A solid interprofessional working relationship with the central specialist.
  The ability to contact specialists in urban centres in a timely fashion is in part affected by a strong, trusted, interprofessional working relationship which may take some time to develop.

- Effective local back up to support the family and the providers.
  It is difficult to work with children and families in isolation. Successful local management relies on collaboration with the extended families and other community members who support the family. This may include childcare workers, teachers,

CaFHS visitors and sometimes other families who have experienced a similar problem.

- Access to further education and training for the local providers.
  Professionals working in isolation in rural and remote parts of the State are often hungry for information on developing expertise within their field. This can be gained from webinars or recorded lectures, but the best professional development can be gained from face-to-face interaction and discussion. Local inter-professional meetings with open information sharing can be very useful, but an informal meeting with any visiting specialists can be of great value in including regional workers with current thinking in urban professional development.

- The inability for allied health workers to refer for ultrasound examinations with full medical benefit coverage. (extended scope practice)
  Particularly in the treatment and management of infant hip problems, there is a need for repeated ultrasound scans or routine x-rays and currently patients are required to make an appointment with their GP to gain a referral for the imaging if they are to receive full medical benefit coverage for this. This requires an extra appointment with an already busy GP, at an added Medicare cost, when it should be possible for such a referral to be made by the treating physiotherapist for the same Medicare benefit.

In order to further understand the differences in the results/uptake between the two regions in the study, it is important that we consider the results of studies which have been carried out by CaFHS and reported' in their Discussion Paper: The Case for Change (South Australian Government, 2016). In this document, five levels of parenting circumstance were identified and considered in conjunction with five levels of birth population. Amongst these were listed the distance from help and advice, the educational standard of the parents, the economic situation of the families, their mental health and ethnicity. The combined barriers of social demographic disadvantage and parental developmental literacy must be considered. It must be established what impact, if any, we had from variability between the areas, such as the availability of infant ultrasound, or knowledge of infant hip problems. In the words of Shonkoff (2014) “Funding restricted to services with previously documented effectiveness eliminates opportunity to try new things” and an analysis of how much the lack of knowledge and awareness about infant hip problems impacted on the study must be evaluated (Shonkoff, 2014).

Some of this information can be gathered from the study of Hugo (2002) into the Accessibility/Remoteness Index as it relates to the two areas. Information of workforce shortages can be found in the “remoteness scale on medical employment” website which outlines the remoteness of an area and what service provision shortfall there may be in the area. Service provision shortfalls allow the employment of overseas doctors and allied health staff to fill a perceived need in areas where there is a shortage.

Riverland General Hospital is in an outer regional area and has a workforce shortage in the obstetrics and gynaecology specialty which may have an impact on birthing numbers given the ease of access to services in Adelaide, with good roads and relatively short travel times. Some parents may choose to have their antenatal visits and birthing in an Adelaide centre rather than locally, if there is variability or uncertainty of service provision. The relative distance from Adelaide may encourage short term locum medical services, rather than a relocation to a more distant area. Continuity of care may be adversely affected by changing providers over a pregnancy. This breakdown in continuity has been described by Jay Biem et al, particularly in relation to older patients being transferred to regional hospitals, but the authors rightly suggest that the same dangers can occur with pregnant women (Jay Biem H, Hadjistavropoulos H, Morgan D, Biem H, & Pong R, 2003).

Tight birthing requirements may also impact on the birthing numbers in the region, as there are strong guidelines for transfer to a major medical centre prior to 38 weeks’ gestation, with high BMI mothers, multiple births, or when any complications may be expected. (South Australian Perinatal Health Guidelines available on the SA Health Government website – www.sahealth.sa.gov.au).

A weakness of our study lies in the fact that I did not properly identify these confounders prior to commencing the study, nor was parental choice factored into the study. It seems that many parents choose to birth in some of the smaller centres in the Riverland region where the facilities are seen to be more aligned to individual choices, particularly when no problems are anticipated. A shortage of anaesthetists is also documented for the Riverland region, and this too could have an impact on availability of analgesic services during birthing, which could impact on decisions to seek another centre for the birth where epidural analgesia may be considered.

Classification of areas of health services in terms of access and availability of services commenced in the 1994, with the Commonwealth Rural, Remote and Metropolitan (RRMA) classification system. This was in an attempt to classify areas specifically into rural, remote or metropolitan areas and such classification influenced payments received by general practices under the practice incentive payments (PIP) scheme.

A new geographic system was introduced in 2001, based on the Australian Standard Geographical Classification system (ASGCS). Areas were calculated on geographic grids and known as the Accessibility Remoteness Index Australia (ARIA). The index identified 4 levels of central service and calculated the distance by road from any locality to the nearest central service area. This was a geographic measure and was not designed to inform health workforce allocations. In introducing this system some areas were worse off in terms of funding received, thereby increasing the difficulty in attracting and retaining staff in those areas that were so affected.

The system was based on population size and distance to the nearest central health point. There was however, no clear definition of what constituted a classification of remoteness. Could this be measured on rurality, population isolation, distance, environmental surrounds or economic value?

There are different variations of these remoteness scales used in the classification of educational as well as health measures. The current measure of remoteness of health services is the Accessibility Standard Geographical Classification – Remoteness Areas (ASGC – RA) which was introduced in 2009. This system is calculated on population density and distance by road to the nearest central health service. There are some inequities, particularly in relation to smaller states with large populations (as in Victoria) (McGrail & Humphreys, 2009).

Because of the frequent adjustments to and variations in usage of these systems, it is difficult to remain current with the most recent classifications in our areas of interest over the period of the research. Until recently the Riverland General Hospital region was classified as a RAMA 5, but this was modified to a 3 in the latest grading.

Mount Gambier is classified as a regional centre and is 3 in the latest Geographic Classification Systems Index scale. Many of the surrounding areas are classified as more remote, according to their postcodes, but are still in close proximity to the regional health service situated at the Mount Gambier Hospital.

Inter-hospital transfers of maternity patients are carried out frequently between MGH and other smaller hospitals across the region if there is a suspected complication or a shortage of skilled staff. Some patients are air-lifted to Adelaide but for most mothers close to term in their pregnancy, road transport to Adelaide is not considered safe or practicable. In some emergency situations a retrieval team is flown from Adelaide to assist with the delivery and then accompany the mother and child to Adelaide after the birth. The same requirements to transfer those mothers with a high BMI or in early premature labour exist in both research sites. High BMI mothers from Mount Gambier are given the opportunity to go to Adelaide well before their expected due date, when they can travel by road, but those in premature labour require medical evacuation by a retrieval team either before or immediately after birth. There are obvious accommodation costs incurred with early transfer to Adelaide. Complicated births from the other hospitals in the region are transferred to Mount Gambier and often returned to their local hospital once mother and baby are stable and well.

For these reasons, the discrepancy in expected birthing numbers was higher than expected and although we should have recognised this at the start of the study, it has served to force a closer look at the discrepancies between the two regions and has highlighted some of the inequities in health provision between the two.

Possible causes of increased late diagnosis

Over the period between the pilot study and the research project there was an increase in the number of infants in whom a late diagnosis of hip problems was made. The possible causes for this must be further explored and could include:

- Reliance on the ADUS. Have those in our region responsible for making the clinical assessment of hips become too reliant on the ADUS?
- Are clinicians forgetting to check infant hips, or assuming that they have been checked by others? Studies in other regional centres have shown that the early hip assessments are being made but there are fewer reports of later hip checks, particularly where the children are not attending CaFHS regularly (Wright, 2017).
- Could DDH develop in hips which were originally assessed as being normal on clinical evaluation? Over the period studied we have had four cases where this may have occurred. These identified children warrant further examination of their assessment history to discover if there were any similarities, or if there is any explanation for what has occurred in each case.

Such problems may be eliminated if there were a clear process of history taking, assessment and documentation, which could be outlined and followed for all infant hips.

Ideally an initial assessment of every infant hip should be made with follow up surveillance over the period until the child starts walking.

The possibility that health professionals in the region are losing the clinical skill to assess infant hips must be considered, but equivocal clinical assessment is one of the reasons for including babies in the “at risk” group, and it is reasonable to assume that all babies born in the region receive early clinical assessment of their hips by either the delivering doctor or the midwife. Experience in conducting the clinical assessment and evaluating the outcome is known to be important and has been shown by Goss and others to require at least 100 examinations to be proficient(Goss, 2002). Such experience can be difficult for doctors and others in the regional setting, due to birthing numbers and staffing changes. Professor Nicholas Clarke has suggested that in the increasing litigious society in which we live, perhaps universal ultrasound assessment of all infant hips may be recommend (N. M. Clarke et al., 2012).

There are some infants who have not taken part in the ADUS when offered, and others who have missed out for reasons such as distance or difficulty of travel. Perhaps there is the assumption in our region that all babies have had an ADUS. If there were a dedicated page in the Blue Baby Book simply requiring a one-line comment on initial clinical assessment, ADUS, and subsequent hip surveillance, we could ensure that it was being rigorously attended and documented. It would be possible in this way, to identify those infants who were missing out on hip evaluation. Even with such a programme in place there will be a few infants in danger of missing surveillance as a result of not being involved with CaFHS, nor attending regular health checks with their doctor. Such visible documentation, if instituted could share some responsibility for ongoing hip surveillance with the family.

A further confounding issue is that of infants born outside the region, when the mother may be transferred to a tertiary centre, as in the case of a premature or difficult labour. These infants are often transferred back to our region, with little documentation of their hip status and many are too old for the eADUS when they are transferred home. Good documentation in the infant health record would allow better sharing of early information, and would also be of use in other regions, where there is no possibility as yet, of an early ADUS. It could act as a reminder to alert health professionals and parents to the need for ongoing assessment of infant hips. A study conducted in the New England area of New South Wales, has also suggested that a reminder should be in the hand-held record of every child, similar to the reminders for vaccination(Wright, 2017).

There is discussion from the International Hip Dysplasia Institute (IHDI), a worldwide convocation of orthopaedic surgeons, that regular assessment and x-ray examination should be conducted if we are to lower the incidence of late-diagnosis of hip problems in children. In a recent podcast from the Journal of the Australian Medical Association accessed June 2018 (Mulpurri K & Schaeffer E, 2018) the claim is made that there is a lack of diagnostic clarity in infant hips, and much use of retrospective criteria which makes comparison between studies difficult. This group also points to huge practice variations in both the timing and duration of treatment and surveillance. Concern is expressed at the mounting numbers of law suits seeking compensation for late-diagnoses of DDH. There is universal acceptance for clinical assessment, with some countries advocating universal ultrasound screening while others preferred selective screening by ultrasound.

This body of specialists found little evidence to support one method over the other. It was claimed that neither had prevented the occurrence of dislocation of the hip, although both screening methods may have improved the prognosis for some infants with dysplasia. They make a strong recommendation for the consideration of cultural and regional differences in decision making about which assessment protocols to follow. Their findings support the difficulties for infants and health professionals alike, in regional and rural areas of Australia and encourage further studies to make better diagnosis and surveillance more readily available for these people.

As a result of having data on more than 500 infant hips in the first weeks after birth, through the research studies and the physiotherapy practice, we are in a position to compare results in our region with studies conducted elsewhere in the world. It is possible to compare both the incidence of instability we have found and the numbers of children receiving treatment as a result of our findings.

Family history

In this time, there have been 2 babies who had normal measurements on their early ADUS, but who have later developed dysplasia of the hip, discovered at 6 months and 4.5 months respectively. This causes some concern and warrants further investigation. Possible causes for false negatives:

- The scan was not correctly performed
- The hips were stable at birth but did not develop correctly.

All ADUS scans are stored as still pictures of the frame where the MM measurement was made. They are stored on a password protected computer and a USB, so it is possible to review them at a later date, although those from the earlier pilot study are stored as movie clips of the movement.

As the reviews of the recorded scans demonstrated that the scans were correctly performed, other possible causes for the late presentation must be considered. The sub-optimal development could have been due to inadequate hip management as occurs with incorrect swaddling, or adduction of the hip such as could encourage the head of the femur to stand out of the acetabulum, thus not making close contact with the base of the acetabulum during the important developmental period. This could then lead to poor acetabular development. Continued asymmetrical posturing of the baby, such as seen with plagiocephaly, can also lead to asymmetrical hip development. The third consideration is the possibility of a strong genetic predisposition to poor acetabular development. If this third possibility is the cause, will primary prevention make any difference to these hips or is there a place for early splinting in these cases? Both cases deserve close scrutiny in an attempt to uncover any similarities and deduce any possible cause of this aberration.

Case 1. R was the second child in her family, born by LSCS after a normal pregnancy. Her older sibling had late-diagnosed dislocation of the hip and had protracted treatment for this. R was born in a tertiary hospital where the attending paediatrician and an orthopaedic surgeon both assessed her hips as clinically normal. The orthopaedic surgeon did not think an ADUS was warranted and ordered a Graf ultrasound examination to be done at 6 weeks. This examination was done in Mt Gambier, and at the mother's request an ADUS was done at the same time. This was within normal range for 6 weeks with 1.1mm on right and 1.2mm on left. A measure of 1mm is taken to be the thickness of the capsule of the hip joint. The Graf ultrasound at this six-week period was within the normal range. The orthopaedic specialist also ordered an x-ray to be done at 6 months. This revealed an enlocated hip with a poor acetabular alpha angle. R has been in a hip brace since the x-ray. She is walking with the brace on and is very active. Her hip x-rays are showing improved development, but she will continue to wear the brace part time for several more months. She is able to have it removed for swimming and bathing but wears it at sleep times and for several hours during her wakeful times.

Case 2. M was a non-identical twin, normal vaginal delivery born in Mount Gambier. She had an older sister with no developmental problems. At birth, M was felt to have some instability in her hips and was referred for an early ADUS. The hip examination for the twin sister was reported as normal. At the ADUS examination, 2 weeks after birth, the hips were within the normal range of movement with 1.2mm movement on right and 1.9mm movement on left. Advice was given to her mother about care with leg position and wrapping, but no further scans were arranged. At her 4-month check at CaFHS she was noted to have asymmetry in her hip movements and was referred for a further Graf ultrasound. This showed that the left hip was enlocated, in a poorly developed acetabulum. There was an ossification centre visible in the head of the femur. Her right hip was normal. An x-ray was then organised. A referral was made to an orthopaedic surgeon and she was placed in a DB hip splint for several months. The mother subsequently revealed that she had DDH as a baby and was treated in a DB hip splint. After three months of continuous wear of the splint, x-rays revealed a satisfactory hip position and she is now free of the splint and starting to walk unaided.

Each of these children had a family history of a close relative with hip problems. Lowry, in his audit of hip ultrasound screening using the Graf method, found family history to be twice as great a risk for dislocation of the hip as either breech or equivocal clinical assessment. He found the 8-week scan to be more reliable than the 3-day scan(Lowry CA, 2005).

Andersson, in his studies, reported one infant thought to have a normal ADUS in the first week and later diagnosed with a dislocated hip at 4.5 months. On reviewing the original ultrasound scan, the leg was noted to be abducted too far during the scan, causing the stress on Palmen-Barlow to be too directly posterior and the transducer did not adequately follow the line of the movement of the hip under stress. This produced a false result in his opinion.

He advocates abduction of 60 -70 degrees when the stress test is applied, so that the movement is a postero-lateral movement. The shaft of the femur should be visible on the scan with the head of the femur in good view.

Considerations as a result of this:

- Should we be pro-active in routinely re-scanning all infants with a first degree relative with a history of DDH, at 6-8 weeks and with an x-ray at 4 – 6 months? In considering the recommendation of Lowry (cited above) this should be a recommendation, as it is with breech babies.
- Do these children have minimal neonatal instability of the hip, but a genetic disposition to poor acetabular development?

- Should direct questioning about parental and sibling hip status be a part of all neonatal assessments? This should not only be a part of the history taking process, but it should be clearly documented in the infant record.

- How many of these poorly developed hips would we discover if we scanned all hips and are these the asymptomatic hips which proceed to early arthritis and early hip replacement? It is possible that the increased interest in early examination is identifying variations in acetabular development in hips which would never cause any problem. A higher degree of arthroplasty has been found in adolescents diagnosed with acetabular dysplasia than in those who have this diagnosis in early infancy (Lee C, Mata-Fink A, Millis M, & Kim Y, 2013). This study confirms the need for more longitudinal studies over the lifetime to better understand the importance of early identification of hip problems.

Resistance to change

The health system in South Australia seems entrenched in guidelines and protocols, such that discussion about new methods or new approaches to problems is often countered by the comment, “It is not what we do here.” This was the response when early discussions were held in Adelaide about the Swedish method of infant hip examination, with the added comments that it was too expensive, led to overtreatment and would not be readily available in some areas.

The same comment was frequently made when a patient returned to our regional hospital having treatment for a joint infection following a total knee replacement in Adelaide. This patient was on an established regime for management of her antibiotic delivery as set out by the specialists in Adelaide but on noticing treatment had changed and questioning why the regime was not being followed, the reply was, “It’s not what we do here, we use the recommended guidelines.” Differences in intravenous equipment between the two centres appeared to go unnoticed and resulted in interruptions in administration of medication and a further three weeks in hospital, rather than the two days which were required to complete the original plan.

Whilst it is recognised that any new methods should be rigorously tested and researched to ensure safety and efficacy, the advantages and any disadvantages should be discussed. There must be a place for the evaluation of emerging techniques, particularly where they have been widely researched and implemented elsewhere. How general is this resistance to change in our health system and what factors influence change?

Flyvbjerg in his discussion on Phronetic Organisational Research in The Sage Dictionary of Qualitative Management Research, discusses the particular way that power and values combine to effect organisations. A change in either of these can change the way the organisation works (Flyvbjerg, 2008).

He suggests that in making change there are factors which must be considered:

- The direction in which the organisation is moving. This requires a general long-term plan which should be regularly measured and evaluated
- Who will benefit and who will lose if organisational changes are made? Clearly the benefits and losses will impact differently on all concerned and should be considered from the viewpoint of the workers, the consumers and the organisation with discussion taking place within and between each group
- Will it make a desirable change? Discussion should take place with those most affected as to possible effects of any change. The effects of any changes must be openly evaluated with particular reference to how they impact on each other and all stakeholders.

- How will we achieve organisational change? Who is responsible for making any changes, how will they be implemented and what measures will be put in place for their evaluation?

Clinical practice guidelines

These are commonly used and often referred to in many areas of health care and medical treatment, covering a wide range of health issues. Guidelines are generated from a consensus of expert opinion which has been applied and tested in varying situations and is used to inform policy and protocols in many areas. There is variable reference to research evidence contained in clinical practice guidelines. Some of the advice, or conclusions drawn from the evidence, places consideration on the universal availability of recommended services (Shipman SA, 2006). This can have an impact on services in rural and regional centres, where there may be different levels of expertise in the workforce but an expectation to adhere to the recommended guidelines. Best evidence, as gathered from research and discussion with experts, and best practice, with consideration given to expertise and experience, must be considered together as each has an influence on individual management in health care.

Kredo describes clinical practice guidelines as, “statements that include recommendations intended to optimise patient care that is informed by a systematic review of evidence and an assessment of the benefits and harms of alternate care systems”(Kredo T, 2016). Adherence to clinical guidelines can be influenced by operator experience and proximity to care, such that compliance may be easier and more timely in urban centres than in regional health situations. What may seem best practice in urban settings may be totally impractical in a rural setting.

More recent guidelines contain not only expert opinion and research evidence, but also give consideration to patient values. There are other important areas which may influence implementation or adherence to guidelines. These include local contextual evidence and resource requirements, cultural issues, feasibility and shared decision making where appropriate. Should some of these things be given more consideration in the particular use of guidelines?

Some writers describe clinical judgement as demonstrating practical wisdom, otherwise described as phronetic knowledge. Phronetic knowledge can be traced back to the writings of Aristotle, who described it as “the ability to deliberate about things that are good or bad for humans”.   Such deliberations are based on values held at the time of contact. Practical experience and power relations will impact on these deliberations(Petersen & Olsson, 2015).

Shared decision making occurs when there is a melding of clinical perspectives and patient preferences. It is therefore a combination of knowledge of clinical guidelines, clinical expertise and patient preferences. The nature of this combination may cause variation in treatment and management of the same condition in different situations. For this to be of value, there must be good knowledge sharing and mutual respect, leading to the generation of effective communication processes. This requires substantial time and skill and may be a barrier to success in implementing a timely decision on management. The adaptation of clinical practice guidelines to various contexts and the measurement of their impact, warrants more investigation.

Further barriers to this model of management may be a lack of knowledge and skills in the area, poor communication processes or an unwillingness to learn and evaluate the evidence. These factors have all influenced in some way, the study of early ultrasound screening of the neonatal hip to understand more about the influence of neonatal hip instability. Further consideration must be given to evaluating the extent of their influence.

The appropriateness and contextualisation in the transfer of clinical practice guidelines internationally or indeed between rural and urban settings in Australia should be considered. The inclusion of birth in a rural or regional setting as an added risk factor for having late-diagnosed DDH, as reported by Chan and Cundy (1999) highlights that this should be considered. These authors have cited possible lack of experience in performing the clinical assessment as contributing to this problem(A. C. Chan, PJ. Foster, BK. Keane, RJ. Bryon-Scott, R., 1999). Other writers have suggested that frequent repeated training is required to achieve competency in evaluating the clinical assessment of neonatal hips(Goss, 2002).

Both of these confounders have been cited as possible problems for health professionals in rural and regional Australia.

Some suggest that the clinical assessment, which forms part of the clinical practice guidelines for the examination of infant hips, is most reliably carried out by paediatric orthopaedic surgeons. The use of neonatal hip assessment by anterior dynamic ultrasound during the performance of the recommended clinical assessment could prove a useful adjunct to reliable results in the non-urban setting, where access to a paediatric orthopaedic surgeon may be limited. Viewing the infant hip in real-time ultrasound can demonstrate if the technique is being properly carried out and can provide a measure of movement to reinforce the clinical judgement of the operator.

A further complication to the implementation of different patterns of care, relates to the feeling that a tried and established plan for treatment and follow up is established within units and rigorously passed down to new members of the team as they join the organisation. Such an established system can be helpful to ensure continuity in units where the personnel are constantly changing. It does however, deny the chance to make clinical judgements which may better suit the condition and particular needs of each patient. In any clinical workplace, there must be opportunity for debate and discussion about new evidence, different results and further research or trials. How do evidence-based guidelines and clinical judgement influence each other? Sackett has stated that, “more effective and efficient diagnosis, more thorough identification and compassionate use of individual patient’s predicaments, rights and preferences in making clinical decisions about their care” will increase clinical expertise(Sackett, Rosenberg, Gray, & Haynes, 1996). Clinical research centred on the patient and founded on precise diagnostic tests, will inform evidence for both guidelines and clinical judgement.

Public and private healthcare funding influences how we move forward in the area of new diagnostic techniques and treatments for common conditions. This has been very evident in our research conducted on the early diagnosis of hip problems in infants. World research has centred on the early assessment of neonatal instability of the hip, which has been discussed as a pre-cursor to later development of dysplastic hips.

The different approaches to assessment worldwide have been related to difficulties with cost, overtreatment or lack of facilities to adequately measure the amount of instability in the newborn hip. Looking at this problem from a purely economic viewpoint it is necessary to consider the cost to families and individuals over a lifetime, between a universally-screened group and a selectively screened group.

Those children who have the condition diagnosed and managed in the early weeks after birth must be compared over the lifetime with those in whom the diagnosis and therefore the treatment, is delayed until the developmental problem becomes a structural problem. Such a longitudinal study over the lifetime is extremely difficult to manage, given that the incidence of developmental dysplasia of the hip is stated to be 7.3 / 1000 in South Australia (Sharpe et al., 2006).

A compounding difficulty for this type of research in Australia is the privacy requirements, which make it extremely hard to longitudinally follow any individual's health needs and expenses over their lifetime. In Scandinavia such studies have been possible due to the government requirement that every individual has a personal identification number which can be used in such studies. Debate must be had about the personal privacy issues that this may raise, but from a medical and research study point of view this is a remarkable system.

Any baby born in Sweden is allocated a number at birth, with a further three digits added to this number when the baby is named. A card with the allocated number awaits the parents when they return home after the birth and when that infant is taken to a health centre or doctor, the details of the birth and any other medical facts can be accessed on computer at any centre the parents may attend. Any birth defects or other abnormalities are recorded there and if access is granted for research purposes, the information is readily available throughout life. There are therefore some very interesting lifetime studies coming out of Scandinavia about the impact of neonatal problems in their population. There are arguments about the privacy and rights of an individual in such a socialistic arrangement, but the research benefits can easily be seen.

To set up a similar lifetime study in Australia, would require a multi-site long term investigation over the lifetime of many researchers or groups – very hard to manage or indeed institute. The Cerebral Palsy Society has set up a central registry for any willing parents to enrol their children diagnosed with cerebral palsy, and this is having great benefit in research and understanding of this condition in all its forms(Smithers-Sheed, McIntyre, & Gibson, 2016). Such a set up may also be of benefit for those with diagnosed hip problems at all stages of life, enabling lifelong studies of the implications and cost of such problems. A deterrent to a register for hip problems may be that those in whom the diagnosis of increased neonatal hip instability is made, may not register, as the problem can be short-lived for these infants, so important information about this group may not be collected. Data sets that could be gained from such a register would have solid implications for funding and research for hip conditions in Australia and allow comparison with similar registers in other parts of the world.

On completion of the research study, there were continuing requests from doctors, allied health professionals, parents of new babies and CAYHS nurses to continue to provide neonatal ultrasound hip scans. Discussion was held with Benson Radiology to consider ways in which this could be done. There was an identifiable funding problem, as there was no Medicare funding to support universal screening despite the well-reported fact that birth in regional Australia could be recognised as a risk factor for late diagnosis of DDH. Our studies have demonstrated an increase in late diagnosis in the periods when universal early scans were not available. The difference for families and individuals over a lifetime between a universally screened group and a selectively screened group must be further evaluated over a lifetime to definitively demonstrate this, but for those affected, can we afford to wait a lifetime?

In my original pilot study, the ADUS was offered to the parents of all babies born in the regional hospital over a four-month period. The results of that study have been reported elsewhere in this thesis. The scans were funded by the research, at an agreed rate with Benson Radiology. At the completion of the study, it was not possible to continue offering the scan to every child, for reasons of funding. The Medicare funding applies to Graf ultrasounds carried out for clinical reasons, in line with current national clinical guidelines. To continue to offer the early scans universally would be considered to be over-servicing, creating problems for the radiology department. Thus, despite best evidence suggesting that we could miss the early diagnosis of hip problems in up to 60% of cases, we were restricted to offering the early ADUS regime only to those who qualified as they were considered to be in the “at risk” population, and therefore eligible under Medicare to receive a scan.

The research study allowed another period of universal screening, in an attempt to evaluate the benefit of ADUS in educating parents about infant hip development and management in one regional centre. The trial, described in the thesis, enabled a further 100 infants to be examined.

The policy of universality which appears to be held by Country Health SA, aiming to provide equitable access to health services to all, reduces health services to the lowest common denominator. This can be seen when services do not fully utilize the expertise of professionals in their area and this can work to the combined detriment of the service, the patient and the family. The inability to fully utilize local expertise is further exacerbated by the inability to work across the public/private divide (Morello F, 2000). Examples of this can be seen in the expertise and experience of the general practitioners in our region who were removed from providing services at the hospital and replaced by junior salaried doctors, many of whom had only provisional registration to work in the one area, as they were international medical graduates who had not completed the requirements for full registration in Australia at the time of their employment (Beatty D, 2000). They were unable to prescribe or consult outside the hospital as they did not have a provider number and therefore could not access Medicare.

The same can be said for the provision of paediatric physiotherapy services such as the correction of infants with talipes equino-varus, which could be treated locally by an experienced, qualified operator. This was not allowed by Country Health SA, because the service could not be provided in other areas of their jurisdiction. Such attitudes do little to engender professional satisfaction. The cost of providing the service is increased when the family must travel to the capital city on a weekly basis to access the treatment which could be provided locally if allowed. Is this a form of cost-shifting?

If a truly patient orientated service is to be offered, encouraging good interprofessional services and greater patient and family satisfaction, a move towards greater collaboration must be instituted, where the social capital of the region is fully utilized. Social capital has been described by O’Toole and Schoo (2010) as networking with collective action for community benefit. It can build on the traits and aspirations of individuals for the benefit of the community by facilitating collaboration and partnerships which will benefit the whole community. They claim that it “can facilitate social entrepreneurship” and “develop capacity to respond to change”(K. O’Toole & Schoo, 2010). Such leadership can help create opportunities for community development. In recognizing local expertise, further career pathways may be encouraged, and this may contribute to the retention of allied health staff in rural and regional areas.

Differences in interprofessional relationships and collaboration between the two sites in our research project may have been an important factor in the failure of the research in the Riverland region. A deeper understanding of the comparison between the two regions may help to explain this. The question becomes, how much should we use the social capital of an area and does this have any impact for equitable services across the State? Is “equitable thinking” dumbing down the health service in our State and is this responsible for the lack of professional satisfaction and the problems of retention of medical and allied health workers in rural and regional Australia? Breaking down the barriers of professions and lack of collaboration and team work, where each member of the team is able to contribute to provide the highest possible standard of healthcare, should be something for which we all aim (Supper I, Catala A, Lustman M, & al., 2015). “Patch protection” and jealous guarding of position can also contribute to a health system set at the lowest common denominator.

The expansion of University Rural Clinical Schools such as has occurred through Flinders University, has contributed to a growth in community collaboration and the understanding of rural medical training (Walters L, Worley P, & Mugford B, 2003; Worley & Maynard, 2011). Community members are being actively involved in study projects run within the community, giving an opportunity for each group to better understand the other. Worley et al have shown that the students gain a better understanding of the community and communities embrace the students and their work with enthusiasm (Worley & Maynard, 2011). The students at the same time, develop a closer understanding of the fabric of the community and the varied economic and social structures within that community. It has been shown that medical students trained in this way are more likely to remain in rural and regional areas to work after graduation.

In the MG region, we have seen that projects begun as student endeavours have gone on to become a regular part of the community framework. For example, the children’s health initiative, run through local shopping centres and schools, which involved both medical students and school teachers, as well as members of the community, has been continued by the schools and community members after the research project was completed.

This use of the social capital of the community has enriched the community and contributed to better understanding and collaboration with long term benefit to the community. Farmer suggests that professional workers may also be social entrepreneurs (J. Farmer & Kilpatrick, 2009). I believe that this has been clearly shown in the Limestone Coast region with the growth of the rural clinical schools and the collaborative work being carried out across the smaller communities in the region. We see networks developing community associations, producing local outcomes which are creating more resilient communities. Paul Worley sees this as building social capital of a community, by developing strong academic ties with the community in the encouragement and funding of health education through rural clinical schools (Worley & Maynard, 2011). We must improve our ability to transfer successes in one area to other areas by generous sharing of ideas, successes and failures, in a sense of true collaboration. A collaborative approach to research, involving shared interest across professions working in the same regions, should be encouraged in the interest of mutual advancement for the benefit of the community and interprofessional development. There is a tendency for groups or individuals to research topics in isolation which can engender silos in information and create research fatigue in populations who are constantly being mined for information.

The huge impact of geographic and environmental differences between the two regions selected for the research project was unpredicted at the commencement of the research. In further exploring some of the causes and effects of this, several other confounders have been uncovered and deserve greater consideration. The experience of the researcher, working in one regional centre at a great distance from the capital city in South Australia, has provided some variable aspects of health service provision which may help in understanding more of the differences between the two regions. Differences in health literacy between the two regions will be further explored in the following chapter.

In this chapter an expansion on the unexpected research difficulties culminating in no data for comparison being collected uncovered regional differences in access to services. The rise in late diagnosis is discussed together with an awareness of some of the risks of having DDH. There is some discussion of resistance to change and the application of clinical practice guidelines.

CHAPTER 7: HEALTH LITERACY

HOW DOES THIS IMPACT ON COMMUNITIES?

The differences in approach to the research project over the two regions alerted the researcher to differences between the two sites in what had previously been considered part of the same health service. Following the extreme difference between the two sites in their response to the research study, three possible environmental and management theories have been further examined to assess what, if any, impact each of these may have had. The impact of social equity differences and the influence of complex adaptive systems have been discussed in the preceding chapter but perhaps a greater influence was the contribution that any differences in health literacy may have had on the outcome.

Health Literacy

What impact does health literacy have on the outcomes for patients and research? Communication is a large part of the growth of health literacy and in the words of George Bernard Shaw, "The single biggest problem in communication is the illusion that it has taken place" (Shaw) accessed online 6th October 2018 www.brainyquotes.com. The art of communication varies greatly across cultures and races and at all stages of life. Communication is an exchange process which is reliant on not only the sharing of words but also the sharing of the meaning of those words. In considering the use of the word, "exchange", it must be considered at least as a two-way occurrence. This presupposes a mutual understanding of the information transmitted and care must be taken to be sure that the speaking and the interpretation by the hearer are aligned.

One's ability to access, understand and apply health related information and the services available, can be described as one's health literacy. The underpinning foundations of health literacy rely on leadership, governance, consumer partnership within the culture of a health organisation and the individual's access to that. The WHO has shown leadership by increasingly promoting health literacy as an essential area for improvement. A global mandate has been developed by the WHO, for public policy action on health literacy, to work towards sustainable development and health equity (World Health Organisation, 2009)

In the UNESCO sustainable development goals released in 2015, health and health education are strongly placed (UNESCO, 2015). Goal 3 addresses health and well-being with health literacy seen to be a part of this. There is strong recognition of the confluence of education and health particularly in developing countries, but the importance of the partnering of these two attributes must not be overlooked when considering infant health and development in any country. It is abundantly clear that the health of an infant is very highly impacted upon by the health literacy of the parent. Preventative health practices are paramount in infancy where we see strong immunisation programmes for the minimisation of communicable diseases, with support for infant feeding and well-being. We should also consider the preventative health measures of early diagnosis of conditions which can cause lifelong health issues if not diagnosed early in infancy, to allow good structural development over life. Early indication of poor hip development is an example of such a situation.

“Health” is defined in the Macquarie Dictionary as, the general condition of the body or mind with reference to soundness and vigour. The same source defines “literacy” as the possession of education (Delbard, Bernard, & Blair, 1981). It can therefore be seen that “health literacy” is a compound term impacted upon by both wellbeing and education

Macken-Horarik has described literacy in four horizontal slices, which is developed through the education process (Marken-Horarik, 1998):

- Everyday literacy is that which guides family and community life, as we develop relationships and understand those around us. This form of literacy is influenced largely by spoken language.
- Applied literacy is gained through both spoken and written material and is the literacy which allows skill development and the growth of some expertise.
- Theoretical literacy allows for the acquisition of knowledge in discipline specific areas and is the literacy gained through exposure to educational environments. Here the learner may be exposed to specialised literature, presenting the opportunity to assimilate information and to reproduce knowledge.
- Reflexive literacy is a deeper form of literacy which probes more finely into alternative methods, challenges common thinking and looks for meaning through diverse channels. It has been described as critical literacy and helps to develop an understanding of social diversity.

Brabazon considers that reflexive or critical literacy must “probe the limits and applications of specialised knowledge systems, challenging common-sense and understanding how meaning is delivered through disparate media and different forms of media” (Brabazon, 2011). It seeks answers to the question of how we could do it better, with an understanding of the social diversity which is seen within communities. Such knowledge may be gained through a range of forms but requires the learner to understand, consider and evaluate the information for situational application.

In considering the horizontal progression of literacy, it can be seen that everyday literacy would be an expected basic attribute for parents, carers, professionals and administrators within the study in our research project. There may be a problem even at this level, for those who are not comfortable with the English language usage, but this could be helped with the use of interpreters.

It might be expected that most parents would have some level of applied literacy in the ability to seek information on pregnancy, infant needs and matters related to new baby management. Such information may have been gathered from family, friends, books, the internet or ante-natal classes (Khoo et al., 2008). Applied literacy would imply the ability to find, read and comprehend the relevant information. For those who are not fluent in English, this may again present difficulties, although information can be sought in an alternative language. The difficulty then, is to be sure that what was accessed is accurate and that it has been understood.

Health professionals and administrators, because of their position, are expected to have good theoretical knowledge and some reflexive literacy. The extent to which they have reflexive literacy is, in part, a measure of their interest and research into the areas in which they are working.

What is Health Literacy?

Health literacy is described by the WHO as “to understand and use information in ways which promote and maintain good health” (World Health Organisation, 2009). It must be an attribute not only of the consumer but also the provider, the funder and the manager in any health service and each must clearly understand the other, to promote a healthy community.

Knowledge and competencies are the prime determinants of health literacy. Competence is further divided into the ability to access, appreciate and apply information which leads to better health decisions. It can be seen that knowledge and competence are augmented by the interaction between personnel in complex adaptive systems such as those described by Jeffrey Braithwaite in his White Paper (Braithwaite, Churruca, & Ellis, 2017). In outlining models of communication in healthcare, Braithwaite describes hierarchical, linear or networked communication, describing the characteristics of each and suggesting that open network situations, where information can flow freely between every level of the health service, will produce a more comprehensive workplace. The subtlety of these differences between the two sites warrants further analysis.

Many definitions of health literacy are revealed in the literature as it is explored across all disciplines in all regions of the world. The early discussions on health literacy described the ability to read and adopt written health advice, to understand numbers and follow medication instructions (St Leger, 2001).

The ability to communicate needs to a health professional became the next advance in discussion about health literacy and this communication had some effect on what advice was given. Communication must be a two-way event, such that there is adequate, appropriate messaging and adequate open listening, both contributing to a better knowledge of the underlying problem. This then leads to an improved understanding between those involved. The listener must be able to understand the health instructions and such instructions rely on the advice-giver comprehending the capacity of the listener to make meaning of the information.

Health communication programmes must be constructed in such a way that the consumer gains empowerment through understanding, thereby motivating engagement with the service. It will then assist in the making of informed choices which suit individual needs, thus leading to shared decision making and mutually agreeable outcomes. The importance of including motivation to empower the learning must not be underestimated. Schulz and Nakamoto have demonstrated this in their study which clearly outlines the need for patient empowerment to meld with health literacy for optimum results for the individual (Schulz & Nakamoto, 2013). We are reminded of the attributes required of an individual in processing health information when we consider the remarks of Nutbeam , “Health literacy in health promotion is demonstrated by the personal cognitive and social skills which determine the ability of the individual to gain access to, understand and use information to promote and monitor good health” (D. Nutbeam, 2000). It can therefore be seen that individual variables will have an impact on health literacy even when a general assessment of any group has been made. Those who are having difficulty in such group situations may not be noticed if they are not contributing to discussion or asking questions. It is useful to seek involvement and interaction from all participants in any health education programmes.

To better understand health literacy, an understanding of the different categories which can contribute to overall health literacy must be further explored. Together these different facets of literacy constitute critical health literacy and the understanding of health information at the individual, group or network level. Clearly, all three components are cumulative, but each relies on adequate understanding of health at all levels.

Health literacy may be categorised into three distinct areas:

- Functional health literacy belongs to the individual and comes when there is engagement with health information, which can then be followed by informed decision making. Nutbeam clearly states the importance of functional health literacy at a community level in its effect on participation in population health programmes (D. H. Nutbeam, E. Wise, W., 2010). Functional health literacy may be negatively impacted upon by poor literacy generally and must never be assumed to be uniform. Therefore, care must be exercised in developing health material which can be clearly understood and accessible to the desired audience.
- Social or interactive health literacy is considered to be a group attribute, underpinning the health literacy of communities, where networks share similar socio-economic backgrounds in a similar environment. This can have an influence on local health care systems and policies if there is an appetite for shared decision making. Shared decision-making will in itself, promote better adherence to such systems and policies if there is perceived ownership between all parties.
- Cultural health literacy is characterized by the ability to recognise and work with beliefs of groups and understand their social identity. Such literacy is also enhanced by shared decision making and requires open understanding from all parties.

Each of these areas may have had an impact on the outcomes of our research experiment which had such glaringly different responses in the two regions in our study. Together these three components form what has been called critical health literacy (CHL).

In improving people’s access to health information and increasing their capacity to select, sort and use this information effectively, they will feel more empowered to own and be part of the management of their health. This in turn, could lead to a more collaborative approach to healthier communities, as the greater understanding may lead to better engagement and discussion of health issues (Chin D, 2011). Increasing the CHL of a population allows people to gain access to information and discriminate between sources of information, to personalise and apply the information and thereby take a more active role in their own health management.

De Wit et al have further discussed CHL at three distinct levels:

- Individual HL where the individual develops abilities and actions for the betterment of their own health. At an individual level, there is engagement with health information and decision making, encouraging more understanding of personal health issues and wellbeing. The current open discussions about mental health issues and suicide have led to a more personal understanding of mental health issues. Individual health literacy around this sensitive issue has helped people identify unique problems and opened the door for discussion.
- Individual HL where the individual's actions have an impact on their social determinants of health. These include social and community networks in which the individual may operate, with some understanding of the socio-economic, cultural and environmental factors affecting their lives. Such social and individual factors may be attributed to and impacted upon by health care systems and policies.
- Group level HL which builds on the social determinants of health, with collective activities and health services, enhancing the strengths and resources within communities. Such community co-operation encourages equitable participation and helps to build the capacity of the whole community. Group health literacy can lead to political lobbying and policy changes in health care, with increased sharing of decision making for the benefit of the whole community. This progression can clearly be seen in the mental health sector, with raised awareness generally and the commencement of community programmes to address some of the identified issues.

Disparities in health status were found between differing social groups in de Wit's systematic review and analysis. Although this study concerned the aged population, I believe that there are similarities with the needs of the young population in our study as well. A strong benefit was found in co-learning, where participants learned health techniques and practiced them together. In the infant hip studies which we conducted, we noticed regional differences in practices between health staff as well as parents. This is believed to be partly explained by increased familiarity with hip problems and practice in infant hip management in one region in comparison with the other. Likewise, social support was stronger in one region than the other, as evidenced by the higher involvement in encouragement from hospital staff, medical practitioners and family members, to enrol in the research programme. The combined effect of these two factors can help in understanding the differences in critical health literacy between the two sites.

There is an expansive need to ensure that health literacy is part of our health systems across all regions. One's ability to access, understand and apply health related information and the services available, relies on leadership, governance, consumer partnership and the culture of a health organisation. These attributes are part of what Braithwaite describes as complex adaptive systems in healthcare.

Figures released by the Australian Bureau of Statistics in 2006 state that 60% of Australian adults have low level health literacy, which renders them unable to choose, or express informed choices, in making decisions about their health care (accessed online at www.abs.gov.au/AUSTATS). Vellar et al, found similar results in their study published in the Australian Health Review in 2017. They claimed that only 40% of consumers in the Australia health system had the appropriate level of health literacy skills to understand everyday health information (Vellar, Mastroianni, & Lambert, 2017). Given these alarming figures about general health literacy, it is sobering to consider the amount of printed information a patient is expected to read and agree to, when consenting to undergo a surgical procedure or other invasive treatment. The same can be said for the instructions which accompany specialised equipment that the patient may be expected to manage at home. Pharmacy staff are frequently questioned about drug dosages and instructions, when such instructions seem quite clear to the staff (personal communication). For example, "take two tablets three times per day" may seem like a simple and straightforward instruction, but staff are frequently asked to explain what this means. It is clear, that despite concerns about critical health literacy over the past decade, there is still much to be done if we are to improve collaborative health care and minimise ongoing health problems, particularly in rural and regional Australia.

Brodie and Dutta have written of the "digital divide", describing the division between those who have access to the internet and those who do not. This divide also extends to those who do not have the ability to understand the information, even when access is available (Bodie & Dutta, 2008). The expectation that a person will benefit from health information disseminated via the internet, relies on many factors. The first assumption is that the person has access to the internet and has adequate eHealth literacy to evaluate both the website and the content presented there. The reader must then have the ability to competently and confidently use the information. Internet information can be disseminated through active or passive channels. Active channels require cognitive effort, relying on motivation and interest. Such information is usually found by searching the internet using key words to source health information.

Passive channels are more commonly found on free to air television channels and include such health advice as provided by Government sources, on public health issues such as smoking or drug and alcohol abuse. Passive channels require little involvement and minimal cognitive effort, often offering sub-liminal messages, which are repeated over short periods of time in the daily programme. Most frequently these messages are focused on specific health issues the government is currently concentrating on in the funding they are providing.

A further difficulty with accessing information via digital means is that there are very limited opportunities to uncover or evaluate the understanding the individual has gained from the provided information. Very often this information is sourced in isolation at home and may be acted upon spontaneously without evaluating the similarities or differences between the online and personal situation. There may be only small similarities between the information provided and the enactment of response to that information, with little or no follow-up to assess any change in situation following the change in management.

In writing about health literacy, Nutbeam talks of its impact on both personal and public health and the provision of good clinical care (D. Nutbeam, 2008). In describing it as a clinical risk, he claims that low levels of literacy contribute to poor decision making, non-compliance with medication and other treatment recommendations and difficulty in self-managing illness. Managing this risk is therefore, a part of providing sound clinical care. When health literacy is low, other methods of providing health information must be used and time must be allocated to ensure understanding of the information. In working with children and families, cartoon like pictures will often assist in explaining the process and particular requirements for optimal treatment and exercise regimes. Increasing health literacy can be considered a public health asset, enabling individuals to have greater control over their own health, thereby influencing the social and environmental determinants of health (Roberts et al., 2017). Better understanding and ownership encourages inclusion in shared decision making and can lead to policy discussion with more informed participant input.

Effective health literacy will influence access to healthcare and build positive interaction between the patient and the healthcare professional while also increasing self-care. Nutbeam purports that good health literacy “IS the outcome of education and communication rather than it being a factor which “MAY INFLUENCE” the outcome”(D. Nutbeam, 2008). Good health literacy places the patient and family at the centre of health discussions and empowers them to take some control over their health and well-being which can impact on the whole community.

Improving Health Literacy for the Individual and the Community

Accessing health information requires understanding, timing and trustworthiness. The information must be provided in an appropriate manner, arousing the interest of the listener, set at a level which can be understood. It must be provided in context, at a time when the receiver is engaged with the educator and the person providing the information must be someone the receiver trusts, whose opinion is valued. Schulz tells us that health literacy is built on patient education which creates empowerment(Schulz & Nakamoto, 2013). Such education requires good communication, specifically tailored to the needs of those being educated. Good education is based on motivation, communication and literacy. These building blocks lead to the making of informed choices and better engagement with the services offered.

Motivation + Communication Access + Literacy
↓
Informed choices
↓
Engagement with Services

The results of improved understanding and engagement will be seen across the health spectrum, from individual patients to communities and may lead to improved health services. A community with a good understanding of its health issues, may lead to more economical health service over time, when prevention may be a higher priority than treatment, with better individual characteristics and health behaviours. Such health changes are determined by differences in social, environmental and economic factors.

It is important to again consider Braithwaite's complex adaptive systems here, to recognise that this kind of engagement requires a change from a hierarchical top down model of healthcare, to a more inclusive multi-networked discussion, where each participant feels that they have some value in health discussion and differing points of view are considered.

Health literacy, in health promotion, relies on individual access and understanding which can then be used to promote and maintain improvements, both individually and within the system. These improvements rely on motivation and self-efficacy. The person seeking to become involved, must be able to see that there is a possibility of improving the situation, both for their own health and for the health of the community in which they are living. They must also be able to feel that their input is valued as part of genuine and inclusive discussions being held.

Within the governance of our health system there is an obvious policy of engagement with health service users, with periodic surveys of patient satisfaction, public meetings about health education on selected topics and media releases on successful outcomes. Church (2002) asserts that such citizen participation has a recurring pattern over time, often beginning with a public forum, followed by more detailed discussion with stakeholders (Church J, 2002). All too often, these engagements seem very top/down, with little time for consumer discussion or involvement. Timing and access are frequent issues with such meetings and within any region there is often a large number of people who feel that their comments and discussion are not being properly heard. The outcomes of public discussion and the opportunity for change are not followed to a shared conclusion. Nutbeam tells us that improvement in the health system occurs when there is better information more easily provided, with increased capacity to use the services.

Growing Health Literacy

Growth in health literacy across all sections of the community will not only assist in better understanding of general health and well-being but may increase ownership of population health by improving shared decision making with a better understanding of health system policies. Increasing health literacy may at the same time, increase the awareness of some of the inadequacies of the health system and lead to transformational changes (Paesche-Orlow M, Schillinger D, Green M, & Wagner E, 2006).

Avenues for growing health literacy must be considered across four groups:

- Patient – the patient must be able to search health services and find the service which most suits their need. They must be able to access relevant information about service provision and to evaluate suitability of the service. The patient must feel able to discuss and collaborate in the management of their condition.
- Community – a community must be aware of the health services within their community, the general health of the community and feel able to have a say in health issues within the community. Such activities can be seen in community awareness of the availability of such services as renal dialysis, which involves prolonged and frequent absences from home, and often the neighbourhood, if there is no nearby dialysis unit.
- Professional – medical and allied health providers must support community education of health issues and work collaboratively in advocating for the health

needs of their communities. Health providers would ideally be aware of areas of expertise within the professional community and share this information between services and among consumers seeking advice.

- Administrator – must appreciate the general literacy and local knowledge of their communities and work with them to maximise the services available to that community.

Health communication must be inclusive of all elements of the service. There appears to be a feeling of “us and them” in some situations, where there is competition between who is providing the service and who can access it. The Mount Gambier regional hospital was once seen as the provider of services to public patients, with privately funded patients directed to local private service providers. There was some limited ability for services to be delivered and billed privately for inpatients. Such privately funded patients were seen as an added source of income for what has been described by administrators as an underfunded hospital, working on a deficit budget and having to seek assistance each financial year.

In order to address the long waiting time for non-privately funded patients, the National Disability Insurance Scheme (NDIS) was instituted, commencing with services to young children and gradually expanding to include all disabled people. This service was intended to assist in providing more timely engagement with services for disabled people, by allowing them to have funding to access services with registered providers outside the public health service. Recognising the inequities of service provision across rural and regional Australia, the NDIS has increased the difficulty of access in some areas, because of a lack of suitable registered personnel. As a measure to help alleviate some of the inequity, public funded services such as Community Health Services were permitted to seek registration as providers under the NDIS but were required to separate their core public services from the extra services which they would provide under the new scheme. In some situations, this has led to competition between services, with a subsequent breakdown in collaboration between services. In the interest of offering a comprehensive service in rural and regional health, co-operation and the ability to maximise the interplay of services available should be of paramount importance. Duplication of services when there are limits of expertise is a waste of a limited resource.

Where do People Access Health Information in Rural and Regional Australia?

Traditionally, health discussions were a family matter. People, particularly in small communities, tended to keep their medical history and stories very much within the walls of their home and in the consulting room of their chosen doctor. Knowledge about their health condition was gained from the doctor, nurse or other family members. Families often had a "Health encyclopedia" where they gained first aid knowledge about common ailments. In some smaller communities there was no resident doctor but there may have been a regular visit from the bush nurse who was able to triage patients and arrange for transfer to a medical centre if needed. In our region such a service existed in a small town just over the border into Victoria (Dartmoor and district Bush Nursing inc, 2016). A doctor from the main centre in Mount Gambier would visit the bush nurse establishment one day per month and see any concerning patients, fill out prescriptions and certificates as required and provide some medical support for the bush nurse.

At that time, before the advent of national registration for health professionals, that doctor was required to hold current registration in both South Australia and Victoria to enable any of the formal documents to be valid – an added cost and time expenditure to allow the service to be carried out. Patients travelling across the border to see the doctor were required to have their prescriptions filled in South Australia before they travelled home, because they were not able to get their medication from the pharmacist in Victoria if the prescription was signed by a doctor who was registered in South Australia. National registration of health professionals has made this much easier, although there is still the need to have Child-safe certificates issued in any area in which one seeks to work, sometimes construed as a revenue producer rather than a genuine safe-guard.

In more remote parts of Australia, the medical workforce is spread over a very large geographic area. Numbers are limited and people living on remote cattle stations rely on the Royal Flying Doctor Service (RFDS). The stations are equipped with a first aid locker which contains medications for a variety of conditions (Royal Flying Doctor Service, 2018). These medications are in numbered containers and not identified by name. When the station contacts the RFDS, they are asked to give an account of the problem and the patient status. They are then instructed to administer drugs and medication by number in response to the reported condition of the patient. If the patient needs to be retrieved for specialist intervention that is arranged as expeditiously as can be organised, but sometimes there may not be a plane available and as happened to the child of a friend, they are asked to drive to the nearest large centre where they can get medical help. In this particular case that was an 8-hour drive to Tennant Creek with a very uncomfortable baby who subsequently underwent an "emergency" surgical procedure on arrival. The importance of health literacy, including communication and collaboration is emphasised in this situation.

Health services generally, have become more aware of disseminating health tips and holding open information days. There has been an increase in public health seminars and publicity about particular health issues. There tends to be an emphasis on a particular condition if the Government is currently directing increased funding into that particular condition and we have seen renal dialysis, some cancers, diabetes and mental health in these categories.

Over the past ten years, there has been a steady increase in the use of social media as a starting point for seeking health advice (Khoo et al., 2008). There are several platforms to which people turn in their attempts to gather information and join discussion groups formed around nominated conditions. Specific websites and other online tools are commonly used, including Facebook, Google, Twitter and YouTube. Health information is reported to be one of the most frequently searched topics on the internet. In internet and smartphone research studies it is reported that more than 60% of smartphone owners have used their phone to obtain health information about a health condition (Roberts et al., 2017). Many smartphone users maintain records of their general health and fitness, exercise levels and pulse rate on their devices. This health advice phone usage has been found to be higher in rural areas and amongst low income earners.

It is then, very important that health messages delivered in this way should be presented in language which is easily read and understood. To be effective, such messages should have a clear purpose, allowing the reader to understand the advice and the reason for the health message to their population. O'Mara warns that health information must be tailored to the demographic profile of the intended population, in order to encourage participation and stimulate sharing of the gained knowledge. This will have maximum effect if there is the creation of conversations between people wanting to discuss similar health issues (O'Mara-Eves & Brunton, 2013). The ability to use these social media avenues relies on familiarity with the technology and a sound socio-economic background with a good understanding of the English language. Once accessed, the user must have a level of media literacy which will enable a critical evaluation of media messages. O'Mara reminds us that "developing health and well-being digital videos in preferred language and cultural contexts" provides community health education which can be transformational in suitable environments (O'Mara- Eves & Brunton, 2013).

Sorenson et al (2012) when discussing accessibility of health information state that it relies both on understanding and appraising that information (Sorensen, Van, Fullam, & Doyle, 2012). One's understanding is influenced by one's expectations of the situation and the perceived usefulness of the information offered. Consideration of how the outcomes will impact on the person receiving the information may affect understanding, alongside the consideration of possible negative issues included in the health education. The appraisal of the information will be affected by the complexity of the information or whether confusing terminology is used, causing only partial understanding.

Personal health status has become much more public recently, with work place and school requirements to establish immunization and disease contact status. Health and disability are more openly discussed, which has had the effect of demystifying many conditions and promoting a much better understanding of health and wellness issues. Australians have been loath to consider personal identity registration with a single unique number and card, as seen in the Scandinavian countries. This has long been considered to lead to a lack of privacy and anonymity in Australia, but it is becoming increasingly obvious that use of, and engagement with, digital devices allows much personal data to be collected without the awareness of the users of such things as mobile telephones, global positioning devices and google maps. We all have tax file numbers, Medicare numbers and some have social security numbers, yet we resist the single personal identifier number. The proposed eHealth Record has seen many people take the “opt out” option because of a fear of who then has access to that information.

Collaboration in enabling Health Literacy

A strong combined medical group, the South East Medical Association (SEMA), which included all the doctors, including GPs and specialists, from across the South Eastern region of South Australia and Western Victoria, was active in the region. Regular meetings were held for professional development and socialisation. The families were included in these gatherings with separate programmes for the partners and children, creating a supportive environment which had an impact on retention of health staff in the region.

Divisions of General Practice were established by the Federal Government from 1992 and were nationwide by 1998. The Divisions were well-funded but excluded specialists form any of their PD or other advantages. This exclusion was more keenly felt in rural and regional Australia and in the South-East of South Australia, led to the abandonment of the SEMA which had included the specialists (Scott A & W, 2007).

With the advent of salaried staff at the regional hospital, many of whom were short term appointments, there was a lowering of specialist services in the private sector (Wallace S, 2000b). It was no longer possible for the surgical staff to remain in the region once they were replaced by salaried staff at the hospital, given that there was no private operating theatre facility. This was not only a personal loss, but it created a divide in the medical services generally as the salaried medical officers were often short-term locums. The difficulty of maintaining specialist surgeons in rural and regional South Australia became apparent (Breuning M & Maddern G, 1998) The GPs were no longer able to admit their patients to the hospital, patient loyalty diminished with people seeking medical attention where it best suited them at the time (Charlton P, Aug 1999). Communication between the hospital staff and the local GPs was at best, slow, and on many occasions, patients were discharged to the care of their GP, with no advice about the treatment they had received, or ongoing requirements. Confidentiality surrounded any attempts to gather information and the working relationship became quite strained (Wallace S, 2000b). The importance of collaborative teams which include the health care provider, the patient and the health service all contributing to shared decision making, seems very far removed from this situation. The Australian Commonwealth Health Department is working towards the introduction of an electronic patient health record accessible to any person to whom the patient concerned allows access. Trials have been extensive and have met with varied responses. In their study of such e-records in regional Australia, Hanna and Gill found that there was improvement in the quality of health care, with better information sharing. The enhancement of patient care for self-management was also found to be significant. It was noted however, that to be successful these systems must be simple to use and readily accessible (Hanna, Gill, & Newstead, 2016).

In an attempt to improve patient health literacy, Schulz notes the importance of what he calls “decision aids” in the preparation of a patient for surgery or screening episodes (Schulz & Nakamoto, 2013) Decision aids are designed to improve the patient’s understanding of the procedure that is to be carried out, explaining not only the reason, but the technique which will be employed and any possible difficulties or side-effects of the procedure. These aids can be in the form of suitably worded written outlines, diagrams, videos or other particular methods suited to the literacy skills of the individual concerned. The use of decision aids is aimed to foster a better understanding of the procedure to be carried out and to encourage collaboration and shared decision making throughout the procedure.

National Policy

The Global Health Summit held in Rio de Janeiro in 2011 concluded that there was a global need to reduce world health inequities, and differences in health outcomes, by growing knowledge translation (World Health Organisation, 2009). Growth in understanding and ownership of health matters relies not only on health literacy but also on knowledge translation. It is important not only to access information but also to determine its relevance to individual and community situations. In any health education activity, it must first be decided what knowledge should be transferred. The information must be available to the appropriate recipient in a meaningful way and be delivered by a trusted source. It is important that the effect of this knowledge transfer has been considered and measures are in place to follow up and continue this process.

The World Health Organisation continued the discussion on world health inequities, putting forward a global mandate for a public policy on health literacy for sustainable development and health equity. A directive was released in 2016 as the Shanghai Declaration with the recognition that such a policy would be influenced by world political and health system complexities (World Health Organisation secretariat, 2016).

A systematic review has studied responses and implementation of health literacy initiatives in some countries following increasing worldwide attention to health issues (Trezonz, Rowlands, & Nutbeam, 2018). Taking health policy documents from Australia, New Zealand, Scotland, Austria, United States of America and China, this group looked at how these countries had addressed policy development in health literacy over the first year after the directive was announced. Identifiable and manageable risks in clinical care, particularly in their relationship to long term care in complex conditions were considered, as was their impact on patient management. The six countries were selected by the researchers as it was possible to gain information from consumers, providers, organisations, government and policy makers from all of these countries, giving a comprehensive view of responses to the WHO directive released in 2016.

In Australia, a National Statement on Health Literacy was developed (Australian commission on Safety and quality in Health Care, 2017). Although this was not a policy in itself, an in-principle agreement for its implementation was made by all health ministers at that time. There was no explicit funding allocated for implementation and it was limited in its reach and impact because of the wide variety of community variations, State and Federal governance and service complexities, in Australia. A complex system of funding and reporting exists in Australia.

Federal, State and Local government bodies develop, implement and manage the healthcare systems through the National Healthcare Agreement in the following division of responsibilities:

- Federal Government.   Hold responsibility for the funding and governance of Medicare, Pharmaceutical Benefit Scheme and Private Health Insurance Rebate. Develops the policies for public health and aged care

- State and Territory Governments. Fund Public hospitals, Ambulance, Community Health and Mental Health. Act for their jurisdictions to set targets for implementation of health care.
- Local Government. Provides some vaccination programmes and oversees local health issues such as cleanliness of food outlets and other local public health issues.

The changing power in Australian politics can make the practicalities of changes in the health system difficult to enact. The Federal Government has a variable three to four-year term and an election can be called by the governing body at a perceived politically expedient time, within some guidelines. The State government has a fixed four-year term, which makes management somewhat more predictable, but elections seem to be timed when there are several regular, large State events taking place, which leads to some distraction from policy development. In the event of major changes in either or both of these levels of government, it can be seen that the development of a collaborative approach to policy development may at times, be quite strained. One gains the feeling that we are always preparing for the next election or evaluating the results of the previous election, with only a small window of opportunity to progress policy growth and public communication.

The National Safety and Quality Health Service Standards Authority conducts audits of services and provides accreditation of health facilities to ensure that high standards are maintained (Australian Institute of Health and Welfare, 2016). The National Statement agreed to by all health ministers in principle aims to:

- Increase understanding of health literacy
- Embed health literacy into systems
- Ensure effective communication
- Integrate health literacy into education

In agreeing to such broad sweeping aims, there is little indication of levels of responsibility between tiers of government, nor is there any obvious method of measurement of starting points or improvement measures. The opportunity for cost and blame shifting between opposing parties in Federal and State Parliaments can be seen, as debate ensues over whose responsibility these aims are.

These overriding principles will be actioned by:

- Consumers
- Health care providers

- Healthcare organisations
- Government organisations
- Policy makers

Indeed, this list comprises all people engaged at any level in health care and would suggest that there is agreement to take a collaborative approach to improving health literacy, but concern must be felt at how this action may take place equitably, across and within these groups. It is unclear who will monitor and drive action over these disparate groups and how their collective views will be managed.

The following priority areas have been set, in response to patient communication and engagement:

1. To improve health literacy and friendliness of health service organisations.
2. To improve individual health literacy
3. To improve health literacy and friendliness of the provider and service section

These priorities are seen to be set as the result of perceived deficiencies in the system and whilst the sentiment of the message can be understood, the actions and implementation of these ideals is not clearly established. One is reminded of long-distance travel in a car, with young children, “Are we there yet?” When will we know we are?

The priority areas for immediate attention are aspirational statements, with little clarity of direction about their implementation. Research has shown that “health literacy” is an over-riding term encompassing many different forms of communication, understanding, implementation and evaluation (Eggerton L, 2011). The disturbing fact that general literacy standards vary greatly, contingent on personal need and motivation, creates a difficulty for those trying to create meaningful policies around the gaining and implementation of health literacy in the wide range of environments seen across Australia and indeed, worldwide.

In China, the response to the WHO directive has been to implement some initiatives and demonstration sites, with the institution of population health surveys, in an attempt to quantify the effect of change.

In USA, it has led to the release of aspirational statements and prescribed pathways for implementation. It is hoped that this will lead to better monitoring and accountability in the provision of health services. One can see that this may lead to more accountable services generally. It must not be forgotten that patient acceptance and access are important components of optimal health service provision, contributing to contextual shared decision making. This then contributes to a level of ownership and collaboration, which further encourages community acceptance and involvement. This community based educational outcome can influence and strengthen political action, personal health and have an impact on the social determinants of health.

The social theory of literacy helps to understand the variations that can be seen in health literacy in different communities. Barton and Hamilton discuss the effect of reading and writing on the social structure of a community (Barton & Hamilton, 2000). Through the literacy practices of a community, there is development of values, attitudes, feelings and social relationships. The reading and writing of a community, seen in public papers and more personal material, shapes that community. There are various outlets for such writing, some freely available and some accessed by selected networks of people, such as perhaps school parent groups or volunteer organisations. Some community material may only be accessed by invitation or password, whilst other information may be freely available, provided one knows where to find it. This too can be a changing scene depending on one's contacts and social strata. Much community information is available freely online, but a knowledge of how to access this on a computer is needed, together with reliable connection to the internet, both of which may be severely lacking in rural and regional Australia.

In perceiving literacy as being part of reading, speaking, listening and interpreting, it becomes clear that in any social group there will be variations in the literacy required to make meaning of communications over a range of subjects. Thus, to read and understand communications about health requires a different form of literacy from reading and understanding a transport timetable. In these two examples, there will be differences in motivation and familiarity with the source material and the desired learning. Literacy in these two scenarios can also be impacted upon by the need to accurately follow the information gleaned, as well as the timeliness and personal importance of the outcome. Social literacy must therefore be purposeful and historically situated to engender the greatest interest for the information gatherer.

Barton and Hamilton tell us that, "literacy is best understood as a set of social practices; these are observable events which are mediated by written texts". There are obvious differences between the literacy of academia, workplace literacy and playground literacy. What is observable is that there are groups of people built around different facets of literacy and they will be moulded by the group to which they most closely align. There are elements of power in the strata of social literacy, where usually the most powerful institutions are seen to support the dominant literacy practices, perhaps thereby providing a less than accurate overview of the general literacy of that society. Barton goes on to say that “some literacies are more dominant, visible and influential than others”.

A variation in literacy can also be observed within the same individual, depending on the situation at that time. There will be a change in literacy between the literacy seen at home, within the household, the neighbourhood or the community. This is clearly seen in children who will use one form of communication between peers, these days often messaging, Instagram or snapchat, a different form with parents, possibly speech, and they may not communicate at all when in an open forum in the community. The same situation can be seen with some of the immigrant population who will try to use English when in the community shopping, for example, but will use a mixture of dialect, local language and English with their children at home and perhaps their classical native language when communicating with their older relatives (personal experience). Clearly accessing and understanding health documents may be very difficult for this group of people, although they may be considered quite literate in their mother tongue – a true example of social literacy differences which may have impacted heavily on our research study.[1]

The Relationship to Variations in Health Literacy and their Impact on the Research Study

This examination of the growth of health literacy has prompted identification of many unforeseen confounders of the research project undertaken in this study. Each of these deserves further discussion with a view to acknowledging and preventing recurrence of the difficulties encountered.

Regional differences

The differences between the two regions far outweighed the similarities, despite the thinking that the two regions were very similar. Management of the two hospitals and their birthing units was vastly different and this, combined with the birth rate in the Riverland being much lower than we had expected, contributed to the unexpected results. This should have only made a difference to the length of time needed to gather the required number of participants, but in fact, we were unable to enlist one participant, a sure indication that birthing numbers were not the principle problem and further differences should be considered.

---

[11] Norman and Skinner (2006) in a report from the US Institute of Medicine found “those with limited literacy skills have less knowledge of disease management and health promoting behaviours, report poorer health status and are less likely to use preventative services than those with average or above average health literacy. They go on to outline the increased requirements for eHealth literacy using the Lily Formula where eHealth is the centrepiece surrounded by the petals of information literacy, traditional literacy, computer literacy, media literacy, screen literacy and general health literacy[1]

The Limestone Coast Regional Hospital, situated over 450 kilometres from the nearest capital city, makes it difficult to consider birthing away from the region, so the majority of babies are born and stay within the region. The availability of ultrasound examinations means that hip examinations can be conducted in the region and treatment when necessary can be instituted. This has the effect of increasing awareness of infant hip problems and improving health literacy around this condition within the region.

The Riverland Hospital is situated in much closer proximity to Adelaide and infants must go to Adelaide to have an ultrasound examination of their hips if there is any doubt about their stability. This could have the effect of shielding the population from awareness of infant hip problems and thus lower individual and acquired health literacy on this condition.

There are economic differences between the two regions too, as the cost of accessing treatment in Adelaide is much higher from the Limestone Coast than the Riverland, when the high airfares or cost of fuel are considered. The need for overnight accommodation may also be added. The fare for travel one-way can be as high as $493.30 for one person (accessed 4/12/2018 online: www.rex.com.au)

In the Limestone Coast a strong collaboration between all health professionals involved in ante and post-natal care can be seen, with regular meetings of all concerned and the stability engendered by staff who reside in the region. As a teaching facility, there are trainees and registrars, so there is considerable professional development contributing to increased health literacy in the professional community.

I was only able to have one brief meeting with some members of the obstetric group in the Riverland. Some of those involved in this meeting were at other hospitals within the region and did not attend the Riverland Hospital. I was able to attend one meeting with the midwives and to discuss the project with them, but I only ever saw one of these nurses on any future visits to the region. Despite several attempts, I was unable to address any joint meeting of general practitioners in the region to discuss the project and although they all received information about the study and were asked to support it by encouraging their patients to enrol in the study, it is unclear if this ever occurred.

In considering De Wit's components of critical health literacy, it can be seen that there were differences in each of the three areas of functional, social and cultural literacy between the two communities. These differences were seen in engagement with health information, in social and environmental networks and in evidence of shared decision making.

What is clear is that rural general practitioners are feeling the pressure of high patient numbers, high requirements for auditing numbers for blood pressure checks, vaccinations and other data collection, to maintain accreditation and to satisfy government requirements for consistency in length of consultation and prescribing habits. Much of this contributes to the oft heard criticism that the doctor was “just tapping his computer” and shortens the time available for the sharing of health literacy, collaboration and shared decision making in setting the pathway for health improvement in many situations.

Complexity Theory

Within the health system in South Australia, we see changes in the hierarchical structure, which historically was structured on a medical model with local management. Funding and management have been increasingly centralised under large distant management and we see an increase in sub-contracting of services much as described by Lash (Lash & Urry, 1994) In their book, Economies of Signs and Space, Lash and Urry describe “large numbers of small bodies acting with the over-riding parent body who is often a large distant company.” There is an interconnectedness within the health system, where an increase of stakeholders can be seen, with a blurring of boundaries between public and private health systems and a greater diversity in interdisciplinary teams and decision making (Hill, 2011). Hill points out that “local” in health can be geographic, thematic or virtual, involving multiple partners and networks. In regional, rural and remote environments this can act as a further point of difference rather than a benefit, when considered with the problems of internet infrastructure, availability and accessibility, combined with variability in health literacy.

There were marked differences between the involvement of the leadership teams in the two sites in our research study and it is clear that applied and reflexive health literacy had a large part to play in these differences. There was much greater awareness of the impact of hip dysplasia on the life of a child in the Limestone Coast leadership team, in comparison with the Riverland. There are several possible explanations for this. Not least of these, is the greater awareness of hip dysplasia as a result of seeing the condition treated locally over many years, from the early days of the resident orthopaedic surgeon, to the resident physiotherapist with paediatric experience and the ability to manage the treatment of these infants within the region.

In the Limestone Coast cohort, the impact of cultural health literacy has been seen in differences in infant management techniques with one young Muslim baby. He was found to have limited abduction in his hips when examined by his family doctor at six weeks of age. His hips were poorly developed on ultrasound examination, but he also had a very restricted range of hip abduction. On questioning his mother, it was disclosed that there is a strong

Muslim tradition of tying the ankles of infants together with ribbon to promote straight legs and good living. Discussion with the mother about infant hips and optimal positions for good hip development, were well received and understood. The mother undertook to educate her peer group about the dangers of this traditional positioning for the developing hip and she became a great advocate for early infant hip development.

In studying health inequities both within and between countries and across population and individual characteristics, Welch et al have recommended a rigorous process (Welch et al., 2013). A system described by the Cochrane Collaboration has offered an acronym, PROGRESS +, to identify those characteristics, particularly in systematic reviews:

- P – Place of residence
- R – Race, ethnicity, culture, language
- O – Occupation
- G – Gender
- R – Religion
- S – Socioeconomic status
- S – Social capital
- + - may include disadvantage, age =, disability

The unpredicted outcome of the research study undertaken in two regional centres in regional South Australia can be seen to have been affected by differences/inequities in all these areas. Health inequities are described as differences in health outcomes which are avoidable, unfair and unjust.

It is important that knowledge gained is transferred. Knowledge transfer (KT) is described by Welch et al, as the gathering of best evidence from studies and helping end-users to make decisions about the application and timing of this knowledge. In discussing the best methods for the transfer of knowledge it is recommended to consider:

- What information is to be transferred? Such information may influence clinical guidelines, patient decisions or perhaps contribute to policy briefs.
- To whom the knowledge is being offered. This could include family members, health practitioners or perhaps national policy makers.
- By whom the knowledge is offered. The knowledge should be transferred by an appropriate and trusted group or individual with consideration for the particular knowledge being transferred and to whom it is being transferred. This will clearly

be contingent on the first two KT requirements. The method of the transfer must be appropriately tailored to the recipient, to allow for best comprehension.

- With what effect. Effects may be expected or unexpected. Effects may be noticed at different levels by the individual, at the organisational level or at the systemic level.

It is clear that insufficient attention was paid to knowledge transfer in the preparation of the research study in the Riverland arm of the experiment. If further studies such as this are to be conducted in regional centres in Australia, it will be important to spend time in disseminating appropriate levels of knowledge about the study to all involved.

O'Mara-Eves asserts that community engagement is of great importance in reducing health inequities (O'Mara- Eves & Brunton, 2013). Community engagement in interventions will improve health behaviours and self-efficacy. This has been clearly demonstrated in the Limestone Coast region where community awareness of early assessment of infant hips is high. Families are requesting regular hip checks for their babies with referral for scans where doubt about stability exists.

In their research, O'Mara-Eves et al used a community health education programme, provided in a co-ordinated way, in an attempt to gain an improvement in reflective, cultural and transformative opportunities. A culturally sensitive approach was used to encourage participation. The production of health and well-being videos and digital information allowed the learner to access the information at personally suitable times and in suitable intensities. Familiar language and storytelling were used to assist understanding for culturally and linguistically different (CALD) people.

Attempts to use internet and digital learning tools in our study proved difficult both in hospital and at home for many participants in the Limestone Coast. This was due to health system difficulties in allowing access to electronic equipment and mobile phone usage in the hospital. Many mothers reported that their days as inpatients were too full and there was not enough time to watch the recommended videos while coping with others sharing the room.

The information sharing and motivation of health care providers, parents and infant welfare nurses in the Limestone Coast has led to shared decision making which has seen the development of ongoing early assessment of neonatal hips by both clinical assessment and early dynamic ultrasound. This in turn, has led to greater understanding of the importance of early management of infant hips, which it is hoped will lead to better hip development over the lifetime and hopefully lead to birth in regional South Australia no longer being a risk factor for late-diagnosis of hip dysplasia in infants.

Should a similar study be undertaken again, it is clear that there must be greater preparation of all staff members at each site to increase ownership of the project and encourage participation. An increased understanding of the importance of networks of communication and support in the success of such a study has been gained. In order to have an assessment of the importance of early detection of early neonatal instability, it is clear that this research must be carried out in the first eight to ten weeks after birth. The benefits of this knowledge can only accurately be measured over the life of the infants involved, if we are to show any change in long term hip status over the adult years. This will require a much larger longitudinal study, with a very large number of people, from birth to fifty years of age. To gain such numbers one can see that this may require a multicentre study over many countries across the world.

Conclusion

What I have learned from this research is that there are obvious differences and inequities in health service provision, access, expectation and structure across two regional centres in South Australia. The importance of networks of health professionals, administrators and healthcare users, working together to promote health literacy and engagement, cannot be ignored and must be strategically carried out, with measurable outcomes in specific areas. It is clear that the highest aim should be on information sharing between all levels in a combined effort to strengthen and nurture communities and their health.

CHAPTER 8: REGIONAL HEALTH SERVICES

HISTORY AND TRAJECTORY

Introduction

The inequities in health service provision and access seen across the two regional centres in our study could be having an impact on early diagnosis of hip problems in infants. A closer study of the development of regional health services is warranted to assist in understanding the differences and inequities observed between the two regions in the research study and discussed in the previous chapters. With more than 40 years' experience of working in one region, the growth and change witnessed over that period affords some grounds for discussion. A clearer understanding of the development of regional health services may stimulate improved protocols for the management of recurring problems such as those seen with late-diagnosed DDH.

Health Services in the Regions

In considering the two regions within this study, the services provided both currently and, in the past warrant further understanding, as this will have an influence on the expectations of those who access the services. In the previous chapter, differences in health service provision, access, expectation and structure have been demonstrated. Changes have occurred in regional health over the last thirty years as has the demographic of the population and a review of some of these changes may explain the regional differences. Such changes can provide some context and help provide the framework for the creation, application, summoning and deployment of health literacies within these communities.

Riverland General Hospital

The new Riverland General Hospital commenced as a regional hospital in 2013, following an extensive upgrade, converting the old hospital at Berri to the new regional hospital. The regional hospital has a bed state of up to 69 general beds with 2 delivery suites. There is also a maternity unit at the Loxton hospital 22 kilometres away, with facility for water births and a family birthing unit, where the family can stay with the mother and new baby after the birth. Radiology services are provided at the hospital by SA Medical Imaging, but infants requiring hip scans are referred to Adelaide.

Mount Gambier Hospital

Mount Gambier has had a government funded hospital since 1869. In 1973, at the time of joining a rural medical practice in South Australia, the local regional hospital was funded by the State Government on a deficit funding model, where the budget was based on the actual spend of the previous year. The Federal Government undertook to pay 50% of the net operating cost of the hospital with the State government funding the other 50%. There was a joint health policy aim to maintain private revenue from the insured population at the highest possible level, through private health insurance. This remains an important general health policy and has led to the continuing subsidization of private health insurance nationally, which is seen by some as a biased spend of the health dollar in favour of those who can afford such cover. Private health insurance does however contribute to the cost of service provision by funding services. (Private communication with C. Overland CEO Mount Gambier Hospital (1989 – 2000) (Overland C, 2018)).

Throughout Australia, from the late 1980 years on, the delivery of health services changed markedly with increasing medical, nursing and allied health staffing shortages. There was a mixture of political, professional and health related issues which affected the recruitment and retention of allied health professionals. Shortages were more marked in rural and remote settings and incentives were developed to attract the recruitment and retention of such practitioners to the country. Incentives for medical and nursing professionals were more attractive than those available to allied health professionals (Struber J, 2004).

Right from the outset of the funding changes, it was clear that people in rural and remote areas would not generally have access to completely free hospital services (Overland, 1999). This immediately created inequities of service between rural and metropolitan health, as medical services in rural areas were provided to patients in the hospital by local general practitioners and specialists on a fee for service basis. The simple reason for this was that there usually were no salaried medical practitioners to deliver these services and private doctors could not be conscripted into providing them. Section 51xxiiiA of the constitution specifically precludes this. (Accessed at www.aph.gov.au). Consequently, for inpatient services, the States and Territories entered into fee for service arrangements whereby private doctors were paid to care for public inpatients at no direct cost to the patient. Specialists services could be called in on the same basis (South-East -Regional- Health Service, 1999).

Funding changes

Medibank was introduced in 1975 by the Whitlam Government, providing part funding for medical treatment with a gap payment by the patient (Hall J, 1999). A Commonwealth schedule of fees was established and agreed to by the Australian Medical Association, providing dollar amounts for different services with differential payments for length of consultation, either short or long. Pensioners and concession card holders were not charged a gap payment. Audits were carried out from time to time, with doctors notified of the results and how their practice profile compared with the local statistics. A similar pharmaceutical benefit schedule was developed and similarly audited, showing the prescribing habits of individual doctors. Doctors were notified of variations in their prescribing habits compared with the average in the area. Little consideration was given to the patient profile of the doctor. Thus, a doctor with an interest in family medicine may well have a different prescribing profile from a doctor working in geriatrics but this was not considered in the audit assessment.

A change of government saw Medibank privatized as an optional medical benefit fund and the introduction of Medicare as the Government funded component for medical services (Hall J, 1999). The Government introduced and encouraged bulk-billing, where the doctor billed Medicare directly and accepted the Medicare payment of 85% of the recommended fee at that time, as full payment for the service, with no gap charged to the patient. Any adjustment to the remuneration from Medicare payment is a political decision and therefore a form of control of medical charges, particularly for those doctors who bulk bill. Those doctors who did not bulk bill continued to charge the AMA recommended fee, which included the Medicare fee plus a gap payment from the patient. Doctors and allied health workers were required to apply for a provider number which was specific to the address at which they worked. They were required to hold a different provider numbers for each address at which they worked.

Patients in metropolitan areas were able to attend their public hospital, staffed by salaried doctors and were bulk billed for their attendance, but in rural and regional areas, the hospitals were staffed by general practitioners who were not paid by the hospital for their attendance and so a fee for service was charged for each patient. Most GP clinics allowed bulk billing for concession card holders but charged a gap payment for others. For the doctors in regional South Australia, providing services in the local hospital meant that they were competing against their own businesses when seeing their patients for a fee in their rooms, where they paid the staff, equipment and running costs, or free of charge in the hospital. Many of the clinic running costs were constant, irrespective of patient numbers, so providing their services in competition was untenable for many doctors. This method of funding outpatient services at the hospital seemed incongruous, with the Federal Government providing funding to the State Government to run hospitals but the State

Government asking doctors to bill Medicare (funded by the Federal Government) for patient attendance. Many doctors saw this as a cost-shifting exercise on the part of the State government. Access to services at the hospital was free to all, with no loading for out of hours work, but it became increasingly difficult to staff the hospital after hours.

There were some allied health personnel employed at the hospital, but services were limited largely to general physiotherapy, with little provision for paediatric allied health. Periodic visits were made to the country areas by the Crippled Children's Association, to provide some support to families with children with special needs.

Recognising this regional/metropolitan discrepancy in service provision, Mount Gambier moved to salaried doctors staffing the hospital. In 2000 the general practitioners were advised that their services were no longer required at the hospital and their admitting rights were removed overnight (Beatty D, 2000). The general practitioners were no longer able to admit their patients to the hospital or to be involved in their care there. It became necessary for any patients seeking admission to be seen in Accident and Emergency before they could be admitted. This move resulted in a marked change for not only the GPs in the region, but also for the specialist, where no longer could the GP continue the medical management of their patients during their hospitalisation, but there was a break down in continuity of care both in hospital and on discharge (McCusker B, 2000). It was the first regional hospital in South Australia to do this and was followed later by the hospital at Victor Harbor. There was a difficulty in attracting doctors to staff the hospital and many international medical graduates were employed with some of the vacancies later filled by local GPs in supervisory positions in the emergency department (Wallace S, 2000b). It was initially thought that four salaried staff doctors would be sufficient to cover the hospital for 24 hours, but this was found to be very inadequate.

In 1996, following a long-running battle with the State government over the provision of obstetric services at the MGH, a resolution had been achieved by the appointment of registrars to work with the specialist obstetricians. This appointment provided continued support for the GP obstetricians who had expressed extreme difficulty with providing continual cover with the hospital, at the same time as conducting their general practice cover (Hoey F, 1996). The GP Obstetricians were contracted to provide obstetric care, with a resident specialist obstetrician, as it proved too hard to attract suitably qualified salaried staff doctors to these positions, and their services have continued to the present.

Over the years the hospital has taken on more responsibility for services across the region, the bed state has lowered and the specialists residing in the region have lessened. There is still a specialist orthopaedic practice and an obstetrics and gynaecology practice in the city, but most other specialist services are provided through staff doctors at the hospital and the training facilities of the hospital have increased markedly.

How have these changes altered patient relationships with the hospital and their doctor over the years since 1973?

In the years before the introduction of Medicare (or Medibank as the first model was called, in the time of the Whitlam government) the casualty department was staffed by a senior nursing sister who had the authority to assess patients and call the duty doctor if urgent medical attention were required. Many people used this service to have their condition assessed, to avoid unnecessarily disturbing the doctor if there was not a serious problem. They considered that the doctor was busy all day and did not want to disturb him at night if it were not necessary. There was also the disincentive of the fee if the doctor needed to be called, but often that was unnecessary as the sister-in-charge had the authority to admit patients overnight if required, so that they could be monitored, and the doctor called as needed.

With the advent of Medicare, patients expected to be seen by the doctor and not triaged by the nursing staff, and attendances at Casualty where the service was provided at no charge to the patient, increased markedly. Attendances at out of hours consultations in the general practice clinics also increased, as in many cases Medicare covered the full cost of the visit. There was a downscaling of health management in the home and medical attendance was sought for simple first aid. It became less important for patients to be seen by the same doctor, thus impacting negatively on continuity of care.

The clinic which we joined at the start of 1973, was a combined practice with general practitioners and specialists working together. All doctors were part of the general duty roster regardless of specialization but also ensured that there was a specialist surgeon on duty if needed. Obstetric patients attended their chosen GP obstetrician or specialist for ante-natal care and were attended by their chosen doctor when admitted for the birth. Difficulties with funding for this service had almost caused this service to end in 1995-6 when out-of-date contracts and rising indemnity costs reached crisis point (The Hon Michael Armitage MP, June 24 1996).

Collaboration between the specialists and general practitioners was strong and led to timely referral and discussion about case management and ongoing treatment. Continuity of care was paramount at this time (Haggerty et al., 2003). Patients were able to choose other specialists if they wished, but many chose to have their entire health management in one place and felt confident in this situation (Walters Lucie, MacLennan N, & Tegan Susi, 2000). An orthopaedic surgeon with paediatric experience was a partner in the medical practice and this meant that babies with hip problems as well as those with many other problems, could be treated in Mount Gambier in collaboration with the paediatric physiotherapist.

As Medicare was expanded and benefits were paid for specialist visits and surgical interventions, it was no longer tenable to have specialists and general practitioners working together in one organization and the specialists were required to leave the partnership and set up in individual practices. There was a feeling that the combined practice situation could be seen as a form of “insider trading” where each group stood to benefit from the work of the other group. The specialist colleges expressed concern that the specialists were providing a general practice component when they were on call for the general practice. It was felt that this move away from the clinics also increased the freedom of choice for the patients, although many continued to prefer to see a local specialist known to them and their doctor. The preference for people to seek local advice when it was available was apparent and many preferred not to have to travel to the metropolitan centre with the accommodation and transport difficulties they may then experience.

On the retirement of the orthopaedic surgeon, his replacement surgeon did not feel experienced enough in the management of DDH to continue the local regime. Families were required to travel to the capital city for advice and treatment under the supervision of a paediatric orthopaedic surgeon, although they could be followed up locally by the physiotherapist.

Geographically situated halfway between Melbourne and Adelaide, people chose to visit the metropolitan centre where they felt most comfortable or had relatives and friends with whom they could stay. The regime for infant hip management was different in each state and this provided the opportunity for the physiotherapist to be involved in different protocols for the treatment of DDH.

Towards the end of the 1970s, the Adelaide Children’s Hospital commenced an outreach service to the region, with a paediatric orthopaedic surgeon making a twice-yearly visit to Mount Gambier, to provide a local service and save families the need to travel so much for treatment. This outreach service did not include a surgical element, so families still needed to travel for procedures but were able to have their conditions managed more locally.

There was difficulty in attracting new general practitioners from the capital cities as many young graduates were pursuing specialist training and did not want to step out of the training possibilities available in tertiary hospitals (Walters Lucie et al., 2000). There were at this time, some doctors trained in recognized universities and hospitals overseas, who were able to be fully registered in Australia if they were sponsored by a practice needing new staff. Several doctors from the United Kingdom joined practices in our region and became long serving members of the general practices in the area (Morello F, 2000; Wallace S, 2000a). They were unable to join Medicare and neither they nor their family could receive benefits until they became Australian citizens.

Following their exclusion from the Mount Gambier Hospital, the GPs were unable to admit their patients to hospital or to take any part in their care after admission (Charlton P, Aug 1999). Any patient referred to the hospital needed to be seen by the salaried doctors in the emergency department to affirm the need for admission and their care was supervised by the staff doctors, with no visiting rights for the local GPs to continue their care. This caused a further disruption to continuity of care, as often, on discharge and returning to their family doctor, it was difficult to find any information on treatment and medications (McCusker B, 2000). Many of the hospital medical staff were not able to write prescriptions for medications and patients were discharged from hospital with only enough medication for one day and no information to their family doctor about what treatment they were on.

The same conditions prevailed for palliative care, whereby the family doctor was not allowed to continue to provide care for a patient on admission to the palliative care area in the hospital. This was a cause of great concern to many who had consistently had their care managed by the same family doctor over a very long period. To be denied this continuity was distressing to all concerned at a very vulnerable time. Although much discussion has taken place about this pitiful arrangement and promises have been made to amend the situation, this has never occurred nor have any contracts for provision of such services been discussed.

Medical staff changes caused uncertainty amongst patients and in areas where there were shortages of doctors, international medical graduates were employed to fill vacancies in the hospital staffing. These staff international medical graduates had a range of specific differences in their work and family situation. Initially their registration was restricted, allowing them to practice only in identified regions of need. They were not able to have Medicare provider numbers and neither they, nor their families, were eligible to receive Medicare funding or free access to public education. This meant that the cost of living might be higher for them in accessing childcare assistance or entrance to tertiary studies for their spouse or children. They were likely to spend some years in the first area to which they were sent, while they gained full registration. Once they had full registration many chose to move to other areas and there were different scales of remuneration between regions. The Australian Medical Association states that IMGs make up 40% of the medical workforce in rural and remote areas.

High turnover in hospital staffing remained a large problem, with frequent changes of medical staff as IMGs transferred to other areas of need. Many specialist services were provided on a roster system by specialists from Adelaide. The churning effect in turnover of medical practitioners in rural Australia is well known. These changes can affect patient confidence and impact on workloads for remaining doctors in the medical practice. Research shows that doctors are most likely to move in the first three years after commencing work in rural or regional Australia. Salaried and contracted doctors under 40 years of age are the most likely to move (McGrail & Humphrys, 2015). Many of the International medical graduates found living in rural and regional areas quite hard and experienced difficulties with their cultural and dietary requirements. Some IMGs had specialist qualifications which were not recognized in Australia and found it difficult when they could not use their expertise to its full potential. The numbers of patients being transferred for specialist care to Adelaide increased markedly and the number of emergency transfers from the region to Adelaide by the Flying Doctor service increased exponentially. In the era of hospital medical management where services were provided by long term local GPs and specialists, there were an average of 30 Flying doctor retrievals from Mount Gambier to Adelaide per year. This figure has risen to more than 700 per year in 2018. During this time, there has only been a small increase in the population in the area, although the population is ageing.

At the same time, there was an increase in training of rural doctors in rural clinical schools in the belief that those who are trained in country areas were more likely to work in rural areas (Myre, Szafrano, Skipper, Dickinson, & Janke, 2018). Research continues to look at the reasons and variables in the recruitment and retention of health staff in rural and remote areas but limited evidence shows that training in rural areas is effective in encouraging health staff to work rurally (Farmer Jane, Kenny Amanda, McKinstry Carol, & Heysmans R D, 2015).

In reviewing this historical information, from the time of the first obstetric medical contract crisis in 1996, resolved with parliamentary intervention (The Hon Michael Armitage MP, June 24 1996), I am reminded that history is repeating itself. There is an extreme shortage of skilled GP obstetricians willing to commit to continuing the provision of services which have been out of contract with the health service for more than twelve months, despite continued attempts on the part of the doctors to have this situation rectified. Their goodwill is presumed upon by the health service, in asking them to continue under the terms of the old contract without any formal documentation or tabled letters of offer for a new contract. One wonders how much this impacts on recruitment and retention of medical professionals in the region.

The Influence of Casemix Funding

Harvard University researchers originally invented Casemix and Diagnosis Related Groups (DRGs) as a way to understand costs, not as a formula for funding services. Casemix was a way of calculating the average costs involved in delivering a wide range of specific services which were then aggregated into DRGs. However, health bureaucrats in the USA and elsewhere almost immediately recognized the potential for this approach to be used to fund services at an “efficient price”. The price attached to each DRG is not merely a function of an objective assessment of the costs involved but also of how much Treasury is willing to allocate overall for hospital services.

Casemix funding was adopted in Australia in 1993 with the aim of changing economic incentives in hospitals by linking payments to the number and complexity of the patients treated. Standards were set for length of stay for particular diagnoses and patients who were not better within the prescribed time set, were obliged to have their diagnosis changed or adjusted to allow for continuing funding (Overland, 1999). Public hospital costs are still shared, with total costs based on the National Efficient Cost as decided by the Independent Hospital Pricing Authority. This is an activity-based funding, based on Casemix funding, as agreed by the States and Territories in the National Health Reform Agreement.

A discrepancy exists in Casemix funding between urban and regional funding, where there are different scales of funding for the same procedure between hospitals in the metropolitan area or those in the regional and rural areas, with regional funding being calculated at a lower rate than urban funding (South-East -Regional- Health Service, 1999). Some smaller rural hospitals would not survive on Casemix funding, as there are few major cases carried out there and it is these cases which attract the greatest amount of Casemix funding. These smaller hospitals are, in practice, still deficit funded and kept open largely for socio-political and economic reasons. Mount Gambier Hospital is too big to be small enough to be deficit funded and too small to be big enough and efficient enough to recover its full costs from Casemix funding (Overland, 1999). Therefore, it struggles with its budget every year and every year seeks increased funding to alleviate the deficit.

Australians have universal access to healthcare through either the public or private sector and the spend for healthcare nationally in 2015/2016 financial year was $170 billion or 10%

of the gross domestic product, which is low when compared with Scandinavia or the United States of America (Australian Institute of Health and Welfare, 2016).

Despite the Australian health declaration that in Australia there is, “universal and affordable access to high quality medical, pharmaceutical and hospital services, while helping people to stay healthy through health promotion and disease prevention activities” (www.health.gov.au accessed Nov 2018), discrepancies exist between availability and access in metropolitan, regional and rural centres with outer rural areas generally having the worst availability of services. Leeder, in his address to the Australian Healthcare Summit in 2003, asserted that “individuals’ need for healthcare is based on both their medical condition and their social situation” (Leeder, 2003) For the health of children, I believe that this availability is further compounded by the parents’ perception of the severity of child’s condition and the parental need/ability to access treatment. Each of these variables can be influenced by the health literacy of the parents. Mooney describes equity in healthcare as, “equal access to equal care for equal need” but when faced with the confounding situation of the under-privileged, he suggests that some people “may need more access to care for the same health problem”(Mooney, 2003).

Funding

Health funding is a combination of Commonwealth, State and Local Government funding Commonwealth and State funds are provided through Medicare, with private health insurance government regulated. The Medical Benefits Scheme and the Pharmaceutical Benefits Scheme are controlled by State and Territory governments in both public and private hospitals through the Australian Healthcare Agreement between the State and Commonwealth governments.

Medicare agreements have existed between the State and Federal governments over the past twenty-five years.   A robust bench marking system is used to determine the “national efficient cost” of a given service. This figure is then debated through the various levels of government to determine the total quantum of funds they are willing and able to allocate to health care. The base payment per case is then a political decision based on these discussions. This system has been criticized as being particularly detrimental to integrated care and open to cost shifting and blame laying (Dwyer, 2002). According to Dwyer, what is needed, is healthcare promotion and more in-home care in community settings rather than hospitals. There is a feeling that quality and outcome are not sufficiently considered in the current system. Dwyer considers that area health services will encourage a move towards this model and some changes in that direction have been recently made with the return to local area health networks in South Australia.

There are also inequities in the distribution of Medicare funding where claims in urban areas far exceed those in rural and remote areas on a per capita basis. This can in some large part, be attributed to the lack of services in rural, regional and remote areas. Over the past ten years in South Australia, there was a shift to five major health networks with four metropolitan networks and Country Health SA, which covered the remainder of the State outside the extended metropolitan area. The metropolitan networks covered the central, northern and southern metropolitan areas with a central children's health network at the Women's and Children's Hospital, covering children's health services across the State including the state-wide Child and Youth Health Services. The focus of healthcare during this period has been more on cost and financing rather than quality and outcome of the service.

With the change of government in South Australia, there has been a return to local health networks, with local governing bodies being formed to particularly advocate for the needs of the local community and better assist inter-relationships between other areas. Currently being established with positions being advertised, this return to local hospital boards and health networks remain to be tested, but the system suggests a more local collaboration and control of services. The return to local health networks is proposed to commence in July 2019 and the appointment of the new chief executive officer of the South-East Local Health Network was announced on 5th December 2018, as an interim position until the commencement of the new network.

How do these issues impact our local service?

In a paper commissioned by the National Health and Hospital Reform Commission in 2008, to consider "options for reform of Commonwealth and State governance responsibilities for Australian health," Judith Dwyer identifies problems in healthcare experienced by the patients and those problems which are attributed to the service provided (Dwyer Judith & Eager K, 2008). For the patients, she claims that inequities of service exist, particularly for patients in remote and isolated rural settings, with financial barriers to fee-for-service availability. She finds fragmentation of ongoing care for chronic and complex conditions, with primary health care not well delivered and little attention given to prevention of illness and injury.

These inequities can be seen in our region, when one considers the difficulty parents have in accessing specialist paediatric care, particularly when their child has complex needs requiring medical input from a variety of specialists. There seems little or no ability to co-ordinate these appointments into one visit to the urban centre for all appointments. Time is lost from work with travel and accommodation arrangements to be made for each appointment. Some primary care services can be provided locally but communication between the specialists in Adelaide and the local care providers can be extremely difficult to conduct in a timely manner.

Problems affecting the health services are varied and deserve discussion to further evaluate their individual influence. There is a varied and confusing array of funding programmes, where each may have a set of requirements which differs from others, needing to be reported on differently. This can increase the need for ancillary staff, thereby absorbing some of the funding and preventing its use for the original purpose. The awareness of available sources of funding is reliant on being aware of what is available and often the preparation of successful applications.

There is a reported tendency for blame and cost shifting between tiers of government, with frequent discussion about who should pay in any given circumstance. This has been increasingly obvious with funding through the National Disability Insurance Scheme when there is much discussion in the preparation of plans for client funding, particularly whether a specific item is a disability issue or a health issue. For example, a child requiring specialised food supplements because of parenteral gastric feeding may be told that such food supplements must be funded through the health system and not the disability service.

There is a loss of job satisfaction among staff when it is perceived that their skills are not being fully utilized. This has been observed in our region when the paediatric physiotherapist has the skills and training to treat some neonatal abnormalities in infants who could then commence their corrective while still in the maternity unit. This service is advocated by the tertiary hospital in Adelaide but not allowed locally as it is not available in other regional centres and would thereby create an inequitable service in our region. Such an attitude makes it unattractive to work in situations like this, when the service can be provided outside the regional hospital, but funding can be difficult – is this really another form of cost-shifting?

Where funding is related to numbers of clients, there is competition between government and non-government organisations and private services as registration of patients with a particular service can have financial benefits for that service. In some instances, this is occurring where the wait-time for an appointment can be quite extended without any thought of suggesting any more timely alternative service to that client. This tendency seems to have increased with the increased.

In many healthcare situations, the decision-making is too far removed from the frontline of the service, with increasingly difficulty in appreciating the circumstance of the health care seeker. This problem is exacerbated in regional centres where travel and access can compound the need to not disrupt home routine such as the collection of other children from school or be home in time for the evening farming work such as milking. In our physiotherapy practice we have seen occasions where parents have been arrived for appointments in Adelaide only to be told that the doctor is unable to see them, and they must return next week. When that involves a five-hour road trip each way, the consternation is palpable.

There is an increasing difficulty in introducing and sustaining new methods of care, best seen in the frequent use of the words, “It is not what we do here” which one often hears in health care. The wisdom of adopting universal clinical guidelines must be questioned when one considers the range of backgrounds and experience across which such guidelines are being applied. In the words of Leutz (2005), “Integration has to be implemented locally to suit local needs and conditions” (Leutz, 2005) In making this statement Leutz was championing integration of medical and social services and attempting how to best work towards the ideal of full integration of services. He observed that medical and social services were differently managed, financed and structured and perhaps it was not possible to universally integrate everything at once. He suggested that there needed to be a focus on health improvement planning with appropriate integration which sought to identify differences and benefits and worked incrementally at achieving some of these. He conceded that the medical need may be common, but accessibility and cost may be different. This became increasingly apparent over the time of the research study conducted in the two regions of South Australia. The proposal of local integration tailored to local needs, management and financing, supports the adaptation of clinical guidelines for optimal care in regional South Australia and may be applied in other regions where there is an appetite to work towards better integration.

Recruitment and retention of allied health and medical staff

In their paper discussing the allied health workforce, O’Toole et al (2008) found that the ability to access continuing education was considered an increased difficulty for health professionals in rural and remote areas. They identified that management within allied health departments was closely related to intention to stay in an area and that continuing education was an important factor in the feeling of competency and ability. They found that access to at least four continuing professional development events per year was the minimum requirement. Allied health professionals felt that they needed appropriate ongoing advice, preferably hands on, when confronted with professional challenges. This information was found to be true for other health professionals as well (K O'Toole et al., 2008). This suggests that access to a good supportive advisory system would be beneficial to the confidence and competency of health professionals working in outer regional centres. The difficulty of any constant contact with one allied health professional in the physiotherapy department at the RGH has highlighted the potential for ongoing support and training of the staff, where new graduates may have difficulty accessing the support that they may need.

Who makes the decisions in rural and regional health and what difference does this make?

Rural and regional areas in Australia have been under extra stress in the last five years with drought conditions prevailing across large areas of the country, where no rain has been recorded in that time. Businesses are moving away from regional centres; vacant shops abound and jobs for young people are hard to find. The health industry however remains strong and growing in most areas. This is partly due to the fact that as a nation, we are becoming less self-sufficient in our own health care, relying on more tests and "instant cures". Perhaps the major contributor to the security of the health industry is the ever-increasing government subsidisation that it receives. People expect that they should be in good health at all times and that when they do not feel "right", they should have access to medical services as required. There seems little expectation that they should look after their own health risks, minimising damage from such things as poor diet, lack of exercise, poor sleep, hygiene and self-care. These topics are talked about through the education system in schools and the health system in public fora, but there is no formal requirement that good health information should be applied. It would be interesting to see how many regular doctor's appointments were the result of direct neglect of health measures for the individual.

In the structure of health systems in two regional centres in South Australia, we have seen two very different management models. Both organisations are a part of Country Health SA and this raises the question of how the two sites can have such a difference in philosophy and management. Our information on these two sites came from a varied relationship with each organisation. It may therefore have some differences in perspective as a result of that. The awareness of the model of management of one region came from an "outsider" point of view, where professional meetings were sought to outline and discuss best implementation of a research project. There was great difficulty in setting up any meetings with any of those who would be concerned with this research, either by telephone or in person. It was difficult to find out who may be the people most concerned with helping to gather information and participants in the study. Despite some discussions and one strong local midwife champion, the research failed through lack of engagement with the site. It appeared that this institution had a strong hierarchical model of management beginning with the medical administrator covering a very large geographical area, with a number of hospitals with different management systems under his control. Any discussion about the research was directed either through this medical administrator or the nursing administrator. It seemed that these two people had little opportunity to talk to each other, as responses to queries took a very long time to arrive.

A greater awareness of the channels of communication and understanding existed in the second region, where the researcher had worked within the organisation and was better known to the community involved. This increased awareness contributed to an increase in health literacy in the region, with both medical and allied health staff and also with the families. The strength of influence of a trusted person providing the information cannot be discounted in the population in this region.

The way forward for infant hip assessment

Over the time of the research into early dynamic ultrasound for infant hips, we have found that there was high acceptance and interest from parents, medical and allied health staff as well as CaFHS. Many people are expressing a desire to self-refer. A number of those wishing to self-refer are parents who were involved in the universal study, now wishing to view the hips of subsequent infants to be confident of their status. Within the hospital setting, it has only been possible to offer early dynamic ultrasound to those infants identified as having a risk factor for having DDH, as explained earlier in this thesis.

The need to return to the radiology department in the regional hospital over a limited period on one afternoon, has proven difficult for some, particularly as the parking and distance to travel within the hospital is difficult when carrying a baby in a capsule.

We have used three sonographers who have been trained by the chief sonographer, who has been part of the programme since its inception. She states that the instruction is easy, and the results are consistent across all the scans performed. Each scan has been checked by the radiologist on duty and reported on advice from the sonographer and the researcher or her assistant.

How do we know the effect?

The effect of the scanning process has been judged in terms of results of the findings, any follow up scans required and numbers of infants requiring secondary prevention in the form of splinting or referral for specialist opinion. These results can be compared with results in other reported studies. Consideration of parental approval or criticism of the process must also be used in judgement of the effect of the scans. This information can be gathered from the results we have recorded. A comparison must be made between the times we were offering universal scanning and the times when only "at risk" hips were scanned. Further studies are required to evaluate this.

Are we causing harm?

Criticism has been directed at the risk of overtreatment when analysing hips in the early weeks after birth, as evidence suggests that many of the hips so identified will spontaneously improve in the early weeks. A comparison of our numbers treated, with numbers reported in the literature, particularly the reported statistics from published studies by Cundy and Williams, must be compared, to gauge a closer comparison. This too will require further study.

How will we progress scanning in our region?

Through attendance as an observer at a cardiac meeting, I was introduced to a small hand held, battery operated ultrasound machine, which was being used in a variety of settings, to show the condition of the heart. In discussion with the manufacturer, it seemed likely that this machine could be satisfactorily used to assess the status of infant hips on ADUS. The machine was trialled in our setting, with a trained sonographer who had conducted the examinations through our research projects. Although a hip picture could be screened, it was felt that the transducer was too large for the particular use we wanted. In further discussion with the manufacturer, we learnt that a smaller transducer was in the process of being developed and we expressed interest in trialling that when it became available.

The smaller transducer became available in March 2018 and we arranged to trial it. The machine is smaller than an iPad and fits neatly in one hand for ease of operation see photo in appendix. It can be connected to a computer and pictures can be stored either on the US machine or on computer. Measurements of movement can be made on images when stored on the computer and can also be made on the screen with the use of a marker placed on the horizontal line drawn across the joint at a point from the anterior cartilaginous edge of the acetabulum to the femoral shaft. A line can be dropped from this marker to the top of the head of the femur and the measurement of movement recorded. LM, the sonographer who has conducted the ADUS programme in Benson Radiology over the past six years, felt that the pictures were good and could be useful in demonstrating the hips which warranted further follow up. She felt that the machine was easy to use and could be used by a technician trained to specifically perform such hip scans, with a trained second person to stabilize the hips and assess the results.

It is therefore possible to offer hip screening to any infant whose parents wish to attend for a scan, in a more central location. Scans will be offered on two separate occasions each week, on the understanding that these are preliminary scans, to identify any hips which warrant a further dynamic scan in the radiology department, for finer identification of any difficulty. The preliminary scan will identify any hip with excess neonatal instability, allowing for education and discussion, similar to that offered in the universal scanning research programme. For those infants with greater than 4mm measured instability on the first scan in the first two weeks after birth, a return scan 4 weeks later will be recommended. At the follow up scan, if there is greater than 2 mm of movement, a referral will be made to the family doctor for a more complete scan in the radiology department as per current protocol. Any infant found to have a dislocated hip at the first scan will be referred for specialist opinion at that time.

Discussion has been held with the radiology department about training a technician or employing a part time sonographer to carry out these scanning sessions and although there has been agreement from the local branch of the radiology department, there has been rejection of this idea from senior management of the parent radiology group. The local radiology department has recognised the close working relationship which has developed over the years of conducting these studies and would be happy to see the initial universal scanning conducted elsewhere. All infants requiring further follow up would be referred to their family doctor and would discuss further action with the doctor. It seems likely that they would be referred in the usual manner, for further investigation under routine national clinical guidelines. Is this another form of patch protection? Discussions continue.

How transferable is this to other regions?

This early dynamic ultrasound technique has been shown to be easily taught to a technician, by a trained sonographer. The scans can be stored electronically and periodically checked to assure maintenance of standards. The results have been shown to be reliable and repeatable. Such preliminary scans could be offered in maternity units or child and family health services. The portability and battery powered status of these small machines suggests that they could be useful even in remote settings, thus saving families the need for lengthy and expensive travel to specialist care and will identify those children who need more tailored specialist management. Many doctors and allied health professionals already use real-time ultrasound in their assessments within their rooms and this service could be expanded to include hip examination if the equipment and expertise were sufficient to allow that.

There is a requirement for a second operator, to stabilise the infant hip while the examiner carries out the Barlow manoeuvre during the scanning process. There will necessarily be some training required about the examination. The great benefit of using ultrasound when teaching the assessment manoeuvre is the instant feedback the operator receives when carrying out the Palmen/Barlow test.

This may be a very useful method of identifying infant hips showing increased and persistent neonatal instability. Such knowledge allows for more directed parent education in the care and management of such hips and allows for early follow up and treatment where required, thus improving hip status over the lifetime of the child. It is clear that this should be an adjunct to assessment but should be carried out in a collaborative way involving the child, parent and family doctor with referral to an orthopaedic specialist when warranted.

Our community has demonstrated a desire to be able to have early infant hip checks which are measurable and recordable. Our discussion with other professionals suggests that this service could be offered to interested parents at a reasonable charge, at regular screening sessions, through the physiotherapy practice. Many physiotherapy practices are already using real time ultrasounds in the diagnosis and management of soft tissue injuries and to give feedback on muscle function in sporting injuries and other conditions. We believe that this is simply an extension of this field in the paediatric area. It requires an understanding of normal hip development and attention to the detail of the Palmen-Barlow assessment test of infant hips. Any hip with a concerning measurement of instability would be referred to the family doctor for consideration of a further traditional ultrasound examination in the radiology department.

In accurately assessing infant hips, it has become clear over the course of our studies that the amount abduction of the hip being assessed during the scan, combined with the maintenance of pelvic stability, are extremely important. Both these variables can be assessed on the video as it is performed and can be corrected on subsequent attempts at the test. Ultrasound examinations have been shown to be safe with minimal risk of radiation and therefore do not pose a health risk.

Any infants with scans considered to be doubtful or abnormal will be referred for follow up by their family doctor and will be requested to have a more detailed scan performed in a radiology unit. In offering this universal scanning there is less chance of missing the 60% of late diagnosed cases of developmental dysplasia of the hip which has been shown to occur when early ultrasounds are only being offered to those in the risk group. In providing this local universal scanning, there is the hope that late diagnosis of DDH will be eliminated in our region and that neonatal hip care and tummy time for young babies will be the infant management of choice.

This chapter has examined some of the changes in rural and regional health over time, giving particular consideration to the changing work conditions experienced over a working life in one regional centre in South Australia. Differences and similarities between the two regions in the study have been discussed. The difficulty of discontinuing the early dynamic ultrasound scanning has led to investigating a model of providing early scans, which warrants further trial and evaluation.

CONCLUSION

INCREMENTAL INTEGRATION: IS IT POSSIBLE IN REGIONAL SOUTH AUSTRALIA?

> “It takes a village to raise a child”. Igboo and Yoruba (Nigerian Proverb)

Identifying local needs and formulating proactive collaboratives improves the situation of citizens. There is a rapid move to universality where world communication and competition have become the standard.

Children deserve to be well-cared for and concern for the child’s growth and development is important for whole communities. Children are not “little adults”, being often perceived as smaller versions of their parents and relatives. While they may have the same skeletal and organ components as an adult, their bodies are in a more mouldable “constructional” phase throughout childhood. Their body growth and strength may be influenced by their activity level their eating patterns, the amount of sleep they have and their environment. The way children grow and develop will depend on how their growth and development are nurtured and managed. They will respond best to child specific management.

The developing hip in a child has been increasingly researched over many years, worldwide. Too often those of us working with infants and young children are faced with hip development problems which could be fixed if discovered early enough, but pose a lifetime problem if they pass unnoticed, until too late to alter their development except by surgery or lengthy splinting, with all the aftermath that may entail.

In an attempt to clarify some of the issues attached to the timely diagnosis of this condition in children born in regional South Australia, a research study was set up in two separate regions. Two separate regions were chosen as it was felt that an unbiased control group could more likely be enrolled in a region where infant ultrasounds were not available. There was therefore considered to be less awareness of early dynamic ultrasound which was being offered to the experimental group in the other regional centre. The unexpected lack of interest in this research in the control group region, despite the agreement with the ethics application and the site-specific agreements to participate, drove a close inspection of regional health and community differences between the two sites.

There was a distinct lack of interest in the control region except for two people who were familiar with the research topic. There was a lack of importance attached to the research, perhaps because it was being conducted by a physiotherapist in an area where the medical model of care was very prominent - not only a physiotherapist, but someone from another region. More time should have been spent in establishing the importance of having a strong control group with which to compare the results, but there may have been a feeling by the people of the region that they were being unnecessarily used and compared. Any benefit to South Australian children which may follow as a result of the research was not clearly enough explained and understood.

This research study with the experimental group has shown the appetite for early knowledge of neonatal instability of the hip in human infants. Simple methods of measuring, recording and monitoring NIH have been demonstrated (J. E. Andersson, 1995) and are shown to be reliable and easy to manage in one regional centre in South Australia (Charlton S et al., 2012). Distance from the capital city with specialist orthopaedic and paediatric services can be a problem but has been shown to be eased with the use of recent improvements in portability of ultrasound machines and ease of transference of results electronically.

The failure of this project was significant, demonstrating the fragmentation of regional health where regionality is plural and cannot be considered as one unit. In discussing fragmentation of the health system in Australia, It has been stated by Mason and Owen that, “structural and financial barriers exist at levels that local projects cannot easily influence” (Masson M & Owen A, 2009). Health regions are plural and there are a number of people working in regional health with specific skills, knowledge and experience. There should be opportunity to spread those skills and knowledge more widely with the sharing of experience gained in regional work over years.

A recent presentation to a perinatal group in the Limestone Coast, on the progress of the infant hip study and the use of ADUS as both a diagnostic and teaching tool, was stimulating. The ensuing discussion reaffirmed the necessity for a change in thinking within the health system, in order to reduce the urban/regional divide in the provision of services. The perinatal group comprised midwives, registrars, GP obstetricians, specialist obstetricians and paediatricians, some of whom had been part of the research programme since its inception and others who had recently moved into the region. Questions were asked about State statistics on incidence and occurrence of DDH and whether there were simply the same number of cases overall, but more were being diagnosed later. There was discussion about clinical practice guidelines, not only about infant hip examination and treatment but also about recommended transfer of mothers and babies to urban centres.

There was consideration of the cost involved in evacuation of people when the principle reason for the transfer was staff shortage, as a result of insufficient staff quotas to cover special needs and extra care. These discussions emphasised the need to create a serious evaluation of the increasing urban/rural divide, staff retention and satisfaction, national clinical guidelines and variable funding buckets, all of which must be balanced across the State, irrespective of the demonstrated local need and expertise. Such thinking has been described as equitable thinking which may have the effect of reducing health services to the lowest common denominator. The attraction of specialised staff to move to a rural area to fill a temporary staff position while a worker is on maternity leave, is a constant source of difficulty (Wakerman J, Curry R, & McEldow R, 2012). The inability to offer continuing positions in this situation, combined with the churning effect seen in rural and regional medical employment, make staffing difficult to manage. When there are staffing shortages, a considerable extra load is placed on remaining staff, which can in turn lead to increased stress levels and lowering of staff morale. The high turnover of staff, or churning effect, has been attributed to decreased job satisfaction and pressure of work when there are staff shortages (McGrail & Humphrys, 2015). Those contemplating relocation to a regional or rural area may require an indication of permanency to make such a move a viable proposition for their families. Absence or uncertainty about the continued provision of suitably qualified staff has already led to ward and facility closures and this will only continue as fewer permanent positions become available.

This short presentation and the resultant discussion at the perinatal meeting, resonated strongly with the knowledge gained from the research and the unusual trajectory of this project. Whilst the project may not have achieved its anticipated goals, it certainly uncovered some major variables needing further explanation if the urban/rural divide is to be meaningfully addressed. Research, by its nature, is unpredictable. If the results were guaranteed, it would not be research. However, in explaining the reasons for the “failure” of my methods and a particular mode of empirical research, the theoretical explanation became much more resonant and important in understanding the value of health literacy and why regional health is complex to study.

Many years of working with families and observing the extreme difference in outcome between early and late diagnosis of DDH led to a desire to improve the reliability of making a timely diagnosis for these families. The added awareness of the heartache and disability experienced by these children and their families is only exacerbated by distance living for those affected by DDH.

Late diagnosis of developmental dysplasia of the hip is reported to be increasing in many areas of the world (Eastwood, 2003) and is particularly reported as being greater in rural and regional Australia than in urban areas(Studer et al., 2016). The importance of early diagnosis and management has been established(J. Andersson, 2002; Elbourne, 2002). Neonatal instability of the hip can be considered a pre-cursor to the development of dysplasia (J. Andersson, 2002) . The incidence of the development of dysplasia has been shown to be adversely affected by tight wrapping and poor positioning of the young infant (Williams et al., 2012). A reduction in "tummy time" for young babies has also been noticed and these positional changes in infant management have all increased over the past decade.

There are four different entities to be considered in the assessment of infant hips:

- Neonatal instability of the hip -
  Early knowledge of excess amounts of instability has been shown by Andersson and others, to be an important, as it may be a pre-cursor to poor development of the hip (J. E. Andersson & Funnemark, 1995; I. L. Engesaeter, T. Labore, L. Lie, S. Rosendahl, K. Engesaeter, L 2011; R. Paton, 2005). Early assessment of the amount of movement can be beneficial in instituting early management and regular surveillance (Mulpurri, Song, Goldberg, & Sevaranok, 2015). This is particularly relevant in rural and regional areas where the rate of late diagnosis has been reported to be increasing.
- Developmental dysplasia -
  This condition is characterized by an improperly located femoral head within a sometimes inadequately formed acetabulum (Bracken et al., 2012; Gomes et al., 1998). If left undetected, this can lead to dislocation of the hip when weight bearing commences or earlier. Successful treatment relies on early commencement of treatment, during the active period of shaping of the socket as the hip joint progresses from early cartilaginous to bony status.
- Dislocation of the hip -
  Some infants are born with one or both hips already dislocated. In some instances, there may be little limitation of hip movement in the early days, yet the hip may be irreducible and therefore not felt to "clunk" back into the acetabulum on the performance of the Ortolani test (Lipton G, Guille J, Altiok H, Bowen J, & H, 2007; Lowry CA, 2005). Such a situation can lead to a delay in diagnosis, particularly in cases where the dislocation is bilateral. Early diagnosis may shorten the treatment time in these cases. Late diagnosis will lead to prolonged

treatment with often a poor result in the long term, leading to early joint replacement to alleviate pain and poor function (Jacobsen & Sonner-Holm, 2005).

- Poor acetabular development -
  This may develop in a hip, where the femoral head may be enlocated within a sub-optimally developed joint. Azzopardi has stated that the incidence of this condition is 1/5000, but questions remain about whether this figure may in fact be higher (Azzopardi et al., 2011). Perhaps this is a silent condition where hips may remain undiagnosed in many cases and become the hips which require total replacement at an early age despite having been apparently symptomless until the onset of early arthritis.

In our study in rural South Australia, I found the early measurement of NIH by the use of eADUS to be a reliable and acceptable method of identifying and monitoring management of those infants displaying an increased range of movement on early examination. We would strongly advocate for the availability and use of universal ultrasound scanning as a screening programme in rural Australia. We have shown that it is reliable and acceptable to parents and allows for improved understanding of neonatal hip management. It has also highlighted several incidents of dislocated and irreducible hips which may have otherwise gone unnoticed until later in the infants' lives. This early diagnosis has allowed prompt commencement of treatment, leading to earlier correction followed by good hip development.

Critics suggest that universal screening may lead to overtreatment in hips which may spontaneously improve over time (Finnbogason et al., 2008b). In our study, we initially applied primary prevention alone (as described on page 46 of this thesis), in all groups except those infants found to have dislocated hips at the first examination. No other children commenced active treatment until completion of their six-week ultrasound examination, in line with current clinical guidelines (SA Maternal & Neonatal Clinical Network, 2010; SA Maternal, 2017). It is well recognised that in scanning only those infants known to be at risk of having a hip problem, we are likely to miss the diagnosis of hip problems in a worrying number, as only 30% of infants having a hip problem have a risk factor placing them in the AR group (Bache et al., 2002).

The improvement in ultrasound scanning devices including extreme portability in battery operated devices, which can be connected to the internet, with scans transmitted for specialist opinion, have made the accessibility much easier in rural and remote areas (World

Health Organisation, 2013). The savings in travel and accommodation to seek expert opinion are of extreme value to those living outside the urban area.

Assessment

It is clear that early knowledge of the stability of a child's hips may have a lasting impact not only on the lives of the child and family, but on the subsequent cost to the health system. The amount of instability in the neonatal hip is extremely difficult to quantify on clinical assessment, even by experienced assessors, when small differences in measurement have been shown to markedly affect the outcome (J. Andersson, 2002; Finnbogason et al., 2008b). Instability is best measured and monitored using dynamic ultrasound, where the amount of movement can be accurately measured, using Andersson's established figures, then stored for comparison with later pictures (J. E. Andersson, 1995).

Developmental dysplasia of the hip is identified, measured and managed by using the Graf method of ultrasound, after six weeks of age. This provides a clear picture of the morphology of the hip joint in the months before ossification. The range of measurements identified on the Graf in the early weeks after birth is too great to be diagnostically useful, except in those hips which are dislocated at this early stage (Cundy, 2004; K O'Toole et al., 2008; Riad et al., 2005).

After the age of four to six months, x-ray is considered to be the most accurate measure of hip status in those hips which, by then, should be exhibiting an ossification centre in the head of the femur (Mulpurri, Song, Goldberg, & Severin, 2015). Thus, it can be seen that each of these means of assessing young hips has a different relevance and is important at various stages of hip development. For those infants born in rural and regional Australia the use of early dynamic ultrasound is a quick convenient method of measurably assessing hip status and expediting referral to a specialist when necessary or instituting preventative management and early treatment when indicated. Therefore, with this considered, effective and mobile strategy for diagnosis, the question is why is it not being used, recommended, promoted and valued? The answer to this question requires an expansive theoretical alignment of health literacy and regional and remote health policy.

Skilled Workforce

A lack of skill in the clinical assessment of infant hips has been blamed for the difference in statistics for diagnosis between rural and urban settings (Azzopardi et al., 2011). This is an over-arching statistic which gives little recognition to differences between regions in the state and lumps "regional" together much as the now replaced "urban/other" divide of State health services did. Our study has demonstrated that there is an array of differences between two of the regions in the State, with differences in professional experience, collaboration and knowledge sharing. Support and training are also variable, not only between regions but also over time. Difficulties of recruitment and the added difficulty of retention of clinical staff to rural areas is seen as a confounder of this situation (K O'Toole et al., 2008). Lengthy and repeated training sessions in the assessment of infant hips have been suggested as a necessity to establish and maintain the skill of clinical assessment of infant hips and experiential differences can affect the outcome (Goss, 2002). Methods of achieving this training and experiential outcome without repeated and inconvenient absences of professional staff from the regions need to be established. Our work with early dynamic ultrasound has shown that this could be a useful tool in training and providing active, timely feedback for those learning the technique of clinical assessment of the infant hip.

Documentation of assessment

The IHDI recommendation that hip surveillance should be regularly carried out over the growing years of every child includes the suggestion of routine x-rays over the first four years of life (Narayan et al., 2015). The availability and accessibility of such surveillance could impose difficulties in rural and regional Australia. An important component of such a programme of surveillance must be a reliable recording of the results of each assessment, in a document which can be accessed by all concerned. A familial tendency to non-optimal acetabular development is noted, particularly with first degree relatives who have had hip problems. In our study we have found some hips, stable on first examination, but later found to have sub-optimal acetabular development on ultrasound, despite the femoral head being located in the joint. Similar findings have been reported in other studies (Rosendahl & Toma, 2007). Many of these infants have subsequently been found to have relatives who have had hip problems leading to early total hip replacements. In many cases, this family history was not recognized at the time of delivery of the child. In a recently published article, it was found that early onset of symptomatic hip pain leading to early joint replacement in a first or second degree relative was a strong predictor of late developing acetabular dysplasia and that the recording of such family history is of great importance (Sink, Ricciardi, DelaTorre, & Price, 2014). This aligns with the findings in our study during the selective ultrasound screening programme and lends strength to the recommendation of better documentation and direct questioning about family history of hip problems for all neonates, with ongoing surveillance for those with significant family history.

Although family history has been recognized as a risk factor for having a hip problem, more attention should be paid to routinely re-examining these hips, as well as documenting and repeating the examination over the early months after birth. It is an anomaly that hip status is rigorously tested with ultrasound examinations and documentation in some pedigree dogs, but we do not afford our human infants the same care.

It has been shown in our study that early identification of those hips needing closer scrutiny is acceptable to parents and could be of benefit in the early management of infant hip care. A dedicated hip page in the infant health record which is provided to each mother on the birth of her baby, would seem a good way to achieve this. Such a page should start with distinct questions about birth and family hip history. This should include relatives with known DDH, as well as any relative with an early onset arthritis requiring early hip replacement prior to 50 years of age. A chart of examination dates should follow, so that parents and relevant health professionals can quickly see if the examination has been carried out and what the status of the hip was at that time. In this way, the responsibility for the ongoing surveillance of the infant hip becomes a collaborative programme.

An important pre-cursor to this surveillance programme is better population education about infant hips and their development. Although national guidelines recommend clinical assessment of all neonatal hips, many parents are unaware of the importance of the results and ongoing testing of hip status. If parental management of wrapping and positioning of infants is to be improved, there must be a better understanding of the reasons for this. Most parents when questioned about hip checks for their child, are not aware if any checks have taken place. The health literacy about infant hips must be expanded and our study has demonstrated that eADUS applied universally is a good introduction to this education programme. It provides a reliable start for documentation of hip status.

Changes through the Study

This research study commenced as an empirical study to demonstrate any benefit of early dynamic ultrasound for infants in one regional centre in South Australia, but the study failed monumentally, to attract participants in the control group. The lack of participants led to an examination of theoretical perspectives in an attempt to understand the failure and to plan future progress to address the problem of the rise in late-diagnosis of dysplasia of the hip in children born in rural and regional Australia. I did not wallow in the “failure” of this mode of research, instead, I probed reasons for its failure, to understand regional and rural health inequalities in a different way. The project moved from an empirical investigation to a theoretical analysis, deploying the recent transformations in health literacy internationally to understand regional and local conditions in South Australia.

Country Health and Regional Variation

Changes in the health system with Country Health SA and Primary Health Networks, may have had some impact on the research results, with staffing and management changes. The research project was started when Country Health SA had only one regional body for the whole of the State outside the urban area of Adelaide and surrounds. This prompted an "urban and other" philosophy for regional South Australia. Competition between regional centres under the jurisdiction of Country Health SA was high. It was deemed unfair to provide services in one area because the expertise was there, if the same opportunity did not exist in other areas of the State (Personal communication and meetings between the author and Jayne Downes, CEO Limestone Coast Community Health Inc., undocumented).

In comparing the two regional centres in the study, there was obvious fragmentation in regional health, with changes in staffing and management and little cross-regional collaboration. This appeared to be overlooked in the dividing of State health into two divisions, urban or country (Australian Government, 2016). It became clear that "regional" was not a singular entity but represented a plurality of services, each with diversity in expertise, geography and economics (Davies G, Perkins D, McDonnell J, & Williams A, 2009).

A change in State Government has seen a return to more regional districts in Country Health with the return to local health networks advocating for the needs of their communities (Country Health SA, 2018). Regional hospital boards have also been reinstated, comprising local community and government appointees. The development of these groups must be watched with interest, particularly to understand the influence they may have on local services. How much these structural differences contributed to the results of our study is unclear but deserves some recognition in the analysis of events.

For the participants, sleep deprivation, anxiety about feeding and changing household management in an attempt to establish a new routine, may all have contributed to inconsistent engagement with the study (Gay C et al., 2004). Research in this potentially sensitive group warrants more attention to simpler methods of data collection. This could include coordinating collection of data with other routine appointments such as visits to the family doctor or CaFHS, where interviews during waiting time may have yielded more comprehensive results. The use of internet technology systems such as online surveys could be considered and may be easier for new parents to access. In our studies, we found unpredictable connection to service a difficulty when attempting to contact participants via telephone. Although new parents appear to use phones to monitor feeding times and other infant facts and information, connection to service providers and paid up mobile telephone plans seems difficult for many.

Clinical Guidelines

Variation between regional centres in addition to the regional/urban divide, makes the expectation for adoption of universal clinical guidelines a very difficult and limiting requirement. A “one size fits all” approach to availability of services can be frustrating for professionals and participants involved in provision and usage of health services. Clinical guidelines applied nationally may not always make full use of the best available services with the potential to foster mediocrity, dumb down providers, discourage experimental interest and hamper shared decision making. This can lead to a breakdown in knowledge sharing and mutual respect, as well as increased cost, if patients must be transferred when they could be managed in their own region. This reminds us again of the words of Leutz, who purported that, “integration has to be implemented locally to suit local needs and conditions” (Leutz, 2005).

Health management and funding

Health service provision consumes a large percentage of the budget of both State and Federal governments and is always a source of much debate at election times, as ways are sought to reduce spending without seeming to reduce services. The National report for 2018 - 2019 places this at 10% of Gross Domestic Product (Australian Institute of Health and Welfare, 2018). The well-being of the population is an emotive issue and any proposed changes to the system at any level can create much comment. Changes in management and funding of health are frequently seen when there is a change in government and these frequent changes can cause discussion and unrest amongst employees and users of the system. The division of funding of services between State, Federal and sometimes Local government compounds these difficulties. Responsibilities for payment are debated and discussion ensues around which services are the responsibility of each level of government. The nature and structure of government in South Australia, where State government has a fixed four-year term while Federal government has a three to four-year term with an election being called at the direction of the Prime Minister, can cause some disruption and uncertainty to services, as new ministers and staff work towards collaboration around issues which can develop strong party-political implications. The frequency of preparing for, or recovering from, an election can only be compounded by the instability which we have observed in our major parties in recent years. How much this impacts on stability within the public health system and overflows into impacting on the private health sector, is difficult to gauge but could conceivably contribute to difficulties with collaborative progress in health service provision.

The result of this funding mix can and has led to cost-shifting and blame-laying at each level of government, as changing political powers attempt to position themselves as providing the best results and blaming others for the deficiencies in service.

Access to services

More definite training and re-skilling programmes have been proposed to ensure universal competency in carrying out the clinical assessment of children's hips, but changing workforce numbers and lack of experience make this a difficult task (Goss, 2002). An attempt has been made in rural and regional areas in Australia, to limit birthing units to larger regional centres, and in our region, we have seen many local hospitals no longer having accredited birthing units with trained staff. Despite the Child and Youth Health Organisations and Government Health services publishing papers stating that every woman should have access to a birthing unit within a reasonable distance from her home, we see in the Limestone Coast region, that there are only 2 licensed birthing units, one in Mount Gambier and the other in Naracoorte (South Australian Government, 2015). For families living in the coastal parts of the region there may be a two to three-hour drive to the nearest unit and this may be a drive through sparsely populated parts of the region and often over unsealed roads. Frequently, in such areas, there is little or no mobile telephone coverage, increasing the danger of such an expedition. Hence mothers are forced to move closer to one of these two sites, or to Adelaide, as their expected birthing date approaches, to ensure that they do not give birth along the way. This has been our personal experience with a daughter living on a farming property between Penola and Robe and needing to stay in Mount Gambier for the weeks prior to her due date. The family disruption that this causes can easily be seen. The increased rate of inductions for obstetric patients seen in the region, may be partly explained by this geographic difficulty.

When such a mother returns home with her newborn baby, the isolation from support services and trained clinical infant assessors compounds the problem of regular hip assessment. It would seem that many of our regional babies are suffering a double risk of poor timely diagnosis of hip problems, firstly because being born in a rural or reginal centre in South Australia has been shown to present an increased likelihood of a missed or late diagnosis due to lack of expertise in assessment. The failure to recognize this as a genuine risk factor which would warrant Medicare funding for early investigation compounds this risk for our regional families.

Difference in health literacy

There was a marked difference in health literacy, noticeable particularly in relation to infant hips, between the two regions in the study. Availability of services and health personnel remains an ongoing problem affecting continuity of care and growth in health knowledge. There was a sense of more integration of services in the experimental region where there was open discussion between all health professionals engaged in maternal and child health areas, with frequent scheduled discussion times, providing opportunity to share progress of the study.

Regional trust

A distinct difficulty existed in the control group region, in holding any combined meetings or open discussion about the study and its failure to progress. This difference in communication and collaboration between professionals in the two regions contributed to the apparent lack of understanding of the project. Some of this observed difference may have been attributable to the fact that I was an “outsider” in the region and as such my motives could be viewed with suspicion. This would be the reverse of any observation made in our time in PNG, when we were hungry for news and information sharing, to lighten our feelings of isolation and to keep us abreast of developments in other areas when communication was challenging.

Over the period of the research, difficulties with interprofessional recognition within the health system, became apparent. Not only was I an “outsider” but I was an “allied health” worker as well. The growth of physiotherapy as a profession has been evident over my professional life. Our undergraduate course at the University of Adelaide was a highly recognised course both nationally and internationally, such that on graduation my qualifications enabled me to work in the UK or Canada without any further examinations. At this time there were varying physiotherapy courses across Australia and most of them did not share this reciprocity. We were still, however, known as “the slap and tickle girls” by most of the senior doctors until we had earned their “respect”. The fee for a consultation with a physiotherapist was $2.10 at that time and there was no recognition of the profession under the Medical Benefits Scheme. A strong belief in continuing education coupled with a diverse variety of opportunities through the Australian Physiotherapy Association has seen a continuous pathway to further education and recognition for physiotherapy across the nation. National registration through Australian Health Professionals Registration Authority with its high standards and ongoing requirement for professional development, places the profession on an equal footing with other health service providers although in many instances we struggle to see that this is a universal feeling amongst some other professions.

I think that differences in local professional standing were obvious between the two sites in the research project and the fact that the project was physiotherapy driven may have had a detrimental impact in the Riverland. It must be considered that variations in health literacy may extend to other regions and other conditions. Accessibility to services was also identified as a problem, with the added burden of cost of travel and accommodation.

The world-recognised need for early identification of problem hips in infancy cannot be denied and should not be an increased danger in rural and regional Australia or any other regional or remote area. Training health professionals to better examine and evaluate the status of infant hips is strongly advocated in the literature. The increasing difficulty of recruitment and retention of suitably trained personnel outside the urban area is also well documented and provides an increased risk in the regions. Recruitment and retention of medical and allied health workers is recognized as an ongoing concern for rural and regional health services (Humphreys J, Hegney D, & Lipscombe J, 2002). The churning effect of this turnover of staff has a negative effect on team spirit and can discourage collaboration in the workplace. Even in the major cities, patients have to rely on their GP to help them navigate a very complex service system to locate the services they need. These services, if provided by publicly funded agencies, are frequently rationed via waiting lists or, if provided privately, can be prohibitively expensive even to the insured population. Demand for medical service is effectively inexhaustible when there is little, or no cost involved to the consumer.

Any registered doctor wishing to practice in the metropolitan area is able to apply for a provider number at their chosen address of practice and is able to make a reasonable living even if bulk-billing patients. If there were some geographic limitation on the provision of provider numbers according to need, perhaps this would assist in the more equitable distribution of the workforce. There is opposition to this method of imposed distribution as it is considered a de facto form of civil conscription in some circles.

Parents in one region have welcomed seeing their child’s hips on ultrasound and understanding more about the early development of the hip (Charlton S et al., 2012). This has led to an increased awareness of the importance of proper care of the infant hip during the early weeks after birth. Early dynamic ultrasound examination of infant hips has been shown to identify those hips in danger of sub-optimal development and to assist in their early management, with positive results. Arguments suggest that early identification may lead to overtreatment and is reliant on expert sonographers and radiology departments to provide accurate screening examinations. It has been shown in Sweden and other centres, that well-trained technicians can perform hip scans accurately (J. S. Andersson, K. , 2000; Finnbogason et al., 2008b). The increasing ability to transmit images via the internet has allowed increased access to specialist opinion for non-urban dwellers and can conceivably lower transport and accommodation costs.

Advances in ultrasound usage

The rise in the use of ultrasound to augment diagnosis in many situations, is evidenced by the increasing numbers of medical and allied health workers using real time ultrasound in their practices. Its use in the diagnosis of such conditions as appendicitis has increased markedly over the last ten years. The World Health Organization states that: "Imaging the human body for diagnosis and treatment purposes……plays an important role in initiatives to improve public health for all population groups." (World Health Organisation, 2013).

Real-time ultrasound is widely used in physiotherapy treatments to educate patients about muscle position and activity (McKiernan, Chiarelli, & Warren-Forward, 2011). It can help in rehabilitation programmes by providing real-time feedback to the physiotherapist and the patient about the amount of muscle activity in a given exercise (Kimberly H, Murray A, & Mennicke M, 2010; Lumsden, Lucas-Garner, Sutherland, & Dodenhoff, 2017). Its use in education about infant hips is to be encouraged and will require an increase in general health literacy about normal hip development.

The continuing development of increasingly portable ultrasound machines, operated by technicians and other suitably trained personnel, has been shown to be very useful in remote areas in Africa, identifying fractures and other conditions which may need to be retrieved to access specialist intervention, thereby expediting the commencement of recommended care (Kimberly H et al., 2010). The use of similar systems could be instituted throughout regional Australia, to identify those infant hips which may require further assessment and management, without the need to travel to major centres when such treatment may not always be necessary.

Using a hand-held portable ultrasound device, it has been possible to offer universal screening to infants of all parents who would like to see and understand the development of their child's hips. Identifying those hips in danger of poor development in the early weeks has enabled advice about optimal management and posturing for good hip development. It has allowed the identification of hips which need specialist opinion and management at an earlier age and thereby shortened the treatment time for these children. Recognising that two thirds of children who are diagnosed with hip dysplasia after three months of age do not have a recognised risk factor for developing dysplasia, it seems that universal rather than "at-risk" screening should be adopted. This not only improves chances for the child, but also lowers the risk of litigation for failure to diagnose the condition. The portable ultrasound machine has the ability to connect to computers and to thereby transmit pictures to specialists anywhere in the world, for advice and ongoing management. It also provides accurate real-time videos, demonstrating the correctness of the technique and could be useful in teaching and evaluating the clinical assessment of infant hips.

If our health system is to move forward in a more equitable fashion, we must make use of developing mobile technology, recognise and celebrate the expertise which exists throughout the health system and endeavour to encourage and disseminate such expertise, rather than "dumbing down" the services to the lowest common denominator. In this way, we have the best opportunity to maximise the health literacy across Australia, both in urban, rural and regional centres. One limitation of using the latest technology to assist this spread, is the difficulty of good reliable internet connections in many parts of rural and remote Australia and there is a need to advocate for better reliability in this necessary access for all.

A study conducted worldwide by the International Hip Dysplasia Institute (IHDI), evaluated world methods and clinical guidelines for the assessment of infant hips. Following this study, a statement with recommendations and benefits of different methods of assessment has been released (Mulpurri, Song, Goldberg, & Severin, 2015). The overall directive is that "Practitioners should follow moderate recommendations but remain alert to new information and be sensitive to patient preferences." This indicates an awareness of the variety of assessments being advocated in these populations worldwide and an inability to clearly identify the most appropriate method at any given time, in locations around the world. It recognises the willingness of the IHDI organization to discuss innovative and geographically sensitive concepts. The recognition that birth in a rural or regional centre in South Australia is an added risk for late diagnosis supports the use of early dynamic ultrasound screening in such areas.

Professor Nicholas Clarke from Southampton UK in his study of screening practices, suggests that universal screening, although not economically proven as yet, is becoming more necessary in safe-guarding practitioners from litigation (N. M. Clarke et al., 2012). It is apparent that Australia's health system, despite its many strengths, is often poorly integrated and coordinated, bedevilled with problems arising from multiple sources of funding and, in the case of people living in rural and remote areas, quite inequitable in terms of access to services (Dwyer Judith & Eager K, 2008). For those of us who have lived and worked in rural and regional areas, we believe that there is much to be gained from the collaborative, community approach to health issues which one more frequently finds away from the urban pressure. Communities must pull together in managing their health problems and working to overcome what they see as their local challenges. Working together to improve the diagnosis and management of infant hips in rural Australia will mean a better start for many children, with a possible lowering of the health budget in hip management as the population ages.

The question is not “can we?” but “how can we?” In the words of the eminent philanthropist Mechai Viravaidya AO who spoke recently at the Australian Institute of Company Directors Dinner in South Australia, “I have never taken “no” as an answer, it is always a question to me.” We have a far better hope of finding answers if we adopt his philosophy.

Through the failure of this study, we have learned much about the fragmentation of regional health and have clearly demonstrated that health cannot be divided into “urban” and “other”. Regionality is plural and must be considered this way and we must create health interventions recognizing the diversity of regional Australia. Clinical guidelines must be tailored with shared decision making and collaborative approaches to best utilize the skills within regions. Advances in ultrasound will allow ultrasound examinations to be made away from major centres and the resulting pictures can be transmitted via the internet where that service can be accessed. We must advocate for better internet services in regional Australia and eventually into remote areas as well. Where current systems are shown to be less than reliable, we must embrace and carefully trial developments in other places, to test their use, reliability and efficacy in our region. This is important in the early diagnosis of neonatal instability of the hip, particularly where we have demonstrated that better knowledge of this instability does not preclude the following of national guidelines but can be an adjunct to earlier identification and better management of these hips.

Attempts are being made to offer universal screening to all infants whose parents wish to have an early dynamic scan in the first weeks after the birth, much as has been done with the universal hearing test which are now a part of all neonatal testings. While there is encouragement for this universal screening programme from the local radiology department, the central radiology office is not happy for this to be a cooperative venture. Discussion is continuing about how this can be achieved.

This system could be transferable elsewhere with suitable training and attention to the safeguards of strict guidelines about any infants needing to be referred for further studies. This could be of great benefit to families in rural and regional centres which are often a great distance from specialist services. Early screening may also prevent unnecessary travel to tertiary centres for some.

In making this proposal we are influenced by the work of Tham in her evaluation of primary health care. She has identified limitations to health services as a cause of inadequate service, with delayed timing of access, impacting on good outcomes. Tham suggests that new services should consider performance, characteristics and sustainability. We believe that these have all been considered in this proposal and can be measured using the system outlined in her study (Tham, 2010).

The recent recommendations for a national approach to policy, planning, design and delivery of services proposes a more reliable, sustainable rural and regional health service. While this may seem idealistically true, care must be taken that this does not reduce health services to the lowest common denominator and prevent the development of innovative methods where the expertise exists. Similar fears can be held for the trend to multi-disciplinary provision of services, where the danger of increased workload with lowered specific expertise may have a dampening effect on implementation of profession-specific developments, in some circumstances.

What have we learnt from eADUS?

There has been broad acceptance from families, health workers and local sonographers to the early scanning. An increase in later diagnosed cases has been noticed when only scanning the “at risk” group, despite the fact that we have increased the awareness of family history as risk and have had better reporting of family members who have had early arthritis and hip replacements. This in turn has increased health literacy about hip dysplasia in our region.

We have kept records of all scans, noting the measurement of movement, birth history, family history, birthweight and any repeat scans for each child and transmitted results of the scans to the referring doctor. Each scan is carried out on referral from a doctor who is notified of the results, with any recommendations for a repeat scan at a later date. Repeat scans require a further referral from the doctor. There has been some inconvenience with this process, as the referring doctor in the first instance, is most often the doctor present at the birth who carries out the neonatal examination. On discharge from hospital the mother and baby return to their chosen family doctor who may not be aware of the initial examination but will receive a copy of the report if there is notification of this at the time of the scan. All parents are provided with a note to place in their baby book to give to the family doctor when they attend for the first time after the birth, but reports indicate that this is not consistently happening. This finding reinforces the idea of a dedicated page in the infant health record which can be accessed by family and health workers.

Those infants found to have excess NIH are required to return for a further scan four to six weeks later and will require a new referral for this scan. At the time of the second scan a Graf ultrasound is carried out, in addition to the repeat ADUS. Using Andersson's guidelines, there should be less than 2mm of movement in the hip at six weeks and any hip showing in excess of this movement is considered to need splinting. We are guided by the results of the Graf in this decision, as frequently the Graf will show a well-covered femoral head in an immaturely formed acetabulum. The decision to splint is made on the measurement at this ultrasound scan. A Graf type IIb is considered suitable to observe for a further six weeks with a review scan at that time. The parents are reminded about optimal hip care and encouraged to place the infant in prone more frequently during play times. We have found that these babies are often somewhat asymmetrical, with one hip scoring well and the other having a low score. There is often a consistent preference for the head to be constantly turned to one side and the contralateral hip is usually the hip with the inadequate measurement. Encouraging more symmetrical posturing can make a significant difference to these hips even over a six-week period, so a further scan is performed at that time and if there is not a satisfactory result at this time the decision to splint is made.

Those infants displaying a IIc Graf result are splinted immediately after the second scan, using a DB hip splint which is kept in place for eight weeks. The decision to splint is frequently made with referral to a paediatric orthopaedic surgeon who will view the scans and confer with the Mount Gambier team as to future management.

All breech babies have a scan at six weeks of age irrespective of their eADUS result, unless the family doctor thinks there is no reason to do this. This is a rare occurrence as most doctors are very aware of the dangers of missing a diagnosis of poor hip development but a referral from the doctor is required to enable a Medicare benefit to be paid. This could be seen as an added cost burden to the health system, as it then requires an appointment with the busy doctor at a cost, to get this referral for what is a guideline recommendation.

As confirmed earlier in this thesis, we have had several cases of later diagnosis in infants who have not qualified for the early scan when only the "at risk" group were being scanned. We have also noticed a small but disturbing number of babies who have had an early scan which did not indicate excess instability in the neonatal period, who have been referred for a further scan at 8 weeks, because there is still concern about the hips. These subsequent scans have shown enlocated hips with immature acetabular development as described above. A common finding with this group of infants is that many of them fall into the family history group with a first or second degree relative with hip problems. This has prompted us to suggest that all FH babies should also be routinely rescanned at six to eight weeks. The numbers of these immature hips that we are seeing causes me to think that perhaps we do not know enough about acetabular development over these early months, and to consider what the numbers might look like if we scanned all children. Perhaps this immaturity persists in some people and is the cause of some of the later hip problems we see in childhood. What result would we see if all infants were routinely scanned and what amount of "immature" acetabular hip development will cause a problem?

The children we have seen with immature hip development have had a later x-ray at six to eight months and most of the hips have been reported as normal. Where does the normal lie in these early acetabular immaturity scans? The clear message is, that knowledge of family history must be firmly documented and closely followed up, in a timely enough fashion to institute proper care to promote better hip development.

A complete birth and family history followed by universal anterior dynamic scanning is advocated in our region to create a more complete picture of hip development. I believe this may go a long way to preventing some of the great cost of later health procedures for arthritis and joint replacement.

Plans to offer universal early dynamic infant hip scans to those parents who wished to know more about their infant's hips, have met another regional/urban divide. The joint local decision for one of the trained sonographers to train a technician or be part of the scanning team in her non-working days, which had been agreed to in principle by the local radiology department, was refused by the head office in Adelaide, as it was seen as a conflict of interest. We have been offering the scans at a set time for one hour, on one occasion per week, at the radiology department in the hospital. The physiotherapist has been attending on a voluntary basis with no remuneration and the scans have only been available to the "at risk" group who are then charged a Medicare fee for the service. It has not been possible to offer the scans universally.

With the purchase of the portable, battery powered machine, it was planned to offer universal scanning to any parent who wished to bring their baby to the physiotherapy rooms for an initial scan in the first two weeks after birth. Scans would be offered on the choice of two days per week, one in late morning and one in mid-afternoon, to offer more choice to parents, at a more central spot. These early scans would identify those hips which needed further follow up and these infants would be directed to the radiology department for more detailed scanning and any further follow up investigations as needed. All results would be transmitted to the family doctor. Who would be directly involved in the follow-up care.

The local radiology team could see that this would have the advantage of offering universal scanning. It would also clear their waiting room of what has become a busy hour with families and baby carriages, as parents awaited their turn for the scan. For the families, this would mean less reason to take their children into a potentially unhealthy environment with sick people awaiting a variety of imaging procedures.

A central Adelaide management meeting of the radiology group denied the opportunity for their part time sonographers to be part of this programme as they saw this as a conflict of interest and not to advantage in their business. Discussion is continuing as to whether the proposal has been fully understood, following the years of collaborative research we have conducted looking at early dynamic ultrasound.

This research and the ensuing discussion have demonstrated that there is a way to improve hip health awareness for all infants, by the careful identification of hip instability variations in early infancy. Such knowledge gives better understanding of hip development for the parents and promotes sound management of wrapping and positioning, with the added benefit of including the parents as part of the team involved in optimal hip development. Early dynamic ultrasound may be more universally available than previously thought and may have an added role in the education of clinicians in the assessment of infant hips.

The status quo is definitely not an option in regional health. Following further deputation and explanation of our intent, a subsequent meeting of directors of Benson Radiology has agreed to allow further collaboration in proceeding with the community universal screening opportunity. Plans are being made to commence the provision of universal scanning of infant hips, to all parents who wish to see their baby's hips on ultrasound. The results of these scans will be recorded in the infant hip record and notified to the family doctor with any recommendations for consideration of further follow-up.

My contribution to knowledge resulted from a challenging research project. When ascertaining the reasons for those challenges in the chosen regions of South Australia, variations were found in health literacy, social equity, access to services and population expectations. These differences have been further explored to determine how they may have affected our research, leading to some recommendations for methods of progressing health literacy about infant hips and their early development. It is apparent that persistent neonatal hip instability must be identified and managed for optimal hip development. This early identification is driven by increased awareness of prevention of late diagnosis of hip dysplasia, with all the lifetime repercussions that this may have. Recommendations are made for continuing surveillance of infant hips, with records of regular assessment documented in an accessible record for each child.

There must be recognition of expertise within regions which can be used to good advantage, particularly in the light of advancing progress in telehealth systems, encouraging specialist consultation without the need for lengthy travel and accommodation costs, to gain expert opinion. Clinical guidelines must be tailored to the specific availability within regions, with the opportunity for preferred choices from providers and participants.

A wise old friend once said to me, “It is alright to glance back over your shoulder, but do not stare.” This is sound advice when examining the changing regional health system over the past 40 years. We must avoid making the same mistakes by undervaluing local expertise, failing to collaborate at all levels, both regionally and with metropolitan advances and not recognising worldwide advances when they are well tested and seen to be working well elsewhere. Children are the future of the nation and those people living in rural and regional Australia deserve coordinated, collaborative, quality health care leading to good hip health over the lifetime.

REFERENCES

Afaq, A. A., Stokes, S., Fareed, H., Zadeh, H. G., & Watson, M. (2011). Ultrasound in the selective screening of developmental dysplasia of the hip. *European Review for Medical & Pharmacological Sciences, 15*(4), 394-398.

Ajzen, I. (2011). Theory of planned behaviour *Theory of Social Psychology* (Vol. 1, pp. 438).

Allinson, L., Doyle, L., Denehy, L., & Spittle, A. (2017). Survey of neurodevelopmental allied health teams in Australia and New Zealandnurseries: staff profiles and standardised neurobehavioural/neurological assessments. *J Paediatr Child Health, 53*(6), 578 - 584. doi:10.1111/jpc.13484

American Academy of Pediatrics. (2005). The changing concept of sudden infant death syndrome:diagnostic coding shifts, controversies regarding the sleeping environment and new variables to consider in reducing risk. *Pediatrics, 116*(5).

Andersson, J. (2002). Neonatal Hip Instability: results and experience from ten years of screening with the anterior dynamic ultrasound method. *Acta Paediatrica, 91*(8), 926-929.

Andersson, J. E. (1995). Neonatal hip instability: normal values for physiological movement of the femoral head determined by an anterior-dynamic ultrasound method. *J Pediatr Orthop, 15*(6), 736-740.

Andersson, J. E., & Funnemark, P. O. (1995). Neonatal hip instability: screening with anterior-dynamic ultrasound method. *J Pediatr Orthop, 15*(3), 322-324.

Andersson, J. E., Vogel, I., & Uldbjerg, N. (2002). Serum 17 beta-estradiol in newborn and neonatal hip instability. *J Pediatr Orthop, 22*(1), 88-91.

Andersson, J. S., K. (2000, 3/08/2013). [Neonatal hip instability - Economic evaluation of screening with anterior dynamic ultrasound].

Atrey, A., Gupte, C., M., & Corbett, S., A. (2010). Review of successful litigation against English Health Trusts in the treatment of adults with orthopaedic pathology: clinical governance lessons learned. *Journal of Bone and Joint Surgery, 9*(18), e36. doi:10.2106/JBJS.J.00277

Australian commission on Safety and quality in Health Care. (2017). Australian Commission of Safety nd Quality in Health Care Standards. online: https://www.safetyandquality.gov.au.

Australian Government. (2016). *Primary Health Networks*. online: www.health.gov.au.

Australian Institute of Health and Welfare. (2016). *Australia's Health 2016*. Retrieved from www.aihw.gov.au

Australian Institute of Health and Welfare. (2018). *Reports and Data*. online: www.aihw.gov.au/reports.

Azzopardi, T., Van Essen, P., Cundy, P. J., Tucker, G., & Chan, A. (2011). Late diagnosis of developmental dysplasia of the hip: an analysis of risk factors. *J Pediatr Orthop B, 20*(1), 1-7. doi:10.1097/BPB.0b013e3283415927

Bache, C. E., Clegg, J., & Herron, M. (2002). Risk factors for developmental dysplasia of the hip: ultrasonographic findings in the neonatal period. *Journal of Pediatric Orthopaedics, Part B, 11*(3), 212-218.

Barlow, T. (1966). Early diagnosis and treatment of congenital dislocation of the hip. *Journal of Bone and Joint Surgery, 44 - B*, 292 -303.

Barnes, M., Pratt, J., Finlay, K., Courtney, M., Pitt, R., & Knight, C. (2008). Laerning about baby: What new mothers would like to know. *Journal of Perinatal Education, 17*(3), 33 - 41. doi:10.1624/105812408x329584

Barton, D., & Hamilton, M. (2000). *Situated Literacies*. New York: routledge.

Baumann M, & Berlio A. (2017). Facilitating and inhibiting factors in transition to parenthood - ways in which health professionals can support parents. *Scandinavian Journla of Caring Sciences*.

Beatty D (2000, 3/10/2000). [Letter of reply to MGH].

Bloch A. (1966). The Kurdistani Crafle Story: a modern analysis of this centuries-old infant swaddling patterns. *Clinical Pediatrics, 5*(641). doi:doi:10.1177/000992286600501012

Bloomfield, L. R., C. Townsend, J. Wolke, D. Quist- Therson, E. (2003). The quality of routine examinations of the newborn performed by the midwives and SHOs: an evaluation using video recordings. *J.Med Screen., 10*(4), 176-180.

Bodie, G., & Dutta, M. (2008). Understanding health literacy for strategic health marketing: eHealth literacy, health disparities and the digital divide. *Health Marketing Quarterly, 25*(1 - 2), 175 - 203. doi:Https:// doi-org.ezproxy.flinders.edu.au/10.1080/0735680802126301

Brabazon, T. (2011). Take the Red Pill: A new Matrix of Literacy. *Journal of media literacy education, 2*(3), 209 - 229.

Bracken, J., & Ditchfield, M. (2012). Ultrasonography in developmental dysplasia of the hip: what have we learned? *Pediatric Radiology, 42*(12), 1418-1431. doi:http://dx.doi.org/10.1007/s00247-012-2429-8

Bracken, J., Tran, T., & Ditchfield, M. (2012). Developmental dysplasia of the hip: controversies and current concepts. *Journal of Paediatrics & Child Health, 48*(11), 963-972; quiz 972-963. doi:http://dx.doi.org/10.1111/j.1440-1754.2012.02601.x

Braithwaite, J., Churruca, K., & Ellis, L. e. a. (2017). *Complexity Science in Healthcare - Aspirations, Approach, Application and Accomplishments: A White Paper. Austraian Institute of Health Innovation, Macquarie University , Sydney, Australia.* Retrieved from National Library of australia:

Breuning M, & Maddern G. (1998). Provision of general surgical services in rural South Australia: A new model for rural surgery. *australian and New Zealand Journal of Surgery, 68*, 764 - 768.

Browne D. (1960). Congenital deformities. *British Medical Journal, Nov 12*(2(5210)), 1450 - 1451.

Buuljens, M., Robinson, P., Murphy, G., Milgrom, J., & University of Melbourne. (2017). The range and accessability of maternity models of care and allied health service delivery across public hospitals within Victoria, Australia. *GSTF International Journal of Nursing and Health Care, 1*(1).

Carson, d., Punshon, K., Schoo, A., & Ryan, V. (2017). *Geographic health workforce distribution from 1986 - have policies made a favourable difference?* Paper presented at the National rural Health Alliance, Cairns Australia. Oral presentation - paper retrieved from

Carter C, & Wilkinson J. (1964). Genetic and environmental factors in the etiology of congenital dislocation of the hip. *Journal of Clinica Orthopaedics and related research, 33*, 119 - 127.

Chan, A., Foster, B. K., & Cundy, P. J. (2001). Problems in the diagnosis of neonatal hip instability. *Acta Paediatr, 90*(8), 836-839.

Chan, A., McCaul, K. A., Cundy, P. J., Haan, E. A., & Byron-Scott, R. (1997). Perinatal risk factors for developmental dysplasia of the hip. *Arch Dis Child Fetal Neonatal Ed, 76*(2), F94-100.

Chan, A. C., PJ. Foster, BK. Keane, RJ. Bryon-Scott, R. (1999). Late diagnosis of congenital dislocation of the hip and presence of a screening programme: South Australian population based study. *Lancet, 354*(9189), 1514-1517.

Charlton P (Aug 1999, aug 1999). [Open Letter to Hospital Board].

Charlton PJ. (1966). Seasonal variations in incidence of some congenital malformatons in two Australian samples. *Medical Journal of Australia, 2*(18), 833-835.

Charlton S, Muir L, Skinner TC, & Walters L. (2012). Pilot Evaluation of anterior dynamic screening for developmental dysplasia of the hip in an Australian Regional Hospital. *Rural and Remote Health Journal (online), 12*(4).

Charlton S, Schoo A, & L., W. (2017). Early dynamic ultrasound for neonatal hip instability: implicatins for rural Australia. *BMC paediatrics (online)*.

Charlton, S., Muir, L., Skinner, T. C., & Walters, L. (2012). Pilot evaluation of anterior dynamic ultrasound screening for developmental dysplasia of the hip in an Australian regional hospital. *Rural & Remote Health, 12*, 2091.

Chin D. (2011). Critical Health Literacy; a review and critical analysis. *Social Science and Medicine, 73*(1), 60 -67. doi:https://doi-org/10.1016/s.socscimed.2011.04.004

Choudry, Q., & Paton, R. W. (2018). Litigation in orthopaedics in children. *Bone and Joint Journal, 2*(3). doi:https://doi.org/10.1302/0301-620x.100B6.BJJ-2017-1389.RI

Church J, S. D. (2002). Citizen participation in health decision-making: past experience and future proposals. *Journal of Public Health Policy, 23*(12), 12 - 32. doi:https://doi-org.ezproxy.flinders.edu.au/10.2307/33143116

Clarke, N. (2014). Swaddling and hip dysplasia: an orthopaedic perspective. *Archives of Diseases of Childhood, 5*(6).

Clarke, N. M. (1986). Sonographic clarification of the problems of neonatal hip instability. *J Pediatr Orthop, 6*(5), 527-532.

Clarke, N. M., Clegg, J., & Al-Chalabi, A. N. (1989). Ultrasound screening of hips at risk for CDH. Failure to reduce the incidence of late cases. *Journal of Bone & Joint Surgery - British Volume, 71*(1), 9-12.

Clarke, N. M., Reading, I. C., Corbin, C., Taylor, C. C., & Bochmann, T. (2012). Twenty years experience of selective secondary ultrasound screening for congenital dislocation of the hip. *Archives of Disease in Childhood, 97*(5), 423-429. doi:http://dx.doi.org/10.1136/archdischild-2011-301085

Connor, M. N., P. (1994). Comparing the helth belief model and the theory of planned behaviour in health screening. doi:doi.apa.org

Country Health SA. (2018). Local Health Networks. Retrieved from www.countryhealthsa.sa.gov.au/

Cummings, K. B., MH. Maile, M. (1980). Bringing the models together: an empirical approach to combining variables used to explain health action. *Joutnal of Behavioural Medicine, 3*(2), 198.

Cundy, P. R., J. (2004). *Longitudinal study of neonatal hip ultrasound*. Retrieved from Adelaide:

Dahlstrom, H., Oberg, L., & Friberg, S. (1986). Sonography in congenital dislocation of the hip. *Acta Orthop Scand, 57*(5), 402-406.

Dartmoor and district Bush Nursing inc. (2016). Retrieved from https://dartmoorbnc.glenelgnow.net/au

Davies G, Perkins D, McDonnell J, & Williams A. (2009). Integrating Primary Healthcare in Australia. *International Journal of Integrated Care, 9*.

De Pellegrin, M., & Tessari, L. (1996). Early ultrasound diagnosis of developmental dysplasia of the hip. *Bulletin of the Hospital for Joint Diseases, 54*(4), 222-225.

Delbard, A., Bernard, j., & Blair, D. (Eds.). (1981). Sydney.

Dezateux, C., Rosendahl K (2007). Developmental dysplasia of the hip. *Lancet, 5*(36), 1541-1552.

Dogruel, H., Atalar, H., Yavuz, O. Y., & Sayli, U. (2008). Clinical examination versus ultrasonography in detecting developmental dysplasia of the hip. *International Orthopaedics, 32*(3), 415-419.

Dunn, P. (2005). Sir Denis Browne. 1892 - 1967 and congenital deformaties of mechanical orogin. *Archives of Diseases of Childhood Fetal and neonatal edition, 90*(1).

Dwyer, J. (2002). The next Australian Healthcare Agreement: what clinicians want. *Australian Health Review, 25*(6), 17 - 23.

Dwyer Judith, & Eager K. (2008). Options for the reform of Commonwealth and State Government responsibility for the Australian Health Systemeform Commission. Retrieved from http://ro.uow.edu.au/ahsri/580

Eastwood, D. M. (2003). Neonatal hip screening. *Lancet, 361*(9357), 595-597.

Edwards, J. (1961). Seasonal incidence of congenital disease in Birmingham. *Annals of Human Genetics, 25*, 89 - 93.

Eggerton L. (2011). Health litercy: more than just the three R's. *Canadian Nurse*.

Elbourne, D. D., C. Arthur, R. Clarke, NMP. Gray, A. King, A. Gardner, F. Russell, G. . (2002). Ultrasonography in the diagnosis and management of developmental hip dysplasia (UK Hip trial). *Lancet, Dec 21-28 360*, 2007 - 2017.

Engesaeter, I., Lehan, T., Labori, L., Lie, S., Rosendahl, K., & Engesaeter, L. (2011). Total hip replacement in young adults with hip dysplasia. *Acta Orthop, 82*(2), 149 - 154.

Engesaeter, I. L., T. Labore, L. Lie, S. Rosendahl, K. Engesaeter, L (2011). Age at diagnosis, previous treatment, quality of life and validation of diagnosis reported to the Norwegian Arthroplasty Register between 1987-2009. *Acta Orthop, 82*(2), 149 - 154.

Engesaeter, L. B., Wilson, D. J., Nag, D., & Benson, M. K. (1990). Ultrasound and congenital dislocation of the hip. The importance of dynamic assessment. *Journal of Bone & Joint Surgery - British Volume, 72*(2), 197-201.

Farmer, J., & Kilpatrick, S. (2009). Health workers as social entrepreneurs. *Social Science and Medicine, 69*(11), 1651 - 1658. doi:doi.org/10.1061/j.socscimed.2009.09.003

Farmer, J., Munoz, S.-A., & Clare Daly. (2012). Being rural in rural health research. *Health and Place, 18*(5), 1206 - 1208. doi:https://www.science.com/science/article/pii/S135.38292120098

Farmer Jane, Kenny Amanda, McKinstry Carol, & Heysmans R D. (2015). A scoping review of the association between rural medical education and rural practice location. *Human Resources for Health, 13*(1).

Finlay, H., . Maudsley, RH. Busfield, PI. (1967). Dislocatable hip and dislocated hip in the newborn infant. *British Medical Journal, 4*, 377 - 381.

Finnbogasan. (2008a). *Dynamic Ultrasonography in Neonatal Hip Instability and Acetabular dysplasia.* Karolinska Instituet, Sweden.

Finnbogason, T., Jorulf, H., Soderman, E., & Rehnberg, L. (2008b). Neonatal hip instability: a prospective comparison of clinical examination and anterior dynamic ultrasound. *Acta Radiologica, 49*(2), 212-219. doi:http://dx.doi.org/10.1080/02841850701775014

Flyvbjerg, B. (2008). *Phronetic organisational research* (R. T. a. R. Holt Ed.). Los Angeles: Sage Publications.

Gardiner M, Sexton R, Durbridge M, & Garrard K. (2005). The role of psychological well-being in retaining rural general practitioners. *Australian Journal of Rural and Remote Health, 13*`(3).

Gardner, F. D., C. Elbourne, D. Gray, A. King, A. Qun,, & A. (2005). The Hip Trial: psychological consequences for mothers using ultrasound to manage infants with developmental dysplasia of the hip. *Archives of Diseases of Childhood Fetal and neonatal Edition, 90*(4), 17 - 24.

Gay C, Lee K, & Lee S-Y. (2004). Sleep patterns and fatigue in nem mothers and fathers. *Biological Research for Nursing, 5*(4).

Gibson CS, v. E. P., Scott H, Baghurst P, Chan A, Scheil W. (2007). *Annual Report of the South Australian Birth Defects Register, incorporating the 2007 Annual Report of Perinatal Diagnosis in South Australia.* Retrieved from Adelaide:

Gomes, H., Ouedraogo, T., Avisse, C., Lallemand, A., & Bakhache, P. (1998). Neonatal hip: from anatomy to cost-effective sonography. *European Radiology, 8*(6), 1030-1039.

Goss, P. (2002). Successful screening for neonatal hip instability in Australia. *Journal of Paediatric and Child Health, 38*(5), 469 - 474. doi:http://doi-org.ezproxy.flinders.edu.au/10.1046/j.1440-1754.2002.00020.x

Graf, R. (1983a). New possibilities for the diagnosis of congenital dislocation of the hip by ultrasonography. *Journal of paediatric orthopaedics, 3*, 354 -359.

Graf, R. (1983b). New possibilities for the diagnosis of congenital hip dislocation by ultrasonography. *Journal of paediatric orthopaedics, 3*, 354 - 359.

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: a multidisciplinary review. *BMJ: British Medical Journal, 327*(7425), 1219.

Hall J. (1999). Incremental Changes in the Ausralian Health Care System. *Health Affairs, 18*(3).

Hanna, L., Gill, S., & Newstead, L. (2016). Patient perspectives on personally controlled e-health record use in regional Australia. *Health information and management journal*. doi:https://doi.ad/10.1177/833583316661063

Harcke, H. T. (2005). Imaging methods used for children with hip dysplasia. *Clinical Orthopaedics & Related Research*(434), 71-77.

Harcke, H. T., Clarke, N. M., Lee, M. S., Borns, P. F., & MacEwen, G. D. (1984). Examination of the infant hip with real-time ultrasonography. *Journal of Ultrasound in Medicine, 3*(3), 131-137.

Hill, P. (2011). Understanding global healthcare governance as a complex adaptive system. *Global Public Health, 6*(6), 593 - 605.

Hoaglund F, Kalamachi A, & Poon R, e. a. (1986). Congenital dislocation and dyslpasia in southern Chinese. *International Orthopaedics, 4*(4).

Hoey F. (1996, 17/03/1996). Obstetric talks continue, Front page. *The Border Watch,* p. 1 and 4.

Holen, K. J., Tegnander, A., Bredland, T., Johansen, O. J., Saether, O. D., Eik-Nes, S. H., & Terjesen, T. (2002). Universal or selective screening of the neonatal hip using ultrasound? A prospective, randomised trial of 15,529 newborn infants. *Journal of Bone & Joint Surgery - British Volume, 84*(6), 886-890.

Holen, K. J., Terjesen, T., Tegnander, A., Bredland, T., Saether, O. D., & Eik-Nes, S. H. (1994). Ultrasound screening for hip dysplasia in newborns. *J Pediatr Orthop, 14*(5), 667-673.

Humphreys J, Hegney D, & Lipscombe J. (2002). Whither rural health? revisiting a decade of progress in rural health. *Auustralian Journal of Rural Health, 10*(1). doi:https://doi-org.ezproxy.flinders.edu.au/10.1111/j1440_1584.2002.tb0002

Jacobsen, S., & Sonner-Holm, S. (2005). Hip dysplasia and osteoarthritis: a survey of 4151 subjects from the osteoarthritis substudy of the Copenhagen City heart study. *Acta Orthop, 76*(2), 149 - 158.

Jay Biem H, Hadjistavropoulos H, Morgan D, Biem H, & Pong R. (2003). Breaks in contiuity of care and the rural senior transfer for medical care under regionalisation. *International Journal of Intergrated Care, 3*(3). doi:https://doi-org/10.5334/ijic.85

Kaijser, M., Larsson, J., Rosenberg, L., & Josephson, T. (2009). Anterior dynamic ultrasound of the infant hip: evaluation of investigator dependence. *Acta Radiologica, 50*(6), 690-695. doi:http://dx.doi.org/10.1080/02841850902933115

Keller, M. S., Weltin, G. G., Rattner, Z., Taylor, K. J., & Rosenfield, N. S. (1988). Normal instability of the hip in the neonate: US standards. *Radiology, 169*(3), 733-736.

Khoo, K., Bolt, P., Babl, F., Jury, S., & Goldman, R. (2008). Health information seeking by parents in the internet age. *Journal of Paediatrics and Childhealth, 44*(7 - 8), 419 - 423. doi:10.1111/j.1440-1754.2008.0132.x

Kimberly H, Murray A, & Mennicke M, e. a. (2010). Focussed maternal ultrasound by midwives in rural Zambia. *Ultrasound in Medicine and Biology, 36*(8), 126 - 127.

Kingston, G., Williams, G., Judd, J., & Gray, M. (2015). Hand therapy services for rural and remote residents: results of a survey of Australian occupational therapists and physiotherapists. *Australian Journal of Rural Health, 23*(2), 112-121. doi:10.1111/ajr.1214

Kredo T, B. s., Mahinpadze s, Young T, Louw Q, Ochodo E, Grimmer K. (2016). Guide to clinical practice guidelines: the current state of play. *International Journal for Quality in Health Care, 28*(1), 122-128.

Krikler, J. (1992). Comparison of results of two approaches to hip screening in infants. *Bone and Joint Journal (online), 74B*(5).

Lash, S., & Urry, J. (1994). *Economies of Signs and Space*: Sage Publishers.

Lee C, Mata-Fink A, Millis M, & Kim Y. (2013). Demographic differences in adolescent diagnosed and adult diagnosed acetabular dysplasia compared with infantile developmental dysplasia of the hip. *Journal of paediatric orthopaedics, 33*(2), 107 - 111. doi:doi-org.10.1097/BPO.0b013e3182745456

Lee, M. C., & Eberson, C. P. (2006). Growth and development of the child's hip. *Orthop Clin North Am, 37*(2), 119-132, v. doi:10.1016/j.ocl.2005.12.001

Leeder, S. (2003). *Achieving equity in the Australian Healthcare system*. Paper presented at the Australian healthcare summit.

Leutz, W. (2005). Reflections on integrating medical and social care: five laws revisited. *Journal of integrated Care, 13*(5), 3 - 12. doi:https://doi.org/10.1108/14769018200500034

Liamputton, P., Lim, V., & Bagley, P. (2003). *Living in a different place at a different time. Health policy and Australian ethnic communities*. Melbourne University Press: Melbourne University Press.

Lipton G, Guille J, Altiok H, Bowen J, & H, H. (2007). A reappraisal of the Ortalani examination in children with developmental dysplasia of the hip. *Journal of Paeiatric Orthopaedics, 27*(1), 27 - 31. doi:doi: 10.1097/BPO-0b013e31802b70e5

Lisle R, B. M., Stannage K, Whitewood C. (2012). Delayed diagnosis of Developmental Dysplasia of the Hip: the Western Australian Experience. *ANZ J Surg, 82*(9), 612 - 615.

Lowry CA, D. V., Murphy J. (2005). Auditing hip ultrasound screening of infants at risk of development dysplasia of the hip. *BMJ Archives of Diseases in Childhood, 90*(6).

Lumsden, G., Lucas-Garner, L., Sutherland, S., & Dodenhoff, R. (2017). Physiotherapists using diagnostic ultrasound in shoulder clinics. How useful do patients find immediate feedback from the scan as part of the management of their problem (Publication no. 10.1002/msc.1213). Retrieved 23.01.2018 https://onlinelibrary.wiley.com/doi/pdf/10.1002/msc.1213

Madge C, & O'Connor H. (2006). Parents gone wired: empowerment of new mothers on the Internet? *Social and Cultural Geography, 7*(2), 199 - 220. doi:https://doi-org.ezproxy.flinders.edu.au/10.1080/14649360600600528

Marken-Horarik, M. (1998). Literacy and scholarship. In F. M. Christie, R. (Ed.), *Literacy and Scholarship* (pp. 30). London: Routledge.

Marma, A. K., & Lloyd-Jones, D. M. (2009). Systematic examination of the updated Framingham heart study general cardiovascular risk profile. *Circulation, 120*(5), 384-390.

Marmot, M. (2005). Social determinants of health inequalities. *Lancet, 365*(19 - 25 March 2005), 1099 - 1104. doi:doi.org/10.1016/Soi40-6738(05)71146-6

Mashi, d. B., G. Korn, C.Heskeren, H (2012). How expert advice influences decision making. *PLoF One, 7*(11).

Masson M, & Owen A. (2009). Linkage, coordination and integration: evidence from rural palliative care. *Australian Journal of Rural Health, 17*(5), 263 - 267. doi:https://doi-org.ezproxy.flinders.edu.au/10.1111/j1440.1584.2009.01089.x

McAbee, G., Donn, S., & Mendelson, R. e. a. (2008). medical diagnoses commonly associated paediatric malpractice/late diagnosis. *Paediatrics, 122*(6), special article.

McCusker B (2000, 15th September 2000). [General Practitioner Care - public patients].

McGrail, M., & Humphreys, J. (2009). Geographic classifications to guide rural health policy in Australia. *Australia and New Zealand Health Policy, 6*(28). doi:https://doi.org.10.1186/174-8462-6-28

McGrail, M., & Humphrys, J. (2015). Geographic mobility of general practitioners in rural Australia. *Med J Aust, 203*(2), 92 - 96. doi:doi.10.5694/mja.14.01375

McKiernan, S., Chiarelli, P., & Warren-Forward, H. (2011). A survey of diagnostic ultrasound within the physiotherapy profession for the design of future training tools. *Radiography, 17*(2), 121-125.

Merriam, s., Cafarella, R., & Baumgartner, L. (2012). *Learning in Adulthood. A comprehensive guide* (Third ed.): Jossey-Bass.

Mooney, G. (2003). Inequities in Australian health care: how do we progress from here? *australi and New Zealand Journal of Public Health, 27*(3).

Morello F. (2000). Clinic recruits new doctors. *The Border Watch*.

(2018). *Developmental dysplasia of hip with Dr Krishnore Mulpurri and Dr Emily Schaeffer* [Retrieved from www.mja.au/podcastep34

Mulpurri, K., Song, K., Goldberg, M., & Sevaranok, K. (2015). Detection and non-operative management of paediatric developmental dysplasia of the hip in infants. *Journal of American Association of Orthopedic Surgeons*. doi:doi: 10.5435/JAAOS0 D-15-00006

Mulpurri, K., Song, L., Goldberg, M., & Severin, K. (2015). Detection and non-operative management of paediatric developmental dysplasia of the hip in infants up to six months of age. *Journal of the American Academy of Orthopaedics, 23*(3), 202 - 205. doi:doi.10.5435/JAAOS-D-15-00006

Myre, D., Szafrano, O., Skipper, S., Dickinson, J., & Janke, F. (2018). Scope of practice of famiy medicine graduates who completed a rural versus urban programme. *Rural and Remote Health Journal (online), 18*(4514). doi:https://doi.org/10.22605/rrh4514

Narayan, U., Mulpurri, K., Sankar, W., Clarke, N., Hosal, H., Price, C., & Group, I. H. D. I. S. (2015). Reliability of a new radiographic classification for developmental dysplasia of the hip. *Journal of paediatric orthopaedics, 35*(5), 478 - 484.

Novick. (1983). Sonography of the Neonatal and Infant Hip
. *American Journal Roentology, 141*(4), 639 - 645.

Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the twenty-first century. *Health Promotion International, 15*(3), 259-267. doi:htts://doi.org/10.1093/heapro/15.3.259

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine, 67*(12), 2072 - 2078. doi:https://doi.org/10.1016/j.socsc.med.2008.09.050

Nutbeam, D. H., E. Wise, W. (2010). *Theory in a nutshell: a practical guide to health promotion theories, Sydney au*.

O'Mara- Eves, A., & Brunton, G. e. a. (2013). Social media, digital videos and health promotion in a culturally and linguistically diverse Australia. *Health Promotion International, 28*(3), 466 - 476. doi:doi:10.1093/heapro/das014

O'Toole, K., & Schoo, A. (2010). Retention policies for allied health professionals in rural areas: a survey of private practitioners. *Rural and Remote Health Journal (online), 10*(1331 (online)), 1 - 12.

O'Toole, K., Schoo, A., Stagnitti, K., & Cuss, K. (2008). Rethinking problems for the retention of allied health professionals in rural areas: a social relations approach. *Health Policy, 87*, 326 - 332.

Ortolani, M. (1976). Congenital hip dysplasia in the light of early and very early diagnosis. *Clinical Orthopaedics Related research, 119*, 6 - 10.

Overland, C. (1999). *Funding Country Health Regions - a Review*.

Overland C (2018, august 2018). [Country Health and MGH].

Paesche-Orlow M, Schillinger D, Green M, & Wagner E. (2006). How healthcare systems can begin to addressthe challenge of limited literacy. *Journal of General Internal Meicine, 21*(8), 884 - 887. doi:https://doi-org.ezproxy.flinders.edu.au/10.1111/j.1525-1497.2006.00544

Palmen, K. (1984). Prevention of congenital dislocation of the hip. Swedish experience of neonataltreatment on joint instability. *Acta Othopedica Scandinavia, 55(supp208*(5), 107. doi:10.3109/17453678409155563

Paris, R., & Dubus, N. (2005). Staying connected while nurturing an infant: A challenge of new motherhoos. *Family Relations. Interdisciplinary Journal of Applied Family Science, 54*(1), 72 - 83.

Paterson, D. C. (1976). The early diagnosis of congenital dislocation of the hip. *Clin Orthop Relat Res, November*(119).

Paton, R. (2005). Screening for hip abnormality in the neonate. *Early Human Development, 81*(10), 803-806.

Paton, R. W., Hinduja, K., & Thomas, C. D. (2005). The significance of at-risk factors in ultrasound surveillance of developmental dysplasia of the hip. A ten-year prospective study. *Journal of Bone & Joint Surgery - British Volume, 87*(9), 1264-1266.

Pearson, H. (2015). Massive UK baby study cancelled. *Nature, 526*, 621.

Petersen, A., & Olsson, J. (2015). Calling evidence-based practice into question: acknowledging phronetic knowledge in social work. *The Britisj Journal of Social Work, 45*(5), 158 - 159. doi:https://doi.org/10.1093/bjsw/bcu020

Plantin, L., & Daneback, K. (2009). Parenthood, information and support on the Internet. A literature review of research on parents and professional advice. *BMC Family Practice, 10*(34). doi:https://doi.org/10.1186/1471-2296-10-34

Reikeras. (2002). Ultrasonography of Infant Hip: the significance of provocable instability with normal morphology. *Orthopedics, 25*(8), 833.

Riad, J. P., Cundy, P., Gent, R. J., Piotto, L., Morris, L., & Hirte, C. (2005). Longitudinal study of normal hip development by ultrasound. *J Pediatr Orthop, 25*(1), 5-9.

Roberts, M., Callahan, L., & O'Leary, C. (2017). Social media: a path to health literacy. *Journal of information services & use, 37*(2), 177-187. doi:10.3233/154-170836

Rogers A, Caruso C, & Aldrich M. (1993). Reliability of sleep diaries for assessment of sleep/wakefulness patterns. *Nursing Research, 42*(6), 368 - 372. doi:https://dx.doi-org/10.1097/0006199-199311000-00010

Roposch, A., Liu, L. Q., & Hefti, F., et al. (2011). Standardized diagnosis criteria for developmental dysplasia of the hip in early infancy. *Cliinical Orthopaedics and Related Research, 469*(12), 3452 - 3461. doi:https://doi.org/10.1007/s/1999-011-2066-9

Rosendahl K, Dezateux C, & Fosse K, e. a. (2010). Immediate treatment versus sonographic surveillance for mild hip dyslasia in newborns. *Paediatrics, 125*(e9). doi:10.1542/paeds.2009-0357

Rosendahl, K., & Toma, P. (2007). Ultrasound in the diagnosis of developmental dysplasia of the hip in newborns. The European approach. A review of methods, accuracy and clinical validity. *European Radiology, 17*(8), 1960-1967.

Royal Flying Doctor Service. (2018). Retrieved from https://www.flyingdoctor.au/sant/our-services

SA Government (Health). (2018). *Patient Assisted Travel Scheme*. website Retrieved from https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/country+health+services/patient+assistance+transport+scheme.

SA Maternal & Neonatal Clinical Network. (2010). *Neonatal hip screening and management of developmental dysplasia*.

SA Maternal, n. g. C. P. (2017). *Cliinical guideelines*.

Sackett, D., Rosenberg, W., Gray, J., & Haynes, R. (1996). Evidence-based medicine: what it is and what it isn't. *BMJ, 312*. doi:https://doi.org/10.1136/bmj.312.7023.71

Saies, A. D., Foster, B. K., & Lequesne, G. W. (1988). The value of a new ultrasound stress test in assessment and treatment of clinically detected hip instability. *J Pediatr Orthop, 8*(4), 436-441.

Schulz, P., & Nakamoto, K. (2013). Health literacy and patient empowerment in health comminucation: The importance of separating the conjoint twins. *Parent education and Counselling, 90*(1), 4 - 9.

Scott A, & W, C. (2007). Whither Divisions of Geeral Practice? An empirical and policy analysis of the impact of Divisions within the Australian health care system. *Med J Aust, 187*, 95 - 97.

Sharpe, P., Mulpuri, K., Chan, A., & Cundy, P. J. (2006). Differences in risk factors between early and late diagnosed developmental dysplasia of the hip. *Arch Dis Child Fetal Neonatal Ed, 91*(3), F158-162. doi:10.1136/adc.2004.070870

Shaw, G., Bernard. Retrieved from https://www.brainyquotes.com.au/quotes/george_bernard_shaw_385438

Shipman SA, H. M., Moyer VA, Yawn BP. (2006). Screening for Developmental dysplasia of hip: a systematic literature review for the United States Prevention Services Task Force. *Pediatrics, 117*, 6557-6576.

Shonkoff, J. (2014). Changing the narrative for early childhood investment. *JAMA pediatrics, 168*(2), 105-106. doi:10.1001/jamapediatrics.2013.4212

Shorter, D., Hong, T., & A, O. D. (2011). Screening programmes for developmental dysplasia of the hip in newborn infants. *Cochrane database of Systematic REviews*(9).

Sink, E., Ricciardi, F., DelaTorre, K., & Price, C. (2014). Selective ultrasound screening is inadequate to identify patients who present with symptomic adult acetabular dysplasia. *J Child Orthop, 8*, 451 - 455. doi:10.1007/s11832-014-0620-1

Sleuwen, V. (2007). Swaddling: a systematic review. *Pediatrics, 120:e*, 1097 - 1106.

Smithers-Sheed, H., McIntyre, S., & Gibson, C. e. a. (2016). A special supplement: findings from the Australian Cerebral Palsy register, birth years 1993 - 2006. *Developmental Medicine and Child Neurology, 58*(52). doi:http://doi.org/10.1111/dmcn.13026

Sorensen, K., Van, d., Broucke, S, Fullam, J., & Doyle, G. e. a. (2012). Health literacy and public health: a systematic review and intgration of defnitions and models. *BMC Public Health, 12*(80). doi:https://doi.org/10.1186/1471.2458-12-80

South Australian Department for Health and Aging. (2014). South Australian Perinatal Practice guidelines, 1 - 77. Retrieved from Normal pregnancy, labour and peurperium management clinical guidelines website:

South Australian Government. (2015). *Standards for Maternal and Neonatal Services in South Australia*.

South Australian Government. (2016). *The case for change - a discussion paper*.

South-East -Regional- Health Service. (1999). *Annual Report*.

St Leger, L. (2001). Schools, health literacy and public healh possibilities and challenes. *Health Promotion International, 16*(2), 197 - 205. doi:https://doi-org.ezproxy.flinders.edu.au/10.1093/heapro/16.2./197

Steiner D L, N. G. R., Carney j. (2015). *Health Measurement Scales - a practical guide to their development and use*: Oxford University Press.

Strecher, v. R., I. (1997). *Health Belief Model* (1997 Ed.). Cambridge: Cambridge University Press.

Struber J. (2004). Recruiting and retaining allied health professionals in rural australia: why is it so difficult? *International Journal of Allied Health Sciences and Practice, 2*(2).

Studer, K., Williams, N., Antoniou, G., Gibson, C., Scott, H., Schell, W., . . . Cundy, P. (2016). Increase in late diagnosed developmental dysplasia of the hip in South Australia: risk factors, proposed solutions. *Medical Journal of Australia, 204*(6), 240. doi:10.5694/mja15.01082

Studer K, W. N., Antoniou G, Gibson C, Scott H, Schell W, Foster B, Cundy P. (2016). Increase in late diagnosed developmental dysplasia of the hip in South Australia: risk factors, proposed solutions. *Medical Journal of Australia, 204*(6), 240. doi:10.5694/mja15.01082

Supper I, Catala A, Lustman M, & al., e. (2015). Interprofessional collaboration in primary health care: a review of facilitators and barriers perceived by involved actors. *Journal of Public Health Policy*, 716 - 727. doi:https://doi-org.ezproxy.flinders.edu.au/10.1093/pubmed/fdu

Terjesen, T., Bredland, T., & Berg, V. (1989). Ultrasound for hip assessment in the newborn. *Journal of Bone & Joint Surgery - British Volume, 71*(5), 767-773.

Tham, R. (2010). Evaluating the impact of sustainable comprehensive primary health care in rural health. *Australian Journal of Rural Health*. doi:doi.org/10.1111/j.1440.15842010.01145.x

The Hon Michael Armitage MP. (June 24 1996). *Armitage delivers State first for child birth*. Media Release.

Thomas SL, W. J., Humphreys JS. (2017). What does it cost to provide primary health care in rural Australia? A pilot study. *Rural and Remote health, 17*(4019).

Thornbury JR, E. W. (1994). Clinical efficacy of diagnostic imaging: love it or leave it. *American Journal Roentology, 162*, 1-8.

Trezonz, A., Rowlands, G., & Nutbeam, D. (2018). Progress in implementing National Policies and strategies for health literacy - What have we learned so far?

International Journal for environment, Resources and Public Health, 15(7), 1554. doi:doi.10.3390/ijerph15071554

Twitchell, T., E. . (1965). Attitudunal Reflexes. *American Journal of Physical Therapy, 45*, 414 - 418.

UNESCO. (2015). *UNESCO and sustainable development goals*. Retrieved from online https://en.unesco.org/sdgs:

Vellar, L., Mastroianni, F., & Lambert, K. (2017). Embedding health literacy into health systems: a case study of regional health services. *Australian Health Review, 41*(6), 621 - 625. doi:doi.org/10.1011/AH16109

von Glasenfeld, E. (2002). Learning and adaptation in the theory of constructivism. *Classical reading on Piaget*. Retrieved from

Wakerman J, Curry R, & McEldow R. (2012). Fly in/flyout health services:the panacea or the problem? *Rural and Remote Health Journal (online), 12*(2268).

Wallace S. (2000a). Hospital doctors strategy. *The Border Watch*.

Wallace S. (2000b). Let the doctors Back in. *The Border Watch*.

Walters L, Worley P, & Mugford B. (2003). The parallel rural commuity curriculum: is it a transferable model? *Rural and Remote Health Journal (online), 3*(3), 236. doi:doi:10.2260/RRH36

Walters Lucie, MacLennan N, & Tegan Susi. (2000). *South-East Regional Workforce Study*. Retrieved from S-E of SA Division of General Practice Inc:

Wang. (2012). Does swaddling influence developmental dysplasia of the hip? An experimental study of the traditional straight leg swaddling model in neonatal rats. *Journal of Bone and Joint Surgery Am, 94*(12), 1071 - 1077.

Weiner A, & Rogers C. (2008). Antenatal Classes: women can't think beyond labour. *British Journal of Midwifery, 16*(2). doi:https://doi-org/10.12968/bjom.2008.16.2834

Welch, V., Petticrew, M., O'Neill, J., Waters, R., Butta, Z., & Francis, D. e. a. (2013). Health equity: evidence synthesis and knowledge translation methods. *Systematic Reviews. BMC online, 2*(43). doi:http,://doi.org/10.1186/2046-40532-43

Williams, N., Foster, B. K., & Cundy, P. J. (2012). Is swaddling damaging our babies' hips? *Med J Aust, 197*(5), 272.

Woolacott, N. F., Puhan, M. A., Steurer, J., & Kleijnen, J. (2005). Ultrasonography in screening for developmental dysplasia of the hip in newborns: systematic review. *BMJ, 330*(7505), 1413.

World Health Organisation. (2009). Track 2. Health literacy and health behaviour. Retrieved from www.who.int/healthpromotion/conference/7gchp/track2/en/

World Health Organisation. (2013). *Manual of Diagnostic Ultrasound* (2 ed. Vol. 2): WHO 2013.

World Health Organisation secretariat. (2016). *Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development.* Paper presented at the 9th Global Conference on Health Promotion, Shanghai.

Worley, P., & Maynard, R. (2011). Social accountability in medical education - An Australian rural and remote perspective. *Meical Teacher, 33*(8), 654 - 658. doi:q0i: 10.3109/0142159x.2011.59025

Wright, S. (2017). Screening for developmentaldysplasia of the hip in a rural health district: an analysis of practice. *Australian Journal of Rural Health*. doi:10.1111/ajr.12400

Yamamuro, T. (1984). Recent Advances in prevention, early diagnosis and treatment of congenital dislocation of hip in Japan. *Clinical Orthopaedics Related research, 1984*(184), 34 - 40.

APPENDICES

Appendix A – Safe Sleeping Brochure

Appendix B – Pilot Study Article Evaluation

Appendix C – Literature Review Article

Appendix D – Research Documentation

Appendix E - Ethics Approvals

Appendix F - Correspondence

Appendix G – SonoSite Portable Ultrasound

Appendix A – Safe Sleeping Brochure

Please refer to:

http://www.imagineeducation.com.au/files/CHC30113/SIDS_20Safe_20Sleeping.pdf

sids and kids®

This brochure has been developed and reviewed
by content experts in the area of optimal infant
care practices and strategies to reduce SUDI.

This booklet is endorsed by:
Paediatrics & Child Health Division,
The Royal Australasian College of Physicians
Australian College of Midwives

FIND OUT MORE

FIND US ON FACEBOOK

Available on the App Store

www.sidsandkids.org

Proudly sponsored by:

PLUM
Phone: 02 9281 2133
www.plumcollections.com.au

Printed February 2013

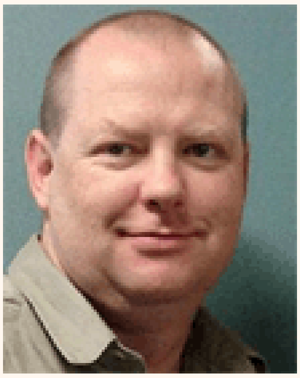
Appendix B – Pilot Study Article Evaluation

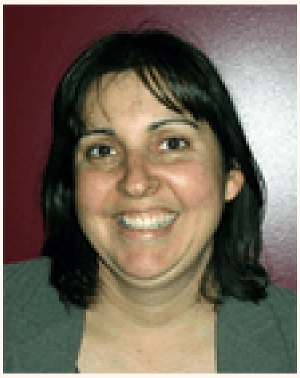
Original Research

Pilot evaluation of anterior dynamic ultrasound screening for developmental dysplasia of the hip in an Australian regional hospital

Submitted: 10 February 2012
Revised: 9 July 2012
Published: 18 September 2012

Full text: You can view the full article, or view a printable version.
Comments: (login to access the comments on this article)


Timothy Skinner


Lucie Walters

Author(s) : Charlton S, Muir L, Skinner TC, Walters L.

Citation: Charlton S, Muir L, Skinner TC, Walters L. Pilot evaluation of anterior dynamic ultrasound screening for developmental dysplasia of the hip in an Australian regional hospital. *Rural and Remote Health* **12: 2091**. (Online) 2012. Available: http://www.rrh.org.au

ABSTRACT

Introduction: Developmental Dysplasia of the Hip (DDH) is the most common notifiable musculoskeletal birth defect in South Australia (SA). Despite routine screening by physical examination of the hips in the neonatal period and at 6 weeks of age, the risk of late diagnosis is increased in rural areas. It is assumed this is due to the examining doctors' reduced clinical expertise. Introducing Anterior Dynamic Ultrasound (ADUS) has reduced the late detection rates in Sweden to almost zero, and may benefit Australian infants in rural areas if routine screening was introduced. This study reports on a small implementation pilot in a SA regional hospital where volunteer postnatal mothers consented to their babies having ADUS examinations.
Methods: The pilot was evaluated by collecting results of physical examination, ADUS, and surveying parental impressions of the screening test.
Results: Hips of 86 infants underwent ADUS during the implementation pilot. Parents' perceptions were mainly very positive and indicated ADUS was an accessible and acceptable screening test. Of the hips scanned, three were found to have maximum movement of the femoral head of >3 mm and were deemed to demonstrate increased laxity. Four hips described as loose or mobile on clinical examination were found to be within normal limits of maximum mobility on ADUS.
Conclusions: This study has demonstrated that a larger scale implementation project would be feasible in regional Australia, and would enable researchers to better understand how to reduce the late diagnosis rate of DDH in rural areas.

Key words: Australia, congenital, hip dislocation, mass screening, ultrasound.

Appendix C – Literature Review Article

Charlton *et al. BMC Pediatrics* _####################_
DOI 10.1186/s12887-017-0830-z

RESEARCH ARTICLE **Open Access**

Early dynamic ultrasound for neonatal hip instability: implications for rural Australia

Susan L. Charlton*, Adrian Schoo and Lucie Walters

Abstract

Background: Neonatal instability of the hip (NIH), where the femoral head can move away from the acetabulum, in the first weeks of life, is an important risk factor for developmental dysplasia of the hip (DDH). In rural areas in Australia, there is a recent trend to increased late diagnosis of DDH. Clinical screening of infant hips, a common practice in Australia, is experience dependent. Best practice early screening techniques are still debated with different techniques and timing used internationally. This systematic review examines early dynamic ultrasound (eDUS) screening for hip instability in the first 6 weeks after birth, and the early interventions informed by these findings and considers the findings for the context of rural Australia.

Methods: The Cochrane Library, Medline, CINAHL and PEDro were searched for original research or systematic reviews, and clinical studies 1998 to 2015 involving dynamic ultrasound. Critical Appraisal Skills Programme tools were used to appraise the studies.

Result: Nineteen studies were included. Early Dynamic Ultrasound (DUS) is consistently described as a reliable assessment of NIH. Early DUS is recommended for risk factors including geographical areas of high prevalence. Approaches to early intervention of hips with excessive movement are somewhat discipline-related and include: primary prevention (advice), secondary prevention (abduction supports), and conservative management (removable splints).

Conclusions: In the context of increased prevalence of DDH in rural Australia, contemporary evidence suggests that introduction of early DUS could provide rural infants with more effective screening than clinical examination alone. Targeted early advice about posturing and simple removable supports to abduct infant hips could prevent some cases of DDH in rural Australia.

Keywords: Screening, Neonatal instability of hip, Dynamic ultrasound, Developmental dysplasia of hip

Background

In order to avoid developmental dysplasia of the hip (DDH), the metaphyseal growth and ossification of the neonatal cartilaginous acetabulum must occur around *"a properly seated femoral head"* [1]. Neonatal instability of the hip (NIH), where the femoral head can move away from the acetabulum, in the first weeks of life is therefore an important risk factor for DDH [2]. DDH is the most common notifiable musculoskeletal birth defect in Australia with an incidence of 7/1000 births in 2007 in South Australia [3].

Despite serious long-term consequences for children with late diagnosis of DDH, best practice early screening techniques are debated with considerable variation in routine screening protocols internationally. This systematic review investigates early dynamic ultrasound screening (eDUS) methods for the detection of NIH, and how results can inform early interventions to potentially prevent either missed cases or delayed onset DDH.

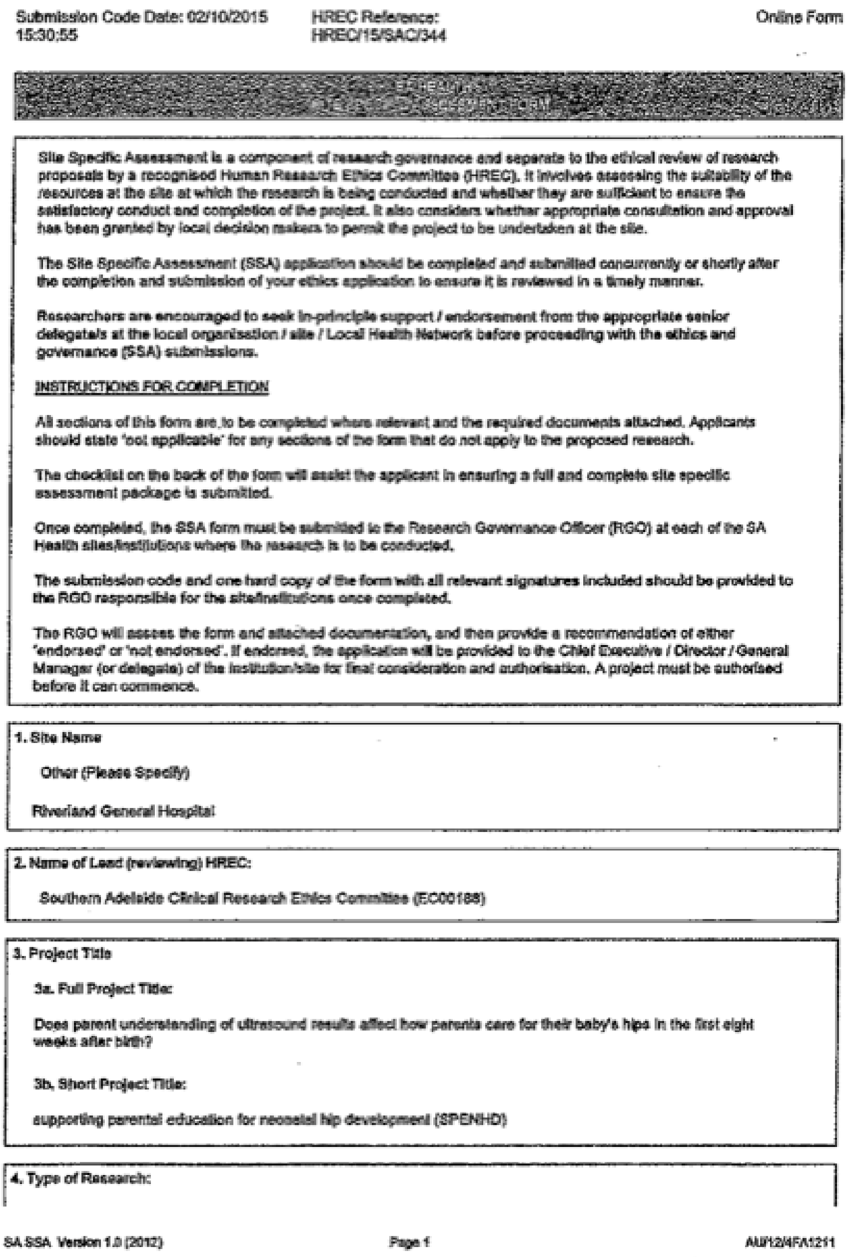
Clinical screening of all neonatal hips is currently accepted as the most economic assessment of hips in many European countries, UK, USA, Canada and Australia, with infants considered at risk of DDH or with hips demonstrating subluxation, then undergoing Graf ultrasound examination at 6 weeks of age. Graf ultrasound [4], a morphological assessment of the infant hip,

---

* Correspondence: sue@suecharlton.com.au
Flinders Rural Health South Australia, Flinders University, Mount Gambier, Bedford Park. Adelaide. SA. Australia

Appendix D – Research Documentation

Site specific approvals



Submission Code Date: 02/10/2015 15:30:55

HREC Reference: HREC/15/SAC/344

Online Form

SA HEALTH
SITE SPECIFIC ASSESSMENT FORM

Site Specific Assessment is a component of research governance and separate to the ethical review of research proposals by a recognised Human Research Ethics Committee (HREC). It involves assessing the suitability of the resources at the site at which the research is being conducted and whether they are sufficient to ensure the satisfactory conduct and completion of the project. It also considers whether appropriate consultation and approval has been granted by local decision makers to permit the project to be undertaken at the site.

The Site Specific Assessment (SSA) application should be completed and submitted concurrently or shortly after the completion and submission of your ethics application to ensure it is reviewed in a timely manner.

Researchers are encouraged to seek in-principle support / endorsement from the appropriate senior delegate/s at the local organisation / site / Local Health Network before proceeding with the ethics and governance (SSA) submissions.

INSTRUCTIONS FOR COMPLETION

All sections of this form are to be completed where relevant and the required documents attached. Applicants should state 'not applicable' for any sections of the form that do not apply to the proposed research.

The checklist on the back of the form will assist the applicant in ensuring a full and complete site specific assessment package is submitted.

Once completed, the SSA form must be submitted to the Research Governance Officer (RGO) at each of the SA Health sites/institutions where the research is to be conducted.

The submission code and one hard copy of the form with all relevant signatures included should be provided to the RGO responsible for the site/institutions once completed.

The RGO will asses the form and attached documentation, and then provide a recommendation of either 'endorsed' or 'not endorsed'. If endorsed, the application will be provided to the Chief Executive / Director / General Manager (or delegate) of the institution/site for final consideration and authorisation. A project must be authorised before it can commence.

1. Site Name

Other (Please Specify)

Riverland General Hospital

2. Name of Lead (reviewing) HREC:

Southern Adelaide Clinical Research Ethics Committee (EC00188)

3. Project Title

3a. Full Project Title:

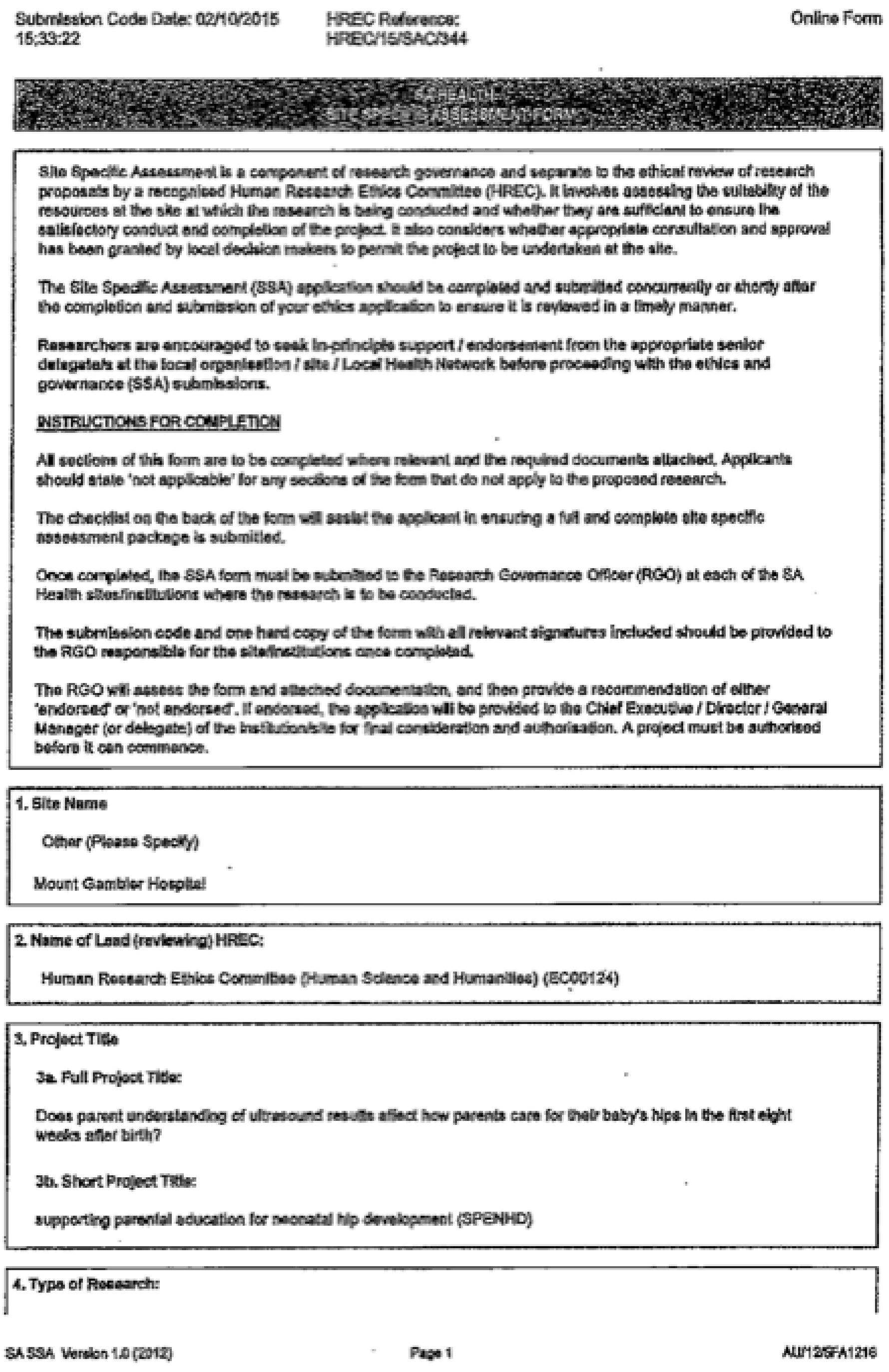
Does parent understanding of ultrasound results affect how parents care for their baby's hips in the first eight weeks after birth?

3b. Short Project Title:

supporting parental education for neonatal hip development (SPENHD)

4. Type of Research:

SA SSA Version 1.0 (2012) Page 1 AU/12/4FA1211



Submission Code Date: 02/10/2015 15;33:22

HREC Reference: HREC/15/SAC/344

Online Form

SA HEALTH
SITE SPECIFIC ASSESSMENT FORM

Site Specific Assessment is a component of research governance and separate to the ethical review of research proposals by a recognised Human Research Ethics Committee (HREC). It involves assessing the suitability of the resources at the site at which the research is being conducted and whether they are sufficient to ensure the satisfactory conduct and completion of the project. It also considers whether appropriate consultation and approval has been granted by local decision makers to permit the project to be undertaken at the site.

The Site Specific Assessment (SSA) application should be completed and submitted concurrently or shortly after the completion and submission of your ethics application to ensure it is reviewed in a timely manner.

Researchers are encouraged to seek in-principle support / endorsement from the appropriate senior delegate/s at the local organisation / site / Local Health Network before proceeding with the ethics and governance (SSA) submissions.

INSTRUCTIONS FOR COMPLETION

All sections of this form are to be completed where relevant and the required documents attached. Applicants should state 'not applicable' for any sections of the form that do not apply to the proposed research.

The checklist on the back of the form will assist the applicant in ensuring a full and complete site specific assessment package is submitted.

Once completed, the SSA form must be submitted to the Research Governance Officer (RGO) at each of the SA Health sites/institutions where the research is to be conducted.

The submission code and one hard copy of the form with all relevant signatures included should be provided to the RGO responsible for the site/institutions once completed.

The RGO will assess the form and attached documentation, and then provide a recommendation of either 'endorsed' or 'not endorsed'. If endorsed, the application will be provided to the **Chief Executive / Director / General Manager** (or delegate) of the institution/site for final consideration and authorisation. A project must be authorised before it can commence.

1. Site Name

Other (Please Specify)

Mount Gambier Hospital

2. Name of Lead (reviewing) HREC:

Human Research Ethics Committee (Human Science and Humanities) (EC00124)

3. Project Title

3a. Full Project Title:

Does parent understanding of ultrasound results affect how parents care for their baby's hips in the first eight weeks after birth?

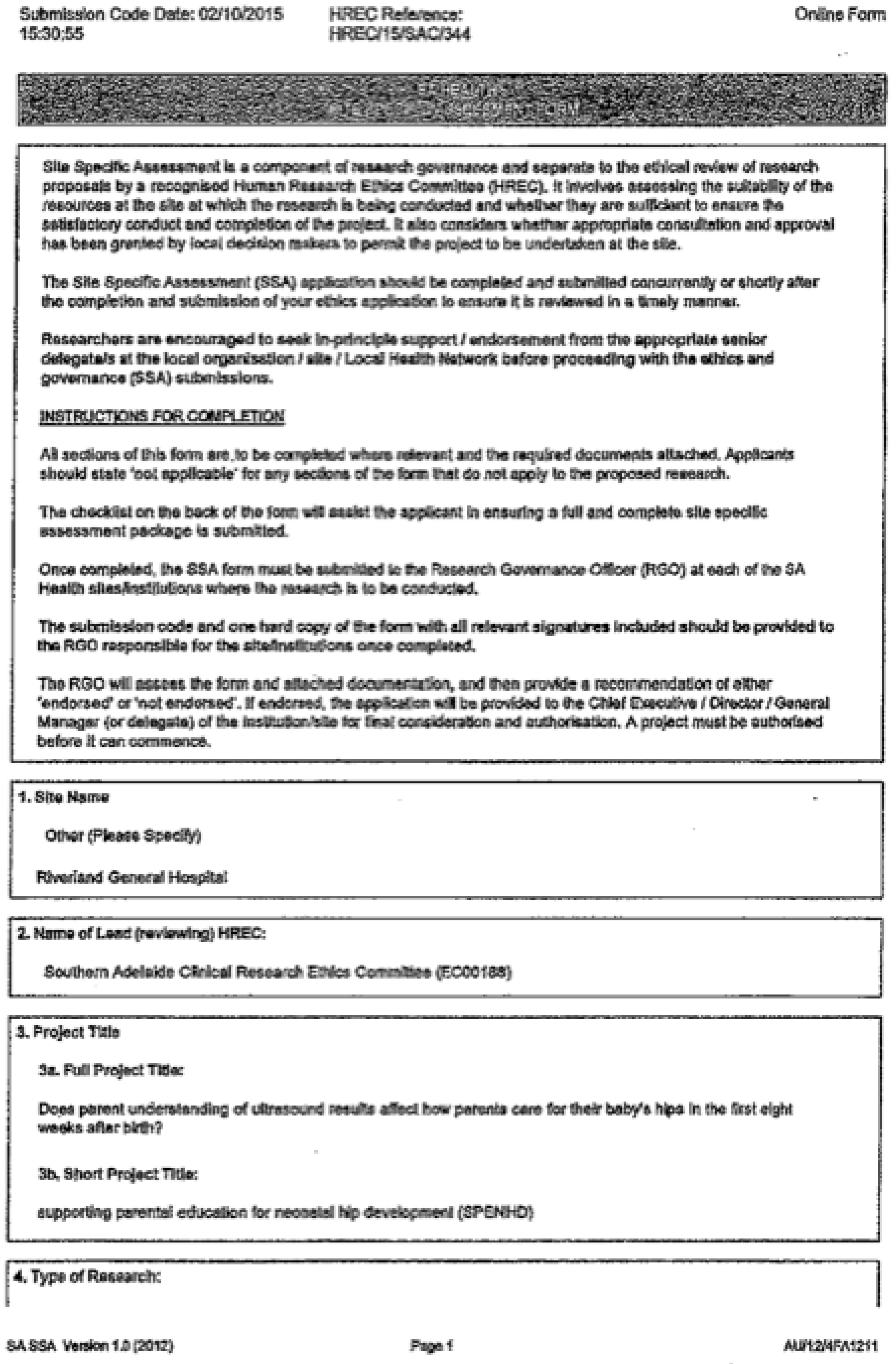
3b. Short Project Title:

supporting parental education for neonatal hip development (SPENHD)

4. Type of Research:

SA SSA Version 1.0 (2012) Page 1 AU/12/SFA1216

Flinders University Rural Clinical School
PO Box 852
Renmark 5341
Tel: 08 87263999
Fax: 08 87236301



Submission Code Date: 02/10/2015 15:30:55

HREC Reference: HREC/15/SAC/344

Online Form

SA HEALTH
[illegible] FORM

Site Specific Assessment is a component of research governance and separate to the ethical review of research proposals by a recognised Human Research Ethics Committee (HREC). It involves assessing the suitability of the resources at the site at which the research is being conducted and whether they are sufficient to ensure the satisfactory conduct and completion of the project. It also considers whether appropriate consultation and approval has been granted by local decision makers to permit the project to be undertaken at the site.

The Site Specific Assessment (SSA) application should be completed and submitted concurrently or shortly after the completion and submission of your ethics application to ensure it is reviewed in a timely manner.

Researchers are encouraged to seek in-principle support / endorsement from the appropriate senior delegate/s at the local organisation / site / Local Health Network before proceeding with the ethics and governance (SSA) submissions.

INSTRUCTIONS FOR COMPLETION

All sections of this form are to be completed where relevant and the required documents attached. Applicants should state 'not applicable' for any sections of the form that do not apply to the proposed research.

The checklist on the back of the form will assist the applicant in ensuring a full and complete site specific assessment package is submitted.

Once completed, the SSA form must be submitted to the Research Governance Officer (RGO) at each of the SA Health sites/institutions where the research is to be conducted.

The submission code and one hard copy of the form with all relevant signatures included should be provided to the RGO responsible for the site/institutions once completed.

The RGO will assess the form and attached documentation, and then provide a recommendation of either 'endorsed' or 'not endorsed'. If endorsed, the application will be provided to the Chief Executive / Director / General Manager (or delegate) of the institution/site for final consideration and authorisation. A project must be authorised before it can commence.

1. Site Name

Other (Please Specify)

Riverland General Hospital

2. Name of Lead (reviewing) HREC:

Southern Adelaide Clinical Research Ethics Committee (EC00188)

3. Project Title

3a. Full Project Title:

Does parent understanding of ultrasound results affect how parents care for their baby's hips in the first eight weeks after birth?

3b, Short Project Title:

supporting parental education for neonatal hip development (SPENHD)

4. Type of Research:

SA SSA Version 1.0 (2012) Page 1 AU/12/4FA1211

Research Papers for Ethics Approval

RESEARCH INFORMATION SHEET RIVERLAND GENERAL HOSPITAL.

Title of Project Does parent understanding of their baby's hips influence care?

Principal Investigators: Mrs Sue Charlton, Professor Adrian Schoo, Associate Professor Lucie Walters

We have given you this information sheet because we would like to ask you take part in our study. Before you decide to take part, you need to understand why the research is being done and what it would involve for you and your child. Please take time to read the following information carefully and the booklet that is attached to this sheet. Talk to others about the study if you wish.

What is the purpose of the study?
We are trying to find out what information is helpful to parents in caring for their new babies who may have extra movement in their hips in the first weeks that could develop into dysplasia of the hip. Attached information on this condition suggests that with early management we can give the hip the best opportunity to develop well and may avoid surgery to correct the problem. At the moment, in Australia, some newborn babies with the condition are missed.

Do I have to take part?
No. Your participation in this research project is completely voluntary. You do not have to take part; it is up to you to decide. If you choose not to contact us, you will not hear from us again, and you need to take no further action. If you have any questions about the study, please contact Sue Charlton, Adrian Schoo or Lucie Walters (contact details are at the end of this sheet) who will be happy to answer any questions you have. If after you have had your questions answered, you do not wish to take part, then we will not contact you again.

What happens if I do decide to take part?
If you decide to take part in the research you will be asked to fill in a short questionnaire giving us some information about you and your baby, what you know about babies' hips and whether you are aware of any children who have had hip problems. You will be given handouts describing hip development in young children and tummy time for your baby. You will be asked to watch a short video telling you about the hip in babies and giving you some advice on caring for the hips.

Following the video you will be asked to complete another questionnaire to gauge how important this information is and how difficult or easy you think it might be to do the things that have been suggested.

Over the next six weeks we will ask you to complete a simple daily diary that will be provided when you complete the second questionnaire. One of the researchers will contact you between weeks 3 and 6 to see how you are going with the diary and to answer any questions you might have.

Finally, we invite you to meet with an independent clinician (not involved in the study) who will collect your diary and ask for feedback about your experiences.

What are the possible benefits of taking part?
Possible benefits include gaining knowledge about infant hip development and care. This research project is looking to find out how important parents think hip care is for babies and how easy it is to follow the advice about positioning and wrapping.

Will my taking part in the study be kept confidential?
Yes, the only people who will access the personal information you provide will be the research team members. No one else will be informed as to whether you do or do not participate. If your child's hip is found to have a problem, we will, with your consent, inform your GP to make sure your child receives the best care available.

The outcomes of this research project will be part of my PhD thesis and may be published in conference papers, journals or lectures as appropriate. You will NOT be identified in any way in these publications. You will be sent a summary of the outcomes of the research at the end of the study if you request it.
On completion of the study all information and data will be de-identified and stored in a locked filing cabinet at Flinders University for at least 5 years from the date of publishing.

What will happen if I don't want to carry on with the study?
If you choose not to participate, and wish to withdraw from the study after you have given consent, then please contact the researchers. When you do this, we will ask you whether you wish us to destroy the information you have already given us, or whether we can keep this information. Once you have let us know what you wish us to do we will action your request, as long as the findings have not been analysed and included in a report. Your decision to withdraw will not affect your relationship with or access to any services as no one will be told of this decision.

What if there is a problem?
If you have a concern or query about any aspect of this study then you can contact the researchers, their contact details are at the bottom of this sheet. If any problems occur during the study then please contact one of the researchers who will respond as soon as possible.
If you suffer an injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

Contact Details
Sue Charlton

1 Stop Paediatric Services, 1 Eleanor Street, Mount Gambier,

Tel: 08 87255383

Email: sue@suecharlton.com.au

Prof Adrian Schoo & A/Prof Lucie Walters

Flinders University Rural Clinical School, 24 Vivienne Avenue, Mount Gambier
Tel: 08 8586 3999
Email: adrian.schoo@flinders.edu.au or lucie.walters@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Flinders University Rural Clinical School
PO Box 852
Renmark 5341
Tel: 08 87263999
Fax: 08 87236301

Attachment 2B

RESEARCH INFORMATION SHEET MOUNT GAMBIER.

Title of Project: Does parent understanding of their baby's hips influence care?
.

Principal Investigators: Mrs Sue Charlton, Professor Adrian Schoo, Associate Professor Lucie Walters

We have given you this information sheet because we would like to ask you take part in our study. Before you decide to take part you need to understand why the research is being done and what it would involve for you and your child. Please take time to read the following information carefully and the booklet that is attached to this sheet. Talk to others about the study if you wish.

What is the purpose of the study?

We are trying to find out what information is helpful to parents in caring for their new babies who may have extra movement in their hips in the first weeks that could develop into dysplasia of the hip. Attached information on this condition suggests that with early detection and management we can give the hip the best opportunity to develop well and may avoid surgery to correct the problem. At the moment, in Australia, some newborn babies with the condition are missed.

Do I have to take part?

No. Your participation in this research project is completely voluntary. You do not have to take part; it is up to you to decide. If you choose not to contact us, you will not hear from us again, and you need to take no further action. If you have any questions about the study, please contact Sue Charlton, Adrian Schoo or Lucie Walters (contact details are at the end of this sheet) who are prepared to answer any questions you have. If, after you have had your questions answered, you do not wish to take part, we will not contact you again.

What happens if I do decide to take part?

If you decide to take part in the research you will be asked to sign a consent form and to fill in a short questionnaire giving us some information about you and your baby, what you know about babies' hips and whether you are aware of any children who have had hip problems. You will be given handouts describing hip development in young children and tummy time for your baby and will be asked to watch a short video about caring for baby hips.

You will be asked to visit Bensons Radiology at the Mount Gambier Hospital on the first Wednesday after your baby is born, between 1.00pm and 2.00m. When you arrive, tell them why you have come at the reception desk so that one of the researchers can talk to you to make sure you understand the study and what it involves. If you are prepared to take part, you will be asked to sign a consent form before the ultrasound of your child's hip joints will be conducted in your presence.

The ultrasound scan involves moving your child's hip, whilst a sensor is placed on the skin. The sensor will show us how much movement there is in the hip joint. The ultrasound is much like those you have had during your pregnancy, and will not cause any discomfort to your child. You will be able to see your baby's hip and the amount of movement while the scan is being done.

Following the scan, you will be asked to complete another questionnaire to gauge how important this information is and how difficult or easy you think it might be to follow up on the suggestions given.

If the scan suggests your child may be at risk of developing dysplasia of the hip (DDH) you will be provided with some information and advice on how to reduce the risk of this happening. You will be recommended to come back for another scan when your baby is 6 weeks old.

What are the possible benefits of taking part?
Possible benefits include gaining knowledge about infant hip development and care. This research project is looking to find out how important parents think hip care is for babies and how easy it is to follow the advice about positioning and wrapping.

Will my taking part in the study be kept confidential?
Yes, the only people who will access the personal information you provide will be the research team members. No one else will be informed as to whether you do or do not participate. If your child's hip is found to have a problem, we will, with your consent inform your GP, to make sure your child receives the best care available.

The outcomes of this research project will be part of my thesis for my PhD and may be published in conference papers, journals or other venues as appropriate. You will NOT be identified in any way in these publications. You will be sent a summary of the outcomes of the research at the end of the study if you request it.
On completion of the study all information and data will be de-identified and stored in a locked filing cabinet at Flinders University for at least 5 years from the date of publishing.

What will happen if I don't want to carry on with the study?
If you choose not to participate, and wish to withdraw from the study at any time after you have given consent, then please contact the researchers. When you do this, we will ask you whether you wish us to destroy the information you have already given us, or whether we can keep this information. Once you have let us know what you wish us to do, we will action your request, and you will not hear from us again. Your decision to withdraw will not affect your relationship with or access to any services as no one will be told of this decision.

What if there is a problem?
If you have a concern or query about any aspect of this study then you can contact the researchers, their contact details are at the bottom of this sheet. If any problems occur during the study, contact one of the researchers so that they can address these as soon as possible.
If you suffer an injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

Contact Details
Sue Charlton

1 Stop Paediatric Services, 1 Eleanor Street, Mount Gambier,

Tel: 08 87255383

Email: sue@suecharlton.com.au

Prof. Adrian Schoo, & A/Prof. Lucie Walters

Flinders University Rural Clinical School, 24 Vivienne Avenue, Mount Gambier

Tel: 08 8586 3999

Email: adrian.schoo@flinders.edu.au or lucie.walters@flinders.edu.au

This study has been reviewed by the SAHS/FUHREC. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the ethics manager on 8204 4507 or email research.ethics@health.sa.gov.au

Attachment 3

CONSENT FORM FOR PARTICIPATION IN RESEARCH

I ………

being the parent/guardian of ……………………………………………………………. hereby consent to participate in a research project on Neonatal Hip Dysplasia being carried out by the Flinders University Rural Clinical School and 1 Stop Paediatric Services.

I have read the information provided.

1. Details of procedures and any risks have been explained to my satisfaction.

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:

   - I may not directly benefit from taking part in this research.
   - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, my child will not be identified, and individual information will remain confidential.
   - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to my child.
   - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I agree/do not agree to the information being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.

7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature…………………………………Date…………………..

I certify that I have explained the study to the parent/guardian of ……………………………………………………. And consider that she/he understands what is involved and freely consents to participation.

Researcher's name…………………………………………………………….............

Researcher's signature…………………………………. Date…………………….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

8. I, the participant whose signature appears below, have read a transcript of my child's participation and agree to its use by the researcher as explained.

Participant's signature………………………………… Date…………………..

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my child's de-identified information as reported.

Participant's signature………………………………… Date…………………..

Attachment 4

Questionnaire 1

Thank you for agreeing to take part in our study.
First we would like to ask you some questions about you and your family. The information we collect will be safely stored in a secure place at the University in such a way that no-one will be able to identify your answers. We are asking for you contact details so that we can contact you during the study to find out how you are getting on.

Demographic data

Your name:

Contact phone number:

Age (in years) ______________________

Your level of schooling:
Primary ☐ Secondary year level ☐ post school eg TAFE, Uni ☐ Other ☐

Language spoken at home: English Other (Please indicate)___________________

Number of adults living at home___________

Number of children <12 living full or part-time at home (including this baby)___________

We would like to find out your thoughts on baby care

Please answer the following questions. This is not a test. Please answer with your first thoughts on the question and don't worry about possible correctness of the answers.

In relation to your previous experiences/expertise:			
	False	Don't know	True
I have a friend or family member whose baby had hip problems			
I have previously worked in a job which required me to know about hip instability in children			
This is my first experience looking after a newborn baby			

In relation to your current knowledge:			
	False	Don't know	True

Hip problems in babies are common			
The hip joint in a newborn baby is a stable, ball and socket joint			
Wrapping helps most babies to settle			
Young babies should not be placed on their tummy when awake.			
Young babies should not be placed on their tummy when asleep			
Baby slings are good for most young baby's hips			
Loose wrapping is better for most babies			

In relation to your plans for the next 4 weeks:					
	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
I intend to wrap my baby firmly for sleeping					
I intend to lie my baby on their back to sleep					
I intend to lie my baby on their tummy to sleep					
I intend to lie my baby on their back when they are awake					
I intend to lie my baby on their tummy when they are awake					

Now we would like you to answer some questions about your new baby

Name of baby: ___________________________________

Male ☐ Female ☐

Date of Birth: __________________

Delivery method: (Please tick one)

Normal vaginal delivery ☐
Breech vaginal delivery ☐
Vacuum extraction or forceps birth ☐
Caesarean Section ☐

Breech Caesarean Section ☐

Baby's due date:

Birth weight:

Is your baby a twin? No ☐ Yes ☐

Does your baby have a family history of hip dysplasia?

Parent Yes or No (Please circle)
Brother Yes or No (Please circle)
Sister Yes or No (Please circle)

Please feel free to provide any comments you believe to be relevant

Attachment 5

Safe wrapping for hip dysplasia

Victorian Paediatric Orthopaedic Network

ORTHOPAEDIC FACT SHEET

Developmental dysplasia of the hip

The hip is a ball-and-socket joint that is held together by ligaments (Figure 1).

In the womb, babies generally lie with their hips in an outward position. This helps the hip joint to develop normally.

In some babies the ligaments around the hip joint are loose, which in most circumstances, corrects during the first few months of life.

If this looseness persists, the hip joint may not form properly, leading to the condition known as developmental dysplasia of the hip (DDH). In some severe cases, the hip may come out of the socket. This is known as dislocation of the hip (Figure 2).

Wrapping and DDH

Wrapping or swaddling newborn babies can help them feel more secure and comfortable. This may assist babies to settle and establish regular sleep patterns.

Research has shown that tight wrapping with the legs held straight can lead to hip dysplasia and dislocation. When this practice is stopped the frequency of dislocation is significantly reduced.

Safe wrapping

There are a number of ways to wrap babies. Whatever method you choose, always remember to leave enough room in the wrap for the legs to move freely. The legs should be able to bend at the hips with the knees apart to help the hips develop normally (Figure 3).

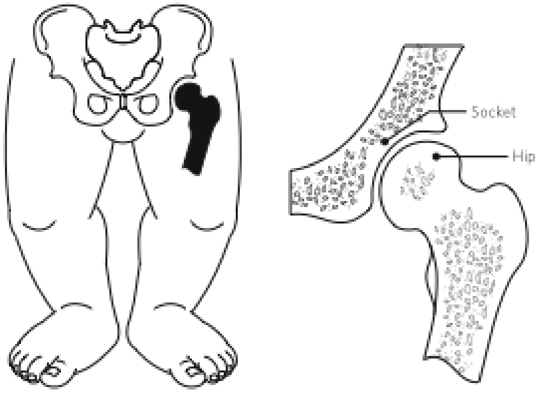


Figure 1. The normal infant hip

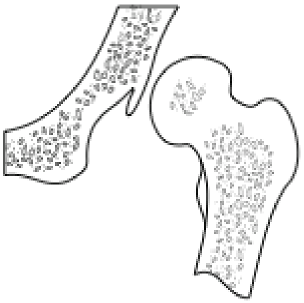


Figure 2. Dislocation of the hip

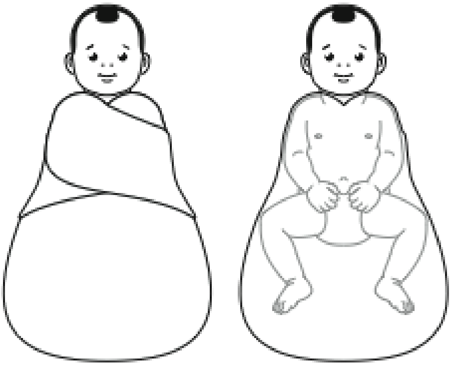


Figure 3. Safe wrapping with the hips bent and knees apart

Last updated October 2011. ERC 100373

Barwon Health | Monash Children's Southern Health | Western Health | The Royal Children's Hospital Melbourne

Attachment 6

Tummy Time – Hip Development

An important part of Baby's awake time.

- It helps my hip development and strengthens my neck, back, shoulder and arm muscles
- It helps prevent flat spots on my head
- Allows me to see the world from a different angle
- You can start putting me on my tummy soon after birth when I am awake. My natural protective reflexes will help me lift and turn my head so that I can breathe easily
- I may only like it for a few minutes to begin with, but this will get longer as I get stronger

Never leave me unsupervised when I am on my tummy

Attachment 7a

Questionnaire 2. (Following video and handout for Riverland group)

Please mark your level of agreement with the statements below by placing a tick in the appropriate box.

In relation to the information you received about hip problems in babies:					
	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
The information I received interested me.					
The information was easy to understand					
I am overwhelmed with advice about my baby					
I now understand more about my baby's hips					
The information about hip problems was confusing					
I found it inconvenient to make myself available to receive this information					
The information has increased my knowledge of how to look after my baby's hips					

In relation to your current knowledge:			
	False	Don't know	True
Hip problems in babies are common			
The hip joint in a newborn baby is a stable, ball and socket joint			
Wrapping helps most babies to settle			
Young babies should not normally be placed on their tummy when awake.			
Young babies should not normally be placed on their tummy when asleep.			
Baby slings are good for most young babies.			
Loose wrapping is better for most baby			

In relation to your plans in the next 4 weeks:					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
It is easier to do things when I understand the reason					
This will all take too much time in my busy day					
Feeding and sleeping are the most important things for my baby at the moment					
Once we have a good routine I will think about wrapping and positioning					
My partner does most of the settling of the baby					

How do you intend to wrap your baby?

____

____

____

In relation to your plans for the next 4 weeks:					
	Never	A few times a week	Once daily	Less than 5 times a day	Five or more times a day
I intend to put my baby on his/her tummy					

In relation to your plans for the next 4 weeks:					
	Never	A few minutes at a time	For 10 to 15 minutes	For 15 to 45 minutes	For more than 45 Minutes
Assuming my baby is happy, I intend to put my baby on his/her tummy					

Please provide any comments you believe to be relevant:

____

____

____

Questionnaire 2. (Following video, handout and ADUS for Mount Gambier group)

Please mark your level of agreement with the statements below by placing a tick in the appropriate box

In relation to the information you received about hip problems in babies:					
	Strongly disagree	Disagree	Uncertain	Agree	Strongly Agree
The information I received interested me.					
The information was easy to understand.					
I am overwhelmed with advice about my baby					
I now understand more about my baby's hips					
The information about hip problems was confusing.					
I found it inconvenient to make myself available to receive this information					
The information has increased my knowledge of how to look after my baby's hips					
I felt confident in the expertise of the ADUS provider					
It was very inconvenient to come for the scan					
I was pleased to see the pictures of my baby's hip					

In relation to your current knowledge:			
	False	Don't know	True
Hip problems in babies are common			
The hip joint in a newborn baby is a stable, ball and socket joint			
Wrapping helps most babies to settle			
Young babies should not normally be placed on their tummy when awake.			
Young babies should not normally be placed on their tummy when asleep.			

Baby slings are good for most young babies.			
Loose wrapping is better for most baby			

In relation to your plans in the next 4 weeks:					
	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
It is easier to do things when I understand the reason					
This will all take too much time in my busy day					
Feeding and sleeping are the most important things for my baby at the moment					
Once we have a good routine I will think about wrapping and positioning					
My partner does most of the settling of the baby					

How do you intend to wrap your baby?

____

____

____

In relation to your plans for the next 4 weeks:					
	Never	A few times a week	Once daily	Less than 5 times a day	Five or more times a day
I intend to put my baby on his/her tummy					

In relation to your plans for the next 4 weeks:					
	Never	A few minutes	For 10 to 15 minutes	For 15 to 45 minutes	For more

		at a time			than 45 Minutes
Assuming my baby is happy, I intend to put my baby on his/her tummy					

Please provide any comments you believe to be relevant:

____

____

____

Attachment 8: Diary

We plan to use simple diagrams of baby faces with expression and tick boxes under each.

Please indicate by placing a tick under the picture that most represents how your baby was at 10.00am, 2.30pm and 8.00pm.

Date:

Time:

In the last 24 hours please estimate the number of hours (to the nearest quarter hour) do you estimate that your baby was:

Number of hours asleep and settled	
Number of hours awake and settled	
Number of hours awake and unsettled	
Number of hours awake and distressed	
Total hours (this should add up to 24)	

My baby is currently well	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

On the first occasion that you put your baby down to sleep after 2.30pm] please describe:

The approximate time:

They were (please circle): Settled / Unsettled / Distressed (face pictures again)

How would you describe their wrapping: Unwrapped / Wrapped

Circle picture:
If wrapped: Firmly around the legs / Loosely around the legs
Firmly around the chest / Loosely around the chest
Arms in / Arms out
Other – please describe

How would you describe the position that you put them in?
On the back / On the side / On the tummy

On the first occasion that your baby had a wakeful time after 0800am today please describe:

You were: At home / You were out

The baby was: Settled / Unsettled / Distressed

How would you describe the position that you put the baby in?
On the back / On the side / On the tummy
Was your baby happy in this position? Yes/ somewhat/no

How long did they remain in this position before you changed their position?

A few minutes	10 to 15mins	15 to 45 minutes	For more than 45 minutes

Why did you change their position?

____
_____

____
_____

	Never	A few times	Once	Two to five times	More than five times
In the last 24 hours I have put my baby on his/her tummy					

Please provide any comments you believe to be relevant:

____
_____

____
_____

____
_____

____
_____

____
_____

____
____

Attachment 9.

Questions for Phone interview 1 :

Thank you for helping us with our study.

Are you finding time to fill in the diary of the way your baby sleeps and plays?

Did your baby spend any time on the tummy yesterday? 1 2 3 >3

Tell me what your baby is doing now.

How does your baby settle best? (comment)

When do you mostly fill in the diary? (comment)

What is your preferred form of carrying your baby? (comment)

Are you getting some sleep?

Is someone helping you with the baby?

Has the CAHYS sister or the midwife been to visit you?

Questions for Phone interview 2.

Thank you for helping us with our study.

Are you finding time to fill in the diary of the way your baby sleeps and plays?

Did your baby spend any time on the tummy yesterday?

What is your baby doing now?

What is your preferred form of carrying your baby?

Are you getting some sleep?

When do you mostly fill in the diary?

Attachment 10.

Questionnaire 3 (at 6-8 weeks)

Thank you very much for taking part in our research. This is the last time we will ask you to answer some questions about yourself and your baby.

Please answer False, Don't know or True to the following questions. There are boxes where you can add a comment if you wish.

I have learnt nothing new about hip development in babies

There are safe ways to wrap a baby

My baby settles well when wrapped.

It is unsafe to put a new baby on its tummy when awake.

The hips of newborn babies are not mature when they are born

I enjoyed keeping a diary of my baby's position when asleep or awake.

I have found it difficult to have time to keep the diary.

I am overwhelmed with advice about the care of my baby.

Feeding has taken up most of my time.

Attachment 11.

To whom it may concern,

Thank you very much for taking part in our study looking at hips in babies and how we care for them. Taking part in a project like this has involved you in sharing your thoughts about how your baby is sleeping and playing and I am very grateful for the information you have provided. We hope you have found the information interesting and it has been a privilege to have you join the research project.
If you would like some follow up on the findings and outcome of the research, I am happy to provide it to you. Please contact me at:
Flinders University Rural Clinical School.
24 Vivienne Avenue
Mount Gambier. 5290

Kind regards from Sue Charlton.

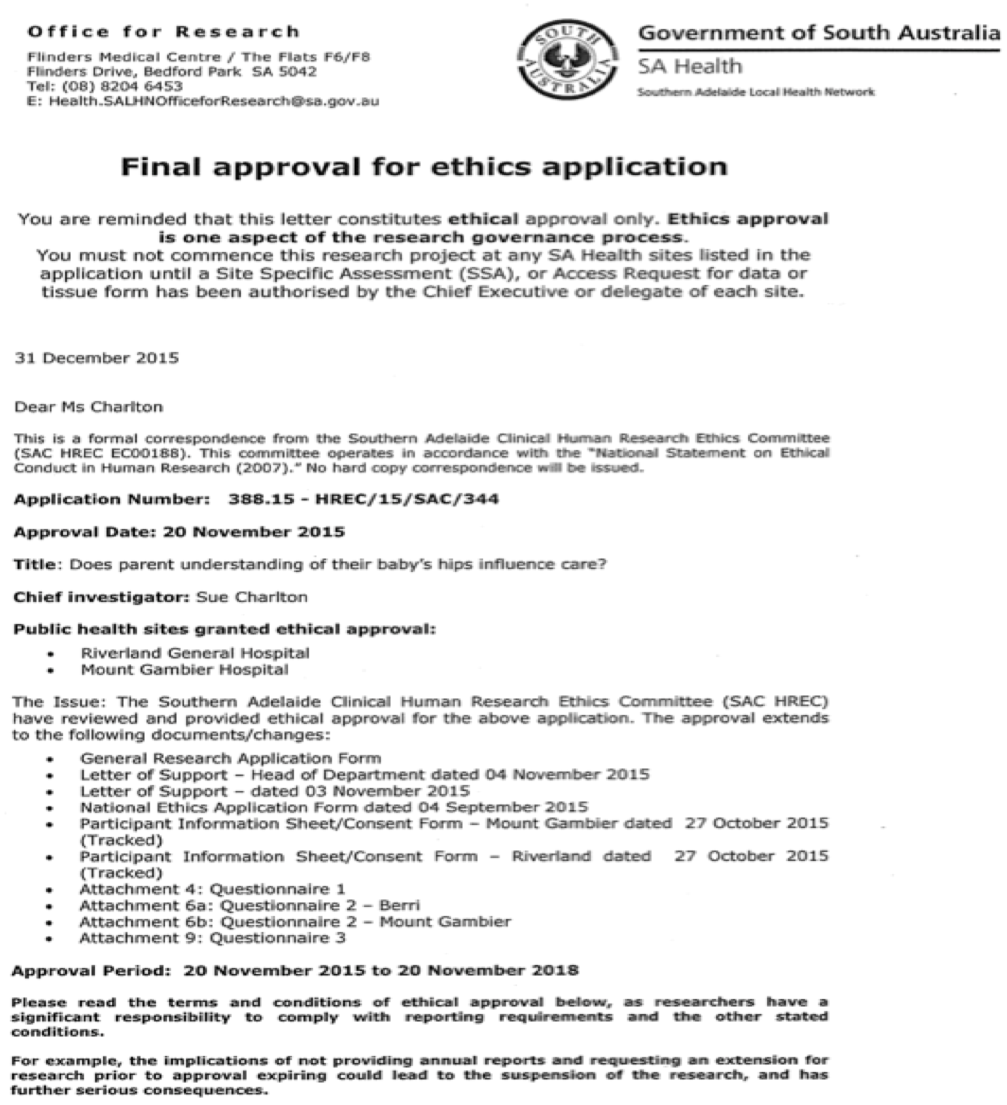
Attachment 12. Indemnity

Hi Lucie
I have now read your ethics application titled “Does parents’ understanding of their baby’s hip development influence care of the newborn” and advise that the University’s general and liability protections will indemnify the Flinders University research participants.
Cheers

Steve Semmler
Insurance Officer
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001
P: +61 8 82012618
Email: steve.semmler@flinders.edu.au W: http://www.flinders.edu.au
| http://www.flinders.edu.au/finance/

Flinders
UNIVERSITY
inspiring achievement

Appendix E - Ethics Approvals



Office for Research
Flinders Medical Centre / The Flats F6/F8
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only. **Ethics approval is one aspect of the research governance process.**
You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

31 December 2015

Dear Ms Charlton

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." No hard copy correspondence will be issued.

Application Number: 388.15 - HREC/15/SAC/344

Approval Date: 20 November 2015

Title: Does parent understanding of their baby's hips influence care?

Chief investigator: Sue Charlton

Public health sites granted ethical approval:

- Riverland General Hospital
- Mount Gambier Hospital

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and provided ethical approval for the above application. The approval extends to the following documents/changes:

- General Research Application Form
- Letter of Support – Head of Department dated 04 November 2015
- Letter of Support – dated 03 November 2015
- National Ethics Application Form dated 04 September 2015
- Participant Information Sheet/Consent Form – Mount Gambier dated 27 October 2015 (Tracked)
- Participant Information Sheet/Consent Form – Riverland dated 27 October 2015 (Tracked)
- Attachment 4: Questionnaire 1
- Attachment 6a: Questionnaire 2 – Berri
- Attachment 6b: Questionnaire 2 – Mount Gambier
- Attachment 9: Questionnaire 3

Approval Period: 20 November 2015 to 20 November 2018

Please read the terms and conditions of ethical approval below, as researchers have a significant responsibility to comply with reporting requirements and the other stated conditions.

For example, the implications of not providing annual reports and requesting an extension for research prior to approval expiring could lead to the suspension of the research, and has further serious consequences.

Final Report / Closeout Form

This final report / site closure form is designed to give researchers the approved mechanism to provide the appropriate notification to the SALHN Office for Research upon the completion of a research project.

Please refer to the National Statement on Ethical Conduct in Human Research, Sections 5.5 (covering all research) and 3.3.19 (for clinical research) for advice on the monitoring and reporting of approved research.

Instructions:

This report is required on completion or close out of the study. Researchers are required to electronically complete and submit this form to the SALHN Office for Research.

Please consider this report acknowledged by the Office for Research on receipt of the automated email response. The Office for Research will only be in contact if further information is required.

Email completed form to: Health.SALHNOfficeforResearch@sa.gov.au

Date: 20/11/2018
Office for Research application number: 388.15
Title: Does parent understanding of their baby's hips influence care
Coordinating Principal Investigator: Sue Charlton
Approval expiry: Does your project still have SAC HREC approval? ☒ Yes - when does your SAC HREC approval expire? 20/11/2018 ☐ No – when did your SAC HREC approval expire? Click here to enter text.

Site details

Site name	Principal investigator	Number of participants recruited	Completion/close out date	Completed/closed out
Mount Gambier Hospital	**Sue Charlton**	**225**	**5/09/2018**	☒Completed ☐Closed out
Riverland Hospital	**Sue Charlton**	**0**	**December 2017**	☐Completed ☒Closed out
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	☐Completed ☐Closed out
Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.	☐Completed ☐Closed out

Please provide a summary of the research outcomes - – please provide the committee with an overview of how the research progressed and any outcomes that are available

The Mount Gambier research arm has gone well with continued interest in the "At Risk" group where 100 more parents have enrolled for the ultrasound examination of their baby's hips and data has been collected on these infants. Four infants were splinted and 23 required follow up scans, 16 of these in line with current clinical guidelines as they were breech babies. The data is being further analysed for comparison with other research studies in the world.

Data retention and storage – please detail how long the study data will be retained, where it will be stored and how it will be disposed of.

The data is stored on the password protected computer of the principle researcher and in a locked file at FURCS Mount Gambier. The “At Risk” data is stored securely at the physiotherapy practice as these children have been referred to that practice.

Please provide a list of all publications to date, including any pending publications, conference presentations, posters etc: Presentation to the perinatal group Mount Gambier November 2018. The results form part of my thesis for a PhD which is currently nearing completion

Please provide copies if available, If not, please email through when they are

Has the project been conducted according to approved protocol, including the reporting of SAE’s, amendments, safety reports, protocol violations etc?

☒ Yes

☐ No (If no, provide comments) Click here to enter text.

Declaration

I confirm the information provided in this form is true and correct.

Chief / Principal Investigator: Sue Charlton

Date: 20/11/2018

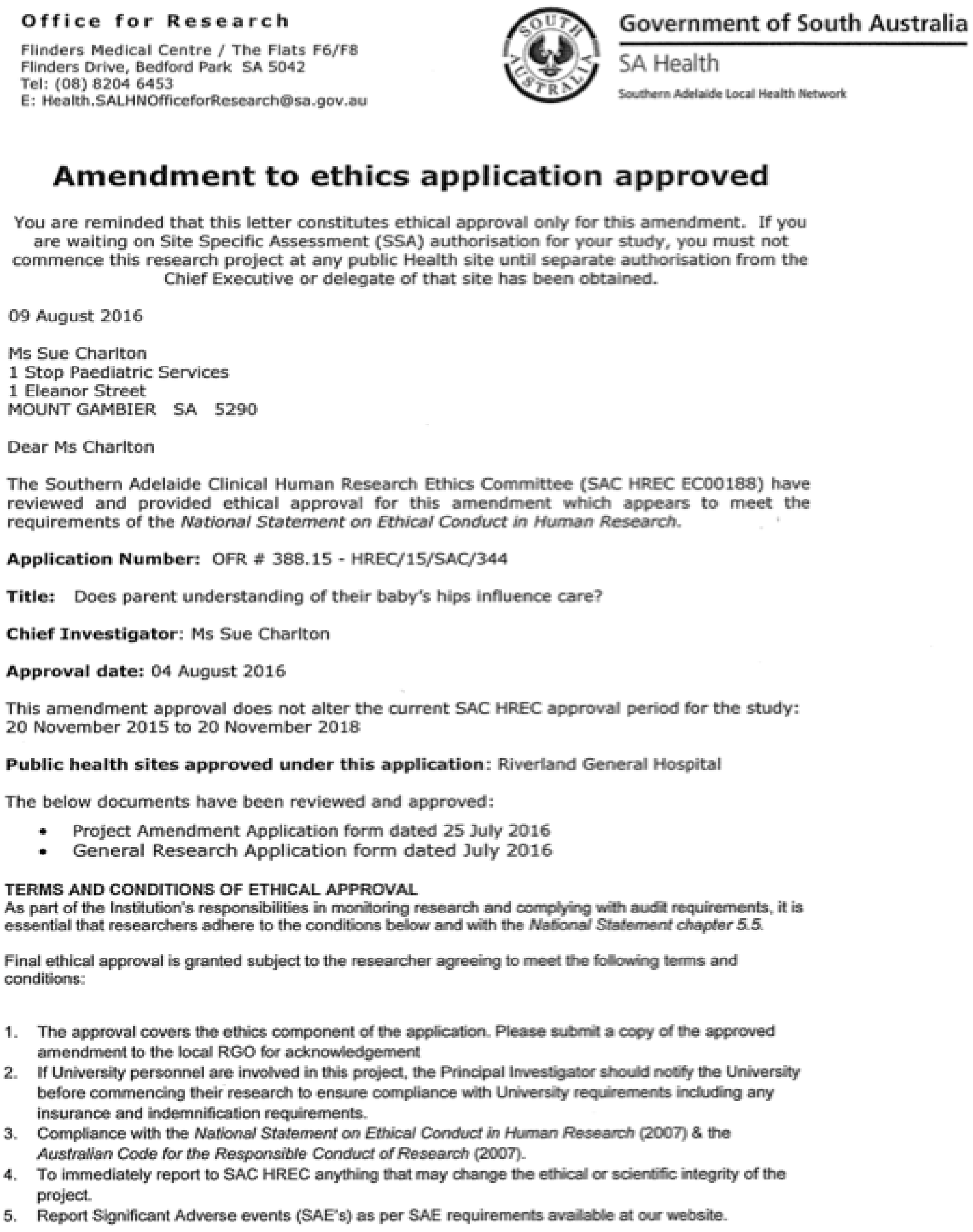
Signature:

For more information

SALHN Office for Research
Ward C / Room 6A – 219
Flinders Medical Centre
Telephone: (08) 8204 6453
Email: Health.SALHNofficeforresearch@sa.gov.au
www. www.sahealth.sa.gov.au/SALHNresearch

If you do not speak English, request an interpreter from SA Health and the department will make every effort to provide you with an interpreter in your language.

Office for Research Final report and closeout form v1
Created: 01.12.2016
Updated 22.03.18
Updated 10.10.18



Office for Research
Flinders Medical Centre / The Flats F6/F8
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Amendment to ethics application approved

You are reminded that this letter constitutes ethical approval only for this amendment. If you are waiting on Site Specific Assessment (SSA) authorisation for your study, you must not commence this research project at any public Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

09 August 2016

Ms Sue Charlton
1 Stop Paediatric Services
1 Eleanor Street
MOUNT GAMBIER SA 5290

Dear Ms Charlton

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this amendment which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 388.15 - HREC/15/SAC/344

Title: Does parent understanding of their baby's hips influence care?

Chief Investigator: Ms Sue Charlton

Approval date: 04 August 2016

This amendment approval does not alter the current SAC HREC approval period for the study: 20 November 2015 to 20 November 2018

Public health sites approved under this application: Riverland General Hospital

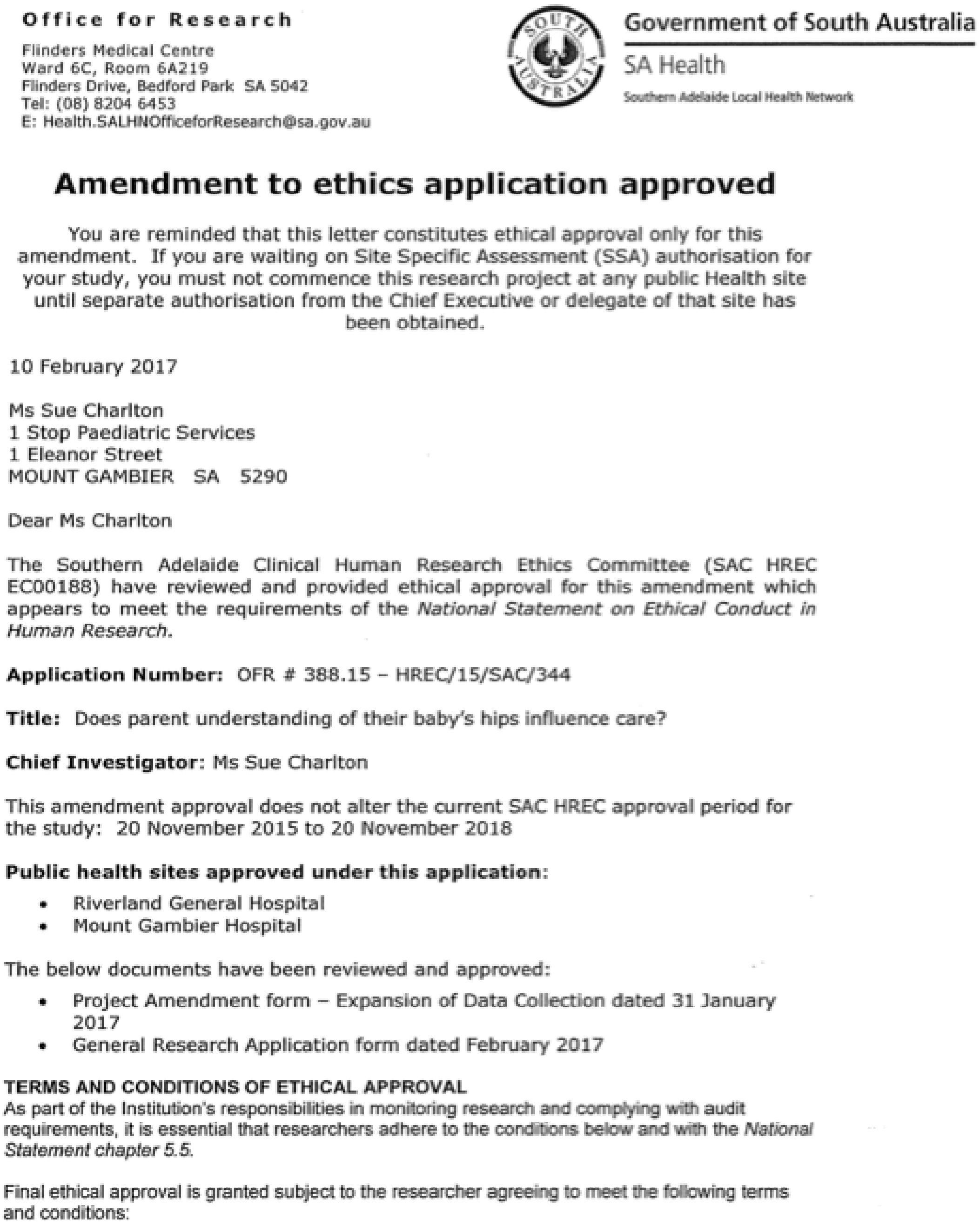
The below documents have been reviewed and approved:

- Project Amendment Application form dated 25 July 2016
- General Research Application form dated July 2016

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval covers the ethics component of the application. Please submit a copy of the approved amendment to the local RGO for acknowledgement
2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to SAC HREC anything that may change the ethical or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.



Office for Research
Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Amendment to ethics application approved

You are reminded that this letter constitutes ethical approval only for this amendment. If you are waiting on Site Specific Assessment (SSA) authorisation for your study, you must not commence this research project at any public Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

10 February 2017

Ms Sue Charlton
1 Stop Paediatric Services
1 Eleanor Street
MOUNT GAMBIER SA 5290

Dear Ms Charlton

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this amendment which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 388.15 – HREC/15/SAC/344

Title: Does parent understanding of their baby's hips influence care?

Chief Investigator: Ms Sue Charlton

This amendment approval does not alter the current SAC HREC approval period for the study: 20 November 2015 to 20 November 2018

Public health sites approved under this application:

- Riverland General Hospital
- Mount Gambier Hospital

The below documents have been reviewed and approved:

- Project Amendment form – Expansion of Data Collection dated 31 January 2017
- General Research Application form dated February 2017

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval covers the ethics component of the application. Please submit a copy of the approved amendment to the local RGO for acknowledgement

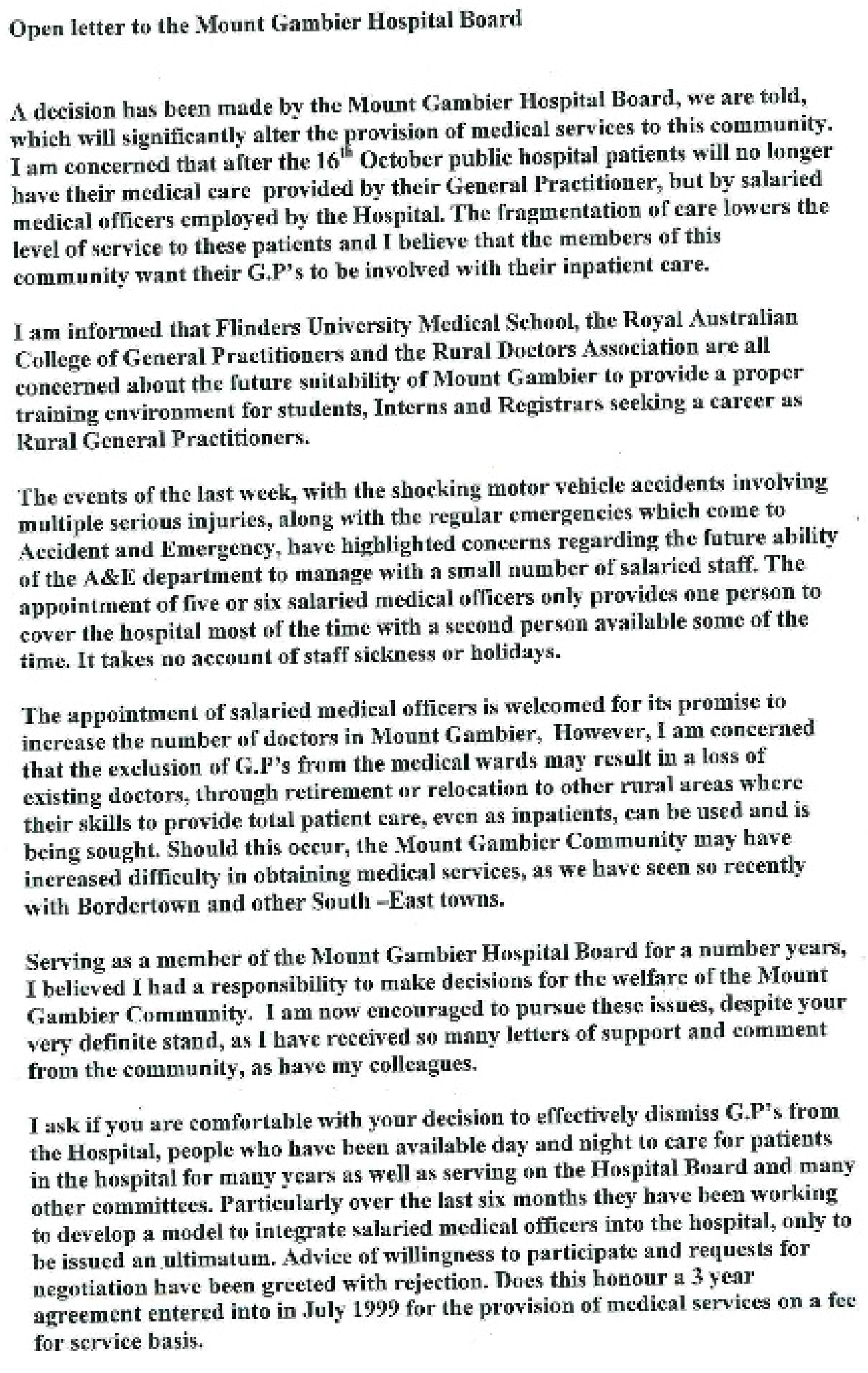
Appendix F - Correspondence

Letter from Lisa (Riverland General Hospital)

Dear Sue ,
The Riverland general hospital is located in Berri it is the main birthing hospital doing 200 births a year with Loxton also doing around 50 births a year.
There are between 8 to 10 midwives on the roster.
The midwives are required to have a patient load in both maternity and general. If they were looking after a post-natal woman, they would still have a patient load which makes them very busy. They also need to attend to assessments and ward outpatients.
When a labouring women comes in the midwife then needs to hand over her general workload to other ward staff.
The problems with getting clients to participate in the hip survey where the midwives where too busy and didn't have the time required and as all babies with hip problems are sent to Adelaide we have little or no contact with them afterwards.
The physios we tried to engage where normally on their 1st year working and rotate through different areas in the hospital
The doctors were hard to engage as they send all babies with hips problems to Adelaide
The clients as I'm sure Sue found in Mt Gambier found the diaries hard to fill out mainly due to time constraints
CAHYS didn't manage to get involved as well
Is this all you wanted Sue just quickly done on night shift. We have a crisis with staffing at moment and are doing a bit more of an on call system with a bit of luck we may have to go to a group midwifery practice to keep birthing at this hospital Cheers hopefully I can catch you when down 26th 27th October
Cheers Lisa

(INCLUDED WITH PERMISSION).

Included with permission



Open letter to the Mount Gambier Hospital Board

A decision has been made by the Mount Gambier Hospital Board, we are told, which will significantly alter the provision of medical services to this community. I am concerned that after the 16th October public hospital patients will no longer have their medical care provided by their General Practitioner, but by salaried medical officers employed by the Hospital. The fragmentation of care lowers the level of service to these patients and I believe that the members of this community want their G.P's to be involved with their inpatient care.

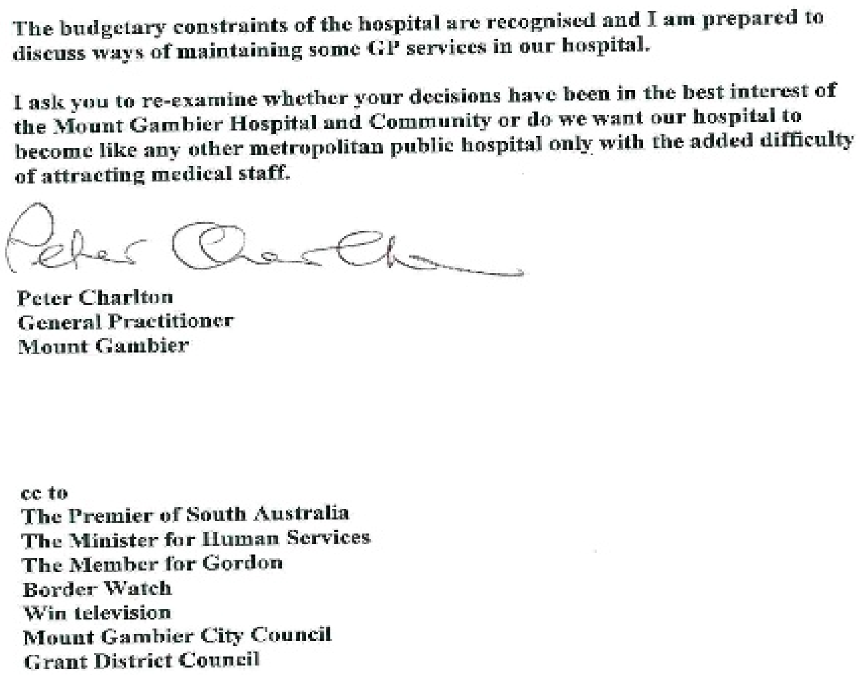
I am informed that Flinders University Medical School, the Royal Australian College of General Practitioners and the Rural Doctors Association are all concerned about the future suitability of Mount Gambier to provide a proper training environment for students, Interns and Registrars seeking a career as Rural General Practitioners.

The events of the last week, with the shocking motor vehicle accidents involving multiple serious injuries, along with the regular emergencies which come to Accident and Emergency, have highlighted concerns regarding the future ability of the A&E department to manage with a small number of salaried staff. The appointment of five or six salaried medical officers only provides one person to cover the hospital most of the time with a second person available some of the time. It takes no account of staff sickness or holidays.

The appointment of salaried medical officers is welcomed for its promise to increase the number of doctors in Mount Gambier. However, I am concerned that the exclusion of G.P's from the medical wards may result in a loss of existing doctors, through retirement or relocation to other rural areas where their skills to provide total patient care, even as inpatients, can be used and is being sought. Should this occur, the Mount Gambier Community may have increased difficulty in obtaining medical services, as we have seen so recently with Bordertown and other South –East towns.

Serving as a member of the Mount Gambier Hospital Board for a number years, I believed I had a responsibility to make decisions for the welfare of the Mount Gambier Community. I am now encouraged to pursue these issues, despite your very definite stand, as I have received so many letters of support and comment from the community, as have my colleagues.

I ask if you are comfortable with your decision to effectively dismiss G.P's from the Hospital, people who have been available day and night to care for patients in the hospital for many years as well as serving on the Hospital Board and many other committees. Particularly over the last six months they have been working to develop a model to integrate salaried medical officers into the hospital, only to be issued an ultimatum. Advice of willingness to participate and requests for negotiation have been greeted with rejection. Does this honour a 3 year agreement entered into in July 1999 for the provision of medical services on a fee for service basis.



The budgetary constraints of the hospital are recognised and I am prepared to discuss ways of maintaining some GP services in our hospital.

I ask you to re-examine whether your decisions have been in the best interest of the Mount Gambier Hospital and Community or do we want our hospital to become like any other metropolitan public hospital only with the added difficulty of attracting medical staff.

Peter Charlton

Peter Charlton
General Practitioner
Mount Gambier

cc to
The Premier of South Australia
The Minister for Human Services
The Member for Gordon
Border Watch
Win television
Mount Gambier City Council
Grant District Council

Appendix G – SonoSite Portable Ultrasound