An investigation into the provision and parents' understanding of discharge information to assist in managing their child following discharge from the Emergency Department of an Australian hospital:

A mixed methods study.

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A thesis submitted in total fulfilment of the requirements for the degree of Doctor of Philosophy

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> > January 2018

# **Declaration of Originality**

This thesis contains no material that has been extracted in whole or in part from a thesis that I have submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the relevant

ethics/safety committees.

Signed:

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January 2018

# Acknowledgements

This thesis represents my research training over a four-year period and my scholarly contribution to the discipline.

I wish to acknowledge and thank my supervisors, Professor Karen Flowers, Professor Geraldine Naughton, Professor Paul Fulbrook, and Dr. George Mnatzaganian. For an international student, the differences in culture and language can make learning more difficult. My supervisors understood the great concerns faced by international students, and encouraged me to try out new and more effective ways to study. Their guidance, expertise, respectful critique, encouragement, and patience turned each supervision meeting into a valued experience. Learning from them, and working with them, has been an amazing journey. Thank you for being so inspiring.

I am particularly grateful to those nurses, medical doctors, research assistants, and participants who participated in this thesis, and who shared their experiences with me. I would also like to acknowledge the hospital in Queensland, Australia, which served as the study site, and provided me with the opportunity to collect data for my research program.

I gratefully acknowledge the support of Suratthani Rajabhat, University in Thailand, for the scholarship that made it possible to complete my research program as a full-time student in Australia. In addition, I would like to acknowledge the support of the School of Nursing, Midwifery and Paramedicine, Australian Catholic University, for their Financial Research Support Schemes for higher degree students, which provided some financial assistance during the progress of the research program.

Finally, I thank my family and friends in Thailand and in Australia for their love and encouragement. Thank you everyone for helping me through all those tough times. I will always remember your kindness, support, and understanding over the past four years.

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# Abstract

# Introduction

Providing useful discharge information is a key priority for Emergency Department staff, especially when children are discharged from hospital because they are vulnerable, relying on their parents or guardians for the care. If these carers do not fully understand the discharge information, their child's health and wellbeing may be compromised. For example, parents may make medication errors, with a risk that their child may not receive the appropriate dosage at the right time. Children may experience oligoanalgesia or be over-medicated for pain. Parents may not understand the signs that indicate they need to seek further medical attention for their child or return unnecessarily to busy EDs, which may increase health costs. A better understanding of the provision of discharge information in ED may reduce these risks.

## Aims

The aim of this thesis is to explore the provision of discharge information to parents to assist in managing their child's care post discharge from the ED. This thesis explores:

- 1. Factors in the ED that support the provision and understanding of discharge information to parents.
- ED nurses' perceptions of factors that influence parents' understanding of discharge information
- 3. Parents' perceptions of the discharge information they received from the ED.

## Methods

This thesis has been guided by the philosophy of pragmatism and the Donabedian Model of Quality of Care conceptual framework. The mixed methods convergent parallel design used for this research, conceptualised as a "triangulation" design where quantitative and qualitative data are used to obtain triangulated results about a single topic. Triangulation data were collected through multiple methods and from four different studies: (i) document analysis; (ii) non-participant observation in the ED; (iii) focus groups with ED nurses; and (iv) a survey of parents of children attending the ED. The setting for data collection was a children's ED at a tertiary referral hospital in Queensland, Australia. Data from each method were analysed separately, and then compared and integrated. Descriptive methods were used to analyse quantitative data, while thematic analysis was applied to qualitative data.

## Findings

For the first time, the provision of the discharge information for parents in Australian ED has been explored using the Donabedian Model of Quality of care. This model provides direction in exploring the structural issues, processes, and outcomes domain of the provision discharge information.

A thematic analysis of the findings from the 4 studies identified three key circumstances under which parents' understanding of discharge information could be compromised or promoted. These circumstances are reflected in three themes: (i) the structures that support the provision of discharge information resources for parents; (ii) the impact of waiting times; and (iii) the structures and processes that underpin the model of care in the ED, and which guide the role of the ED staff in minimising the risk of parents' misunderstanding information provided to them.

# Conclusion

This thesis has investigated the structures, processes and outcomes relating to parents' understanding of discharge information in an ED setting. Recommendations on strategies and future research to improve the provision of discharge information have been outlined. Ultimately, the findings from this study could inform future research endeavours to help ED staff and parents provide a high quality of care for children following discharge from the ED.

# Abbreviations

- ATS Australasian Triage Scale
- **CIN** Clinical Initiatives Nurse
- **CNS** Clinical nurse specialist
- ED Emergency Department
- **GP** General Practitioner
- ISCED International Standards of Care for Children in Emergency Departments
- **NEAT** National Emergency Access Target

NHS National Health Service

NP Nurse Practitioner

- NSW New South Wales, Australia
- **QHEPS** Queensland Health Electronic Publishing Service
- **RA** Research Assistant
- RCHM Royal Children's Hospital, Melbourne

**SMOG** Simple Measure of Gobbledegook

- UK United Kingdom
- USA United States of America

# **Chapter 1: Introduction**

#### **1.1 Introduction**

The role of parents in caring for their child's health is important, because parents are responsible for taking care of their children in every-day living. However, when their child incurs an acute injury or contracts an illness, parents often present with their child at the Emergency Department (ED). ED nurses can make an important contribution to supporting parents to confidently care and manage their child after leaving the ED. Advice given by ED staff to patients prior to their discharge from the ED is referred to as discharge information.

My interest in children's health arises from my professional interest following a paediatric nursing background in various healthcare settings in both the public and private sectors in Thailand. As a paediatric nurse, I am interested in gaining a better understanding of parents' perception of discharge information and parents' satisfaction with discharge information provided in the ED for the ongoing management of their child at home.

This first chapter introduces the thesis, which aims to explore the provision of discharge information for given to parents to assist in managing their child's care post following discharge from the ED. It also presents the background to the thesis defines the research problem, lists the research aims and objectives, explains the significance of the thesis, and provides a chapter by chapter overview of the Thesis.

#### 1.2 Background

Presenting to an ED can be an anxious time for children and their families, particularly as the need for treatment may be urgent. Within a short span of time in the ED, young patients and families encounter numerous staff, and may be subjected to unfamiliar and often anxiety-provoking procedures. The ED is a dynamic and often busy healthcare setting, which may not be an ideal place to educate parents on the care of their sick or injured child. However, this is exactly the place where discharge planning and patient and family teaching and learning should begin (Gozdzialski, Schlutow, & Pittiglio, 2012; Howenstein & Sandy, 2012).

A poor understanding of discharge information is an important issue, because it potentially exposes patients to unnecessary risks, including re-admission to the ED (with associated increased cost of health services), (Morrison, Myrvik, Brousseau, Hoffmann, & Stanley, 2013), mismanagement of medications and dosing errors (Samuels-Kalow, Stack, & Porte, 2013), disruption of family and social life, and emotional distress. Therefore, it is essential for parents of children who have presented to the ED to understand all discharge information provided to them; this may include how to manage their child's ongoing care.

There are five key aspects of the background of this research which are discussed in the following sections: (i) The context of an Emergency Department; (ii) Child presentations to the ED; (iii) Discharge planning in the ED; (iv) Parent's anxiety in the ED; and (v) Health literacy.

#### 1.2.1 The context of an Emergency Department

An ED is a medical treatment facility or hospital department, providing 24-hour emergency care, and specialising in the diagnosis and treatment of urgent illnesses and injuries in patients who present without prior appointment, either by their own means or by ambulance (Queensland Health, 2016). The ED may be part of a children-only or adult-only service, or may be mixed, with its own staff (International Federation for Emergency Medicine, 2012). Emergency departments are like other hospital medical units, and will characteristically have an organisational structure that includes a director, and senior medical and nursing staff (Australasian College for Emergency Medicine, 2012). ED staff (doctors, nursing and allied health professionals) work in a team, with fewer boundaries between their roles than their colleagues working in an in-patient environment (International Federation for Emergency Medicine, 2012). As with all health services in Australia, the ED can also be a place for staff training and education. Staff can include medical students, interns, and residents who rotate shifts in various departments as part of their hospital-based training, or pre-service nurses, paramedics or physiotherapists who are also in training.

Various roles can be assigned to ED nurses in Australian hospitals, and include: triage nurse, clinical nurse specialist, and emergency nurse practitioner. Triage nurses assign scores to patients based on the severity of their condition on presentation to the ED. Triage scales are summarised in Table 1. A modified Delphi study recently reviewed the understanding of the relatively new role of triage nurses in the highly complex and ever-changing environment of an ED (Ebrahimi et al., 2016). It was concluded that skills in prioritising were the major workplace demand for triage nurses. The overarching consensus was that educational programs and dedicated research could best support the prioritising skills of triage nurses in

providing diagnostic and therapeutic interventions in caring for patients (Ebrahimi et al., 2016).

Clinical nurse specialists (CNS) in emergency nursing (Australian Nursing & Midwifery Federation, 2014) are registered nurses who have completed additional training in emergency medical care; specialising in advanced and complex patient care for acute illness and injury. These specialists can also play a role in hospital policy development and peer or student education (College of Emergency Nursing Australasia, 2013). However, NSW has established a specific position known as the Clinical Initiatives Nurse (CIN) (Emergency Care Institute New South Wales, 2017), whose role is to provide care to patients in ED as they wait to see medical consultants following the allocation of a triage score. The role of the CIN can have the following priorities: maintaining an ED nursing presence within the waiting room to ensure safety within this clinical setting, engaging, and communicating with both patients and carers about ED processes, communicating expected waiting times, and ideally providing relevant information on patient-specific health issues (Emergency Care Institute New South Wales, 2017).

Emergency Nurse Practitioners (NP) are highly educated and skilled nurses, who are permitted to prescribe medications and to order and interpret tests, diagnose, and treat disease, and provide referrals to other health professionals; points of difference between roles of NP and CNS/CIN (Doetzel, Rankin, & Then, 2016). The scope of practice for the Emergency NP can also include managing patient care for minor illness or injury, which have been assigned a triage score of 4 to 5 (Lowe, 2010).

Patients are seen in order of curative urgency with non-urgent patients being seen after more acute patients. Patients who require urgent attention will commonly be seen first. On arrival at the ED, patients are assessed by a triage nurse and provided with a triage score (Australasian College of Emergency Medicine, 2016). "A triage score is a ranking from one to five (one being the most urgent and five being non-urgent)" (Mnatzaganian, Braitberg, Hiller, Kuhn, & Chapman, 2016, p. 4). Triage scales are used by staff to prioritise and categorise patients, for medical and nursing care in the ED, based on their illness or the severity of their injury or need (Queensland Health, 2016). Table 1 presents the five categories of the

Australasian Triage Scale (ATS), the recommended response to each category, and a description of each category.

# Table 1: Australasian Triage Scale

(Australasian College of Emergency Medicine, 2016, pp. 5-8)

| ATS Category | Response  | Description of Category   |
|--------------|---|---|
| Category 1   | Immediate<br>simultaneous<br>assessment and<br>treatment  | Immediately Life-Threatening<br>Conditions that are threats to life (or imminent<br>risk of deterioration) and require immediate<br>aggressive intervention   |
| Category 2   | Assessment and<br>treatment within 10<br>minutes<br>(assessment and<br>treatment often<br>simultaneous) | Imminently life-threatening<br>The patient's condition is serious enough or<br>deteriorating so rapidly there is the potential<br>of threat to life, or organ system failure, if not<br>treated within ten minutes of arrival<br>or<br>Important time-critical treatment<br>The potential for time (e.g. thrombolysis,<br>antidote) to make a significant effect on<br>clinical outcome depends on treatment<br>commencing within a few minutes of the<br>patient's arrival in the ED<br>or<br>Very severe pain<br>Humane practice mandates the relief of very<br>severe pain or distress within 10 minutes |
| Category 3   | Assessment and<br>treatment start within<br>30 mins   | Potentially Life-Threatening<br>The patient's condition may progress to life or<br>limb threatening, or may lead to significant<br>morbidity, if assessment and treatment are<br>not commenced within thirty minutes of<br>arrival<br>or<br>Situational Urgency<br>There is potential for adverse outcome if time-<br>critical treatment is not commenced within<br>thirty minutes<br>or  |

|            |   | Humane practice mandates the relief of severe   |
|------------|---|---|
|            |   | discomfort or distress within thirty minutes  |
| Category 4 | Assessment and<br>treatment start within<br>60 mins | discomfort or distress within thirty minutes Potentially serious The patient's condition may deteriorate, or adverse outcome may result, if assessment and treatment is not commenced within one hour of arrival in ED. Symptoms moderate or prolonged Or Situational Urgency There is potential for adverse outcome if time- critical treatment is not commenced within one hour Or Significant complexity or Severity Likely to require complex work-up and consultation and/or inpatient management Or Humane practice mandates the relief of discomfort or distress within one hour |
| Category 5 | Assessment and                                      | Less Urgent   |
|            | treatment start within<br>120 minutes               | The patient's condition is chronic or minor<br>enough that symptoms or clinical outcome will<br>not be significantly affected if assessment and<br>treatment are delayed up to two hours from<br>arrival<br>or<br>Clinico-administrative problems<br>Results review, medical certificates,<br>prescriptions only  |

Emergency departments are a critical constituent of Australia's health-care system, providing care for patients who require urgent attention, in both public and private hospitals in Australia. In 2014–15, there were about 7.4 million presentations to the 290 Australian public hospital emergency departments that reported to the National Non-Admitted Patient Emergency Department Care Database; this corresponded to over 25,000 patient presentations each day across Australia. Presentations to EDs in Australia increased

approximately 65% between 2001 and 2011 (Silk, 2016) and by 2.4% between 2013–14 and 2014–15 (Australian Institute of Health and Welfare, 2015). Non-urgent presentations represented 9.5% of all cases. However, proportions differed by state, with Queensland having the lowest non-urgent percentage of cases (5%), but also having the highest percentage of most urgent cases (44%) (Australian Institute of Health and Welfare, 2016). With such growth in demand for ED services for urgent and non-urgent presentations, there are times when overcrowding occurs in Australian EDs.

Informed by National Health Service [NHS] reform in the UK, and as a direct response to increasing media and political concerns in Australia about ambulance diversions, congestion of ambulances, and overcrowding of patients within EDs (Queensland Government, 2015) [all of which could potentially delay emergency care and increase the length of hospitalisation and patient outcomes (Silk, 2016)], the National Emergency Access Target (NEAT) was announced by the Council of Australian Government in April 2010. The objective of the NEAT is to progressively increase the percentage of patients whose total time in the ED is less than 4 hours, whether an admission, a transfer or a discharge occurs, while at the same time ensuring safe, timely and high-quality patient care. A trial of the four-hour rule commenced in Western Australia in 2008, and was subsequently adopted Australia-wide in 2011. The NEAT was to have a staggered five-year roll out; with a target of 95% of patients being discharged within four hours the initial priority was to implement the four-hour rule with the most severe triage scores in all states (Queensland Government, 2015). Table 2 presents the stages of the rollout by triage category.

| Stage | Year of      | Targeted triage category identified for the |
|-------|--------------|---|
|       | introduction | 95% goals of meeting the 4-hour rule with   |
|       |              | patients in these categories                |
| 1     | 2011         | 1   |
| 2     | 2012         | 2   |
| 3     | 2013         | 3   |
| 4     | 2014         | 4   |
| 5     | 2015         | 5   |
|       |              |   |

Table 2: Development of the five-stage roll out for specific ATS categories

The Australian government announced that EDs would embrace the National Emergency Access Target rule in 2011 (Sullivan et al., 2016), which generated a new-challenge to the ED working environment. At the time of NEAT introduction in Australia, concern, and criticisms about the implementation of the UK four-hour target had been focused on time targets undermining patient care, placing more value on time rather than patients, and potentially pressuring doctors to make inappropriate clinical decisions. Moreover, it was argued that the four-hour target was not founded on evidence but on a belief, that timeliness correlates closely with quality of care and patient satisfaction. Then, the expert panel clearly differentiated the Australian adoption of the four- hour target from the UK model, with one variation being a change in the title from the National Access Target for Emergency Departments to National Emergency Access Target (NEAT) to widen the focus from emergency departments to the necessary whole-of-hospital change process. A phased approach towards a 90% compliance target was preferred, with the expert panel acknowledging the different circumstances required some variability in setting targets within different states and territories in Australia, and mandated alternative implementation trajectories. However, all targets were to be set at the beginning of the 2012 calendar year with the ultimate target of 90% compliance being reached in each state by 2015 (Queensland Government, 2015).

NEAT compliance improved between 2010 and 2014 in Australia. Results (from data from 59 hospitals involving 12.5 million cases) showed declines in the hospital standardised mortality ratio from emergency admissions. However, a direct inverse relationship was negated once total and admitted NEAT compliance exceeded critical thresholds. Specifically, this inverse association between NEAT compliance and the hospital standardised mortality ratio was less clear after total and admitted compliance rates exceed 83% and 65%, respectively. Thus, the success of the 90% NEAT target remains contentious (Sullivan et al., 2016). Achieving the NEAT target and managing the other complexities of the ED can make discharge planning difficult, particularly when overcrowding is common situation.

#### 1.2.2 Child presentations to the ED

Children (0-14 years) who present to the ED can have particular needs, such as being unable to give a clear history, and they come with parents and or family. Children frequently succumb to illness more quickly than adults; however, they also normally recover more rapidly, and are less likely to have underlying chronic illnesses (International Federation for Emergency Medicine, 2012). EDs regularly see a high proportion of children aged younger than 2 years because of viral illnesses, and children aged less than 2 years also attend with non-specific symptoms including fever, poor feeding, and vomiting (International Federation for Emergency Medicine, 2012).

One of the most frequently cited reasons given by parents for taking a child to ED, even without referral by the child's primary care physician, was they had a habit of going to the ED (Wong, Claudet, Sorum, & Mullet, 2015). Other reasons for presenting to a paediatric ED include an expectation of child-specific expertise and care, quick diagnosis and treatment, and dissatisfaction with recent previous medical consultations (such as a local GP) (Wong et al., 2015). Non-urgent use of the ED may lead to overcrowding, long waiting periods, increased costs, high ED staff dissatisfaction, and lower quality of care for patients requiring urgent care (Kua et al., 2016). Some international statistics on the relative percentage of non-urgent to urgent presentations to paediatric EDs include 58% in North America, 57% in Italy and 40% in Belgium (Wong et al., 2015).

In Australia, the 0–4 year age group were over-represented within the number of presentations receiving a triage category 4 or 5 (non-life-threatening presentations), but this proportion steadily decreased as age increased (Freed, Gafforini, & Carson, 2015).

Within the national statistics (July 2015 to June 2016) on overall emergency presentations, 11% of cases were younger than 4 years of age, and more boys than girls aged 0 to 14 years presented to EDs (56% and 44%, respectively) (Australian Institute of Health and Welfare, 2016). Statistics collected between 2005 and 2010 at a large children's ED in Western Australia, suggested children under 5 years of age were highly vulnerable to injury, accounting for 42% of all presentations by children under 15 years old. When injury data were extended to include children under 10 years of age, this age group accounted for 66% of all the injury presentations to this children's ED by children under 15 years old. These injury statistics from Australia are supported elsewhere.

The Australian Sports Commission (2016) reported that children's involvement in organised sport was highest between the ages of 9-11 years, with 87% of males and 92% of females engaging in sport outside of school over a 12-month period. Previous studies show large numbers of children present to the ED with sports-related injuries (Carter & Micheli, 2012; Hanson, Pomerantz, & Gittelman, 2013). These sports-related injuries included skateboarding, and rollerblading, riding a scooter and cycling. Overall, the sport most frequently represented in young people was categorised as roller sports (skateboards and roller blades) followed by rugby, soccer, and cycling (Finch, Clapperton, & McCrory, 2013). More than one third of these children received ED diagnoses ranging from dislocation, fracture, joint injury, amputation, laceration, sprain, ligament injury, and soft tissue inflammation to contusion or abrasion (Gourde & Damian, 2012). These types of injuries require ongoing home care, including pain management.

In comparison with adults, children can be more difficult to diagnose. As EDs are frequently noisy and chaotic, children are more easily frightened, cry, or are unhelpful. Parents are, therefore, often required to assist in determining the presence and severity of symptoms and also communication involves both the child and their parents. Thus, ED staff need to be familiar with the stages of child development, and be able to communicate with children at

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all developmentally appropriate levels. Effective communication with children and parents is a key for best patient outcomes (International Federation for Emergency Medicine, 2012).

Many children with acute illness or injury will only require a limited number of visits to the ED. Children with acute presentations may undergo relatively short and non-invasive treatments such as suturing, plastering and the administration of pharmacological and non-pharmacological pain relief. Non-pharmacologic strategies for children include distraction techniques using toys, music, television, storytelling, tablet computers and video goggles and also, other techniques such as blowing bubbles or balloons combined with the relaxation of deep breathing (Williams & Ishimine, 2016). As treatments for injuries usually require aftercare, providing information to enable parents to continue their child's care in the home is an important responsibility of the ED staff.

#### 1.2.3 Discharge planning in the ED

Discharge planning is an important multi-faceted component of quality care in the ED, which enables continuity of care. The expected standard of care for patients who are discharged from EDs is that all patients receive verbal and written information including a discharge summary, symptoms and signs of clinical worsening in the written information and discharge instructions (The Australasian College for Emergency Medicine, 2015). Discharge planning by ED staff encompasses individualising patient self-care information and instructions, referring patients to other medical or health services, and ensuring patients or carers comprehend the information and have the capacity to provide the necessary care in the home setting (McCarthy, Engel, Buckley, Forth, Schmidt, Adams, & Baker, 2012; Samuels-Kalow, Stack, & Porte, 2012). Effective discharge planning is vital to the patients' safety and quality of care after leaving the ED, and central to this is an appreciation of how much the patient and/or their family understands and agrees with the information provided.

Continuation of medical care after discharge from an ED is dependent on parents' understanding of, and compliance with, follow-up instructions and on adherence to medication recommendations. However, without understandable information at discharge, parents may not be well placed to manage their child's care at home. For example, abdominal pain and fracture in children are common causes in triggering presentations to the ED (Caperell, Pitetti, & Cross, 2013; Gourde & Damian, 2012; William et al., 2012). Yet, previous

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studies have reported that some parents are poor judges of children's pain and do not adequately understand pain management at home (Crocker, Higginbotham, King, Taylor, & Milling, 2012; Gourde & Damian, 2012). Therefore, when children leave the ED, appropriateness of information for parents appears to be required.

Discharge planning requires consideration of how effectively information can be provided, and the type of information that is provided prior to discharge in order to optimise quality patient care at home.

#### 1.2.3.1 Discharge Information

Discharge information is defined as verbal or written information given by ED staff to the patient or carer, prior to discharge to the home, for the intent of enabling safe and suitable continuity of care (Al-Harthy et al., 2016). Discharge instructions are guidelines patients should follow after discharge to deal with any remaining symptoms that need to be taken care of personally by the patient, home care attendants, or other health care providers on an outpatient basis. For paediatric patients, a nurse or other health care providers usually provides ED discharge instructions to the child's parents and/or carer, in simple language.

ED discharge information can be more poorly understood by patients than any other hospital discharge information (Kaestli et al., 2014). Therefore, providing useful and understandable discharge information is a key priority for ED staff, and is especially significant when children are the patients.

There are numerous delivery models for the provision of discharge information, for example illustrative, video, audio-recorded and internet information (McCarthy, Engel, Buckley, Forth, Schmidt, Adams, & Baker, 2012). The process of providing discharge information includes: communicating essential information; checking the patient's comprehension of discharge information; and modifying information in response to perceived anxiety or difficulties with understanding (Engel et al., 2012; Samuels-Kalow et al., 2012). Discharge information also includes patient education about self-care, and the symptoms which may require a return visit to the ED, such as signs of infection and uncontrollable pain (McCarthy, Engel, Buckley, Forth, Schmidt, Adams, Baker, et al., 2012). However, it is possible that multiple factors can interfere

with both the provision and understanding of these instructions and information (Samuels-Kalow et al., 2012).

For the purposes of this research, discharge information is any written and verbal information (Gozdzialski et al., 2012) provided by ED staff to parents and/or guardians, prior to patient (their child) discharge. Such information may include strategies and instructions for the management of the child at home, information about potential signs and symptoms requiring further medical follow-up or return to the ED, follow-up referral to other health care professionals, and information on community health services (Engel et al., 2012; Samuels-Kalow et al., 2012). Discharge information provided by ED staff encompasses parent education about child's care. There is less anxiety and perceptions of isolation if this communication between staff and parents is interactive, with opportunities for questions from parents (Gozdzialski et al., 2012). Standardised information provided to parents at discharge can improve knowledge and satisfaction with ED care (Curran et al., 2014).

Parent education about post-discharge care is essential for safe and effective care after discharge. The majority of strategies to improve discharge communication have been educational strategies targeting parents (Curran, 2014). However, parents of children presenting to the ED have more difficulty comprehending their discharge information and home care plan than any other aspect of their child's visit (Samuels-Kalow et al., 2013). To improve this situation in the ED, the Department of Health in Victoria, Australia, for example, provides Fact Sheets in six languages (Arabic, Greek, Italian, Mandarin, Turkish, and Vietnamese). They are designed to provide better communication between ED staff and patients and/or carers, in condition-specific health and medical areas (Nieswiadomy, 2012).

However, despite the importance of discharge information, many parents leave the ED without fully understanding their child's discharge information.

#### 1.2.4 Parents' anxiety in the ED

Parents' anxiety may limit their understanding of the information provided by ED staff for the child's care following discharge. Many factors may contribute to parental anxiety, including the severity of symptoms of a disease (Serinken et al., 2014; Zemek et al., 2013), family history of illness, perception of the child's general health and parental feelings about the hospital

(Wong et al., 2015). In addition, families who perceive their children as being vulnerable may be at particular risk for anxiety (Chappuy et al., 2012). Furthermore, basic procedures performed in the ED can be stressful, and may increase anxiety (Zemek et al., 2013).

Parents of persistently symptomatic children remain significantly more anxious than those whose children's symptoms are likely to readily resolve (Zemek et al., 2013). Moreover, stress and anxiety may prevent parents from thinking about the specific information needed to effectively manage their child at home after discharge (Engel et al., 2012).

#### 1.2.5 Health literacy

Health literacy is an all-encompassing term, referring broadly to the capacity of an individual to read, understand and apply knowledge and skills to manage health-related practices. It is inclusive of skills and proficiencies developed to find, understand, assess, and apply information about health and health issues to make informed decisions, to decrease health risks, and to improve quality of life (Goodman & Evans, 2010a). Health literacy problems include difficulty reading and interpreting medical instructions, medication labels, and appointment slips, and poor understanding of chronic conditions and accompanying management (The Independent Hospital Pricing Authority, 2015). Patients with a lower level of health literacy are more frequently admitted to hospital, have poorer health outcomes such as a higher level of morbidity, low overall health status, and as a consequence will continue to rely on health resources

Children with parents who have lower levels of health literacy are over-represented in nonurgent ED use (Morrison, Schapira, Gorelick, Hoffmann, & Brousseau, 2014).

Limited language skills, along with other demographic and disease-specific factors such as chronic disease, Health insurance, age, time of arrival, region of residence, has been associated with increased risk of a return visit to the ED (Samuels-Kalow, Stack, Amico, & Porte, 2015). Moreover, several studies show that written ED discharge instructions can be beyond the limits of the patients' health literacy (Herndon, Chaney, & Carden, 2011; Morrison et al., 2013; Morrison et al., 2014).

Because of poor understanding of children's illnesses, parents with low health literacy may inaccurately assess their child's illness as serious, and misunderstand the severity of the child's symptoms, all of which may lead to unnecessary ED presentations (Morrison et al., 2014).

#### 1.3 The Clinical Problem: Parents not understanding discharge information

Parents' understanding of discharge information is important because parents are responsible for the care of their children and if they do not fully understand the discharge information this may lead to errors in the care of children or they may return unnecessarily to the EDs or more significantly not bring their child back to the ED if their condition worsens. Many factors may limit a parent's understanding of discharge information: inadequate communication between ED staff and parents at discharge (Curran et al., 2017); parents' anxiety; stress and anxiety may prevent parents from thinking about the type of information they may need to manage their child at home, after discharge (Curran et al., 2017); and parental concern that their child is in pain (Chappuy et al., 2012).

Other factors impacting parents' understanding include the parents' level of education (Al-Harthy et al., 2016), health literacy (Ismail et al., 2016), language skills (Samuels-Kalow et al., 2013), and perceived confidence to manage the situation at home which may result in parents missing key concepts, either in the written information provided, or in the verbal delivery of discharge information by the ED staff (Al-Harthy et al., 2016); in particular, any unfamiliar medical terminology (Samuels-Kalow, Stack, et al., 2016). Parents with a low level of health literacy have a higher probability of not understanding discharge information (Ismail et al., 2016; Samuels-Kalow et al., 2012), which is important because they parents are responsible for the management of their young children at home.

Parents who are lacking in health literacy are more likely to make medication errors, often confusing the dosage (Samuels-Kalow, Stack, et al., 2016). In addition, previous studies assessing parents' knowledge of appropriate dosages, and their decisions regarding the use of medication, found parents often do not provide their children with the appropriate dosage, leading to oligoanalgesia (Gorodzinsky, Davies, & Drendel, 2013). Oligoanalgesia defines "under treatment of acute pain" (Albrecht et al., 2013). Oligoanalgesia is a consequence of an inadequate use of the medication to relieve pain, inducing negative sensory and emotional experiences (Decosterd et al., 2007). Oligoanalgesia remains a major issue in children's health

care (Ali et al., 2014) and providing medications inefficiently may be very detrimental for children (Gorodzinsky et al., 2013).

Moreover, a previous study in the United States of America (USA) revealed parents with inadequate health literacy are more likely to make increased rates of emergency department use for children, with roughly one in three parents of children presenting to the ED have low health literacy (Morrison et al., 2013). For parents with low health literacy, unscheduled returns to the ED may reflect a lack of understand of medications, return instructions, follow-up plans, or other reasons resulting in failure of patients to activate follow-up plans as intended. Importantly, providing useful discharge information for parents with low health literacy is a key priority for the ED staff promoting children's health and in reducing ED utilization.

One way to overcome problems that parent lack of understanding discharge information is through a better understanding of the provision of discharge information for parents to assist in managing their child post discharge from the Emergency Department.

#### 1.4 The aim, objectives, research questions

Based on the issues discussed above, the following aim, objectives and research questions were developed to guide in this thesis.

#### 1.4.1 Research aim

The aim of this thesis is to explore the provision of discharge information given to parents to assist in managing their child following discharge from the ED, and help fill a significant gap in the current literature.

#### 1.4.2 Research objectives

The aim of this research will be addressed by exploring and identifying:

- 1. Factors in the ED that support the provision and understanding of discharge information to parents;
- ED nurses' perceptions of factors that influence parents' understanding of discharge information; and
- 3. Parents' perceptions of the discharge information they received from the ED.

## 1.4.3 Research Questions

In addressing the above aims and objectives, this research sought to answer the following four questions:

- 1. What protocols, procedures, guidelines, and resources are used to inform and support the provision of discharge information in the ED?
- 2. What are the current practices in the provision of discharge information?
- 3. What are ED nurses' perceptions of factors that influence the provision of discharge information to parents?
- 4. What are parents' perceptions of the quality of discharge information received in the ED?

Each of these four questions were answered by the findings from four separates, but connected, studies.

The aim, objectives and research questions are based on the underlying assumptions that issues identified in the literature, such as parents' anxiety, time-related related stress on staff, communication issues between ED staff and parents and a diversity of ED staff roles within a children's ED setting, would be observable within a mixed methods design, and findings from the research would be informative for improving child health outcomes through policy, practice, and further research.

## **1.5 Significance**

The outcomes of this research program have the potential to reduce the risk of parents misunderstanding information on care of their child, which may lead to cost savings to the health system when re-presentations are prevented, allow parents to manage common problems at home, and provide parents with knowledge of when to take children to the family doctor rather than the ED. In the long term, it is hoped that quality of care will improve by enabling ED staff to improve the standard of care in the discharge plan, as well as to better inform parents on the care of their child at home following discharge from the ED. The research findings may also enable the development of evidence-based guidelines for discharge information that will lead to improved parental management of the child at home following discharge from the ED.

#### **1.6 Thesis overview**

This thesis is presented in 10 chapters. This first chapter has set out a detailed examination of issues surrounding ED care of children, in particular the ED as a context of care and the preparation of parents to care for their child after discharge from the ED, receiving discharge information, and the aims, objectives, research questions, and the significance of this thesis.

The second chapter examines existing literature on parental understanding of discharge information, and critiques previous research on this topic to demonstrate a gap in the current literature.

The third chapter presents the conceptual framework which guides this thesis. The Donabedian Model of Quality of Care offers a framework in the three domains of structure, process and outcomes of patient care that is useful for examining quality indicators such as parents' understanding of discharge information. Using this model, the research explores the characteristics of the structure of the ED, including policies and clinical guidelines, the processes involved in delivering the discharge information, and, finally and importantly, the outcome variables of parents' perceptions of, and responses to, discharge information provided in the ED for the ongoing management of their child's condition.

The fourth chapter outlines the methodology and methods of this thesis, and the rationale for the choice of a mixed methods approach. Pragmatism provides the philosophical paradigm for this mixed methods research. The design is underpinned by the Donabedian Model of Quality of Care. The four studies of this thesis are introduced: (i) the Document analysis; (ii) nonparticipant observation in the ED; (iii) focus group discussions with ED nurses; and (iv) a survey of parents who attended the ED with their child. The recruitment and site selection processes are explained, followed by an outline of data collection methods. The description and justification for the use of these methods includes details on data sources, the stages of data collection, and the implementation of data collection. It also provides an explanation of the process of triangulation of data in this thesis, ethical considerations, and a summary of measures for quality assurance and rigour.

The fifth, sixth, seventh and eighth chapters present the research design, methods and data analysis, findings, and discussion of the Document analysis, the non-participant observation study, focus group discussions with ED nurses, and of the parents' survey, respectively.

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The ninth chapter presents the integration and discussion of findings from the four studies in this thesis.

The final chapter outlines the contribution of the thesis to the area of research, recommendations for policy, ED nurse practice, and further research and the strengths and limitations of the thesis.

# 1.7 Summary

This first chapter has introduced the thesis and established the context within the thesis: Emergency Departments as a health service for children, the role of ED staff in preparing parents to care for their child following discharge from the ED, and the importance of parents' perceptions of information they receive prior to discharge to care for their child at home.

# **Chapter 2: Review of literature**

## **2.1 Introduction**

This chapter presents the literature review that informs the research design, including the literature search and review processes and findings. The overall goal-of this chapter is to evaluate previous research on the provision of discharge information with a particular interest in parents and children leaving EDs, justify the rationale for this thesis, and identify a place where a new contribution could be made. While previous research has reported that some parents may have difficulties understanding discharge information and identified factors that may influence understanding, only one Australian study was identified that focused on parents' understanding of discharge information to care for their child at home.

The key findings of this literature review are presented in three themes:

- (i) Measurements of understanding of discharge information
- (ii) Parents' health literacy
- (iii) Promoting understanding of discharge information

## **2.2 Literature search process**

Research-based literature relevant to this thesis was identified from a range of primary and secondary sources. An online search process with no language restrictions accessed electronic databases, with the following keywords: discharge or 'discharge planning' or 'discharge instructions' or 'discharge information', AND understand\* or 'health literacy' or 'readability' or complian\* or comprehens\*, AND ' emergency department' or emergency' or ED, AND staff or nurse\* or doctor or 'care provide\*' or physician\* or clinician, AND parents or guardians or care giver\* or caregiver\*, AND child\*or pediatric or paediatric. To capture a short history behind discharge information and some of the challenges faced by staff in delivering discharge information to parents and challenges of parents in understanding the information, the search was initially conducted on literature published between 1995 and 2016.

The search for this literature review was performed twice, once in October 2014, and again in December 2016 using library search engines at the Australian Catholic University. The databases accessed included: CINAHL, EMBASE and MEDLINE Complete, Google Scholar. Reference lists of relevant articles were searched for additional studies; particularly relating

to adults and relevant discharge information studies. Figure 1 shows results from results from the search strategy. To reiterate, each of these identified studies provided the sources for additional manual searching.



#### Figure 1: Study selection process

Thirteen key studies were identified on two separate occasions, three years apart, in searching for research directly relating to the provision of discharge information to parents of children admitted to the ED (Al-Harthy et al., 2016; Bloch & Bloch, 2013; Bucaro & Black 2014; Camp et al., 2014; Considine & Brennan, 2007; Curran et al., 2016; Ismail et al., 2016 ; Kaestli et al., 2015; Nibhanipudi, Chirurgi, & Hammad, 2015; Waisman

et al., 2003; Waisman et al., 2005). Appendix 1 presents a table summarising the papers about the provision of discharge information to parents.

In the 13 child/parent-related studies, the notion of understanding was related to a willingness to receive discharge information, the comprehension of information received at discharge and any related consequences of using the information received. Of these 13 studies, 12 were quantitative (Bloch & Bloch, 2013; Bucaro & Black 2014; Camp et al., 2014; Considine & Brennan, 2007; Curran et al., 2016; Ismail et al., 2016; Kaestli et al., 2016; Kaestli et al., 2014; Lion et al., 2015; Nibhanipudi, Chirurgi, & Hammad, 2015; Waisman et al., 2003; Waisman et al., 2005), none had qualitative designs and one used a mixed methods design (Al-Harthy et al., 2016). In evaluating the provision of discharge information to parents within emergency departments, six intervention studies were noted (Bloch & Bloch, 2013; Bucaro & Black 2014; Considine & Brennan, 2007; Ismail et al., 2016; Kaestli et al., 2016; Lion et al., 2015). The remaining seven non-intervention studies, investigated parents' experiences and understanding of discharge information from the ED (Al-Harty et al., 2015; Camp et al., 2014; Curran et al., 2016; Kaestli et al., 2014; Nibhanipudi, Chirurgi, & Hammad, 2015; Waisman et al., 2003; Waisman et al., 2005). However, none of these studies reported specific details on what influenced parents' understanding of discharge information in the ED and multiple methods were employed to investigate the provision of discharge information.

During secondary searches of the paediatric literature, an additional nine papers were found relevant to the provision of discharge information from ED in adult patient populations (Clarke et al., 2005; Engel et al., 2012; Engel et al., 2009; Gignon, Ammirati, Mercier, & Detave, 2014; Hastings et al., 2011a; Logan, Schwab, Salomone, & Watson, 1996; Spendorfer, Karras, Hughes, & Caputo, 1995; Vashi & Rhodes, 2011; Zavala & Shaffer, 2011) (Appendix 1). Of these 9 studies, three were quantitative (Clarke et al., 2009; Gignon et al., 1996; Spendorfer et al., 1995; ), three were qualitative (Engel et al., 2009; Gignon et al., 2014; Hastings et al., 2011a) and three used mixed methods designs (Engel et al., 2012; Vashi & Rhodes, 2011; Zavala & Shaffer, 2011) to evaluate patients' or adult caretakers' (Engel et al., 2009) understanding of discharge information or emergency department experiences. Appendix 1 also includes a table of papers on adult patients relating to discharge information from EDs. All studies collected data prospectively, which is a design strategy that is more likely to support patient

recall than retrospective studies. Also, most of the studies used both open-ended and closed questions in data collection.

## 2.3 Findings

Findings from the 22 studies reviewed following the literature search demonstrated various research approaches to measuring the understanding of discharge information and patient or carer perceptions of EDs. Measurements methods included subjective and objective methods: surveys, questionnaires, interviews, observations, and telephone calls. As previously noted, not all studies targeted parents and not all studies provided details on factors that might have influences parents' understanding of discharge information. Even when researchers used similar questions in more than one study (Engel et al., 2012; Engel et al., 2009), objectives differed; with the latter study (Engel et al., 2012) more rigorously investigating the knowledge deficits previously identified (Engel et al., 2009). Thus, this review of literature provides substantial details on measuring discharge information. Within the process of reviewing the literature, additional papers were identified beyond these 21 studies and are cited in the following sections. Thus, the reviewed literature involved critical appraisal of existing strengths and limitations within an extensive search of literature on understanding discharge information.

The key findings of the literature review are presented in three themes:

- (i) Measurements of understanding of discharge information
- (ii) Parents' health literacy
- (iii) Promoting understanding of discharge information

#### 2.3.1 Measurements of understanding of discharge information

Without gold standards for measuring literacy, existing measures continue to demonstrate strengths and weaknesses of evidence for articles addressing included telephone interviews, surveys, and questionnaires and mixed methods at or after discharge about understanding of after-care instructions used a range of questions and rating scales, which are described and critiqued.

A recent study conducted in France; examined adult patient understanding of ED discharge information (n = 36) (Gignon et al., 2014). During an individual interview, patients were invited
to provide information about their demographic profile, and their understanding, compliance, and satisfaction with information provided at discharge from the ED. The interview featured both qualitative and quantitative data collected via open-ended questions and Likert scale questions, respectively. However, the authors may have extended the data they collected through focus groups with patients and the health care providers. Nonetheless, patients' answers were categorised and summarised into groups, showing opinions and actions. The findings demonstrated that nearly half of the patients reported difficulties understanding their drug prescription (the dose or purpose of the treatment); as well, most patients reported that their poor understanding was primarily related to lack of clarity of the written prescription. Patients admitted that they had not felt confident enough, or had forgotten to request further explanation before leaving the ED, or they did not seek further information because they had made a prior appointment with their family doctor (Gignon et al., 2014). This study does not adequately give reasons for this poor understanding; specifically, which part of the written prescription was unclear or difficult to follow. However, unlike the proposed studies in this thesis, the focus of an *adult population*, responsible for their own self-care may not reflect additional concerns that adults may have when their child is the patient.

One questionnaire-based study on drug information in a Swiss paediatric emergency setting was developed by medical staff (doctors and pharmacists) for both parents and patients (Kaestli et al., 2014). Authors used a Likert scale from 1 (useless) to 6 (very useful) to assess what parents and or, patients expected to see on drug information prescribed from a paediatric ED. However, the 18 questions asked of parents, differed from 6 questions asked of the paediatric patients. Although the questionnaire was more about expectations (missing information) than understanding of existing drug information, the findings could strongly support future audits of prescribed information to improve continuity of care in this setting.

A study conducted in the USA, aimed to identify specific areas of patient misunderstanding about ED discharge information (Zavala & Shaffer, 2011). Data were obtained via follow-up telephone calls to adult ED patients (n = 50) on the day following discharge. More information on the level of triage may have helped explain the importance of discharge information to the patients. Patients provided a contact number at the time of registration. Specific questions inquired how patients were feeling and whether they had any additional questions about their aftercare instructions. Results showed that 15 participants (31%) requested further clarification of information in their aftercare instructions, and a similar proportion (31%) identified a diagnosis-related concern that showed their poor understanding of instructions. Many patients' questions about discharge instructions involved necessary information. When provided with an opportunity to clarify information, many patients still did not understand the aftercare information, which followed treatment in an ED.

In a USA study, adult English-speaking patients or their primary caregivers were qualitatively interviewed after discharge from the ED (*n* = 140), in one academic teaching hospital and one community teaching hospital (Engel et al., 2009). During the interview, participants were required to rate their perceptions of their experience in the ED on a 5-point scale (poor to excellent) for each of 4 domains: "(1) diagnosis and cause, (2) ED care (tests and treatments), (3) post-ED care (prescriptions, ancillary measures, and follow-up), and (4) return instructions" (Engel et al., 2009, p.456). However, it was not clear how much time elapsed between discharge and survey completion. The results showed most patients who were discharged from the ED had trouble understanding their ED care and discharge instructions. Specifically, 78% of patients had a lack of understanding in one of four areas studied, and 51% of patients had a lack of comprehension and reported an exaggerated confidence in their comprehension and recall. However, those factors influencing the patients' ability to understand the discharge information, such as low education, or a failure to fully read the instructions (as described above) were not explained by study authors.

In a second phase of the study, Engel et al. (2012) used qualitative methods to investigate a knowledge deficit, relating to discharge information that had been provided to adult patients. To minimise recall bias, the survey took place within 24 to 36 hours following discharge. The telephone survey was conducted with 159 patients falling into 5 diagnostic groups: ankle sprain, back pain, head injury, kidney stones, and lacerations. Knowledge was assessed on the concordance between direct patient recall and the documented diagnosis from ED staff combined with chart review. The patients were then asked about the information and instructions received during the visit. Questions targeted five domains: [1. Diagnosis: 'what were you told was wrong with you?' 2. Medications: 'what medications, if any, were you told to take' 3. Home care: 'were you told to do other things to take care of this problem besides taking medication?' 4. Follow-up: 'are you supposed to follow-up with any doctors about this

problem?' 5. Return to ED instructions: 'which symptoms or changes should cause you to come back to the ED?'] (Engel et al., 2012, p.1038). The study found that the most frequent knowledge deficits related to patients' understanding of their home care and return instructions. The research did not measure factors that could have had an influence on the patients' capacity to comprehend discharge information. The strength of the study however, could be seen as identifying five relevant domains for questions compared to four in the previous study that may also apply to parents of child patients in this thesis. The point of difference between the two studies from the same author split a previous question on home care into providing more separate information about medications and home care instructions. The latter version, possibly improved the quality of information being sought from patients.

In another quantitative study, Hastings et al. (2011b) described older patients' comprehension of the ED's discharge information and explored the relationship between this understanding and a negative result. An understanding of discharge information was evaluated via a telephone survey that was carried out within three days of the discharge from the ED. Patients or their representatives were questioned about their knowledge of 4 areas of discharge information including the following: "(1) diagnosis (or cause of their problem), (2) self-care instructions, (3) expected duration of symptoms or illness and (4) return precautions (such as, symptoms that might be danger signals that they were getting worse)" (Hastings et al., 2011b, p.21). The authors appeared to use similar questions to the studies by Engel and colleagues but lacked the focus on separately understanding prescribed medications. Each question was formulated in the following way: "Based on what you were told by the doctor and/or nurses in the ED, at the end of your visit, did you have a clear understanding of xxx?" (Hastings et al., 2011b, p.21). However, in agreement with the studies by Engel and colleagues (2009 and 20112) Hastings et al., (2011) described that patients were also questioned asked about their knowledge of discharge medications and follow-up information. The study found that a significant number of participants were at risk of poor health outcomes because of a limited understanding of discharge information under these four broad categories of potential issues for misunderstanding discharge information. Expected duration of symptoms or illness was identified as most poorly understood 63% of 88 patients.

In another USA study, Spendorfer et al. (1995) investigated patients' knowledge of their ED discharge instructions with the goal of determining whether urban patients' literacy levels

were sufficient to comprehend written discharge instructions. In contrast to previously described studies (Engel et al., 2012; Engel et al., 2009; Hastings et al., 2011a) three questions were asked of two hundred seventeen patients, discharged from the ED, during 12 separate time spans, regarding their understanding of instructions: "1. What did the doctor tell you was wrong with you? 2. Did the doctor tell you to take any medications? If yes, how did he or she tell you to use each of them? 3. Were you told to return to the ED or to see another doctor?" (Spendorfer et al., 1995, p.72). Questions on care at home were omitted. Despite their overall comprehension being judged to be good, 23% of patients appeared to not understand at least one of three components of their discharge instructions. Those patients with low levels of literacy (assessed via Simple Measure of Gobbledegook [SMOG]) were more likely to have a poor understanding of instructions.

Another USA study aimed to ascertain whether 153 patients were able to read their ED discharge information sheets and to remember their discharge diagnosis, treatment, and follow-up plan when they were interviewed immediately after discharge from the ED (Logan et al., 1996). The following questions were then asked: "1. Can you please read me your instruction sheet? 2. What did the doctor think was wrong with you? 3. What did the doctor want you to do at home? 4. When did the doctor want you to follow up?" (Logan et al., 1996, p.771). The results showed 72% of the 153 patients could read the discharge instructions. Those patients with less than 9 years of education and those patients aged 50 to 59 years had low literacy rates. Illiteracy could have also influenced the lack of recall. Table 3 provides a summary of the domains used to clarify specific aspects of understanding discharge information.

| Domains of<br>information<br>assessed for<br>understanding | Diagnosis   | Home Care  | Medication  | Return to ED  | Follow up   | Other   |
|--|---|--|---|---|---|---|
| Spendorfer et al.,<br>1995                                 | What did the<br>doctor tell you<br>was wrong with<br>you? |  | Did the doctor tell<br>you to take any<br>medications? If yes,<br>how did he or she<br>tell you to use each<br>of them? | Were you told to<br>return to the ED or<br>to see another<br>doctor?" | When did the<br>doctor want you to<br>follow up?" |   |
| Logan et al., 1996   | What did the<br>doctor think was<br>wrong with you?       | What did the<br>doctor want<br>you to do at<br>home? |   |   | When did the<br>doctor want you to<br>follow up   | Can you please<br>read me your<br>instruction<br>sheet? |
| Engel et al.,2009  | diagnosis and cause,                                      | post-ED care<br>(ancillary<br>measures)              | post-ED care<br>(prescriptions)   | Return instructions   | Follow-up   | ED care (tests<br>and<br>treatments)                    |

# Table 3: Summary of the domains used to investigate patients' understanding of discharge information

| Engel et al.,2012       | Diagnosis: 'What<br>were you told<br>was wrong with<br>you?' | Were you told<br>to do other<br>things to take<br>care of this<br>problem<br>besides taking<br>medication? | What medications, if<br>any, were you told<br>to take? | Return to ED<br>instructions: 'which<br>symptoms or<br>changes should<br>cause you to come<br>back to the ED?'   | Follow-up: 'are<br>you supposed to<br>follow-up with any<br>doctors about this<br>problem? |   |
|-------------------------|--|--|--|--|--|---|
| Hasting et al.,<br>2011 | diagnosis (or<br>cause of their<br>problem)                  | self-care<br>instructions  |  | expected duration<br>of symptoms or<br>illness and<br>return precautions<br>(such as, symptoms<br>that might be<br>danger signals that<br>they were getting<br>worse)" |  |   |
| Zavala & Shaffer.,      |  |  |  |  |  | Do you have   |
| 2011                    |  |  |  |  |  | any questions<br>about your<br>treatment or<br>discharge<br>instructions? |

Although, the three to five domains of information measured for understanding described in the seven studies appraised thus far, appeared relevant to the ED, there was little information around the structure or policies that staff were meant to follow in providing discharge information. Also, the studies, as previously noted largely targeted adult patients only. It is postulated that in contrast to adult patients, parents of paediatric patients may have different anxieties that effect their comprehension and capacity to effectively manage their child's care when discharged from an ED. However, independent of the accuracy of the information provided, the communication of the discharge information is not always perfect. Waisman et al. (2003) conducted a quantitative survey based study to determine the level of parents' understanding of ED discharge instructions. Specifically, they aimed to analyse the factors that may affect understanding and to use this evidence base to suggest other auxiliary methods for delivery of medical information. A convenience sample was recruited and comprised of 482 parents attending one tertiary and one secondary hospital in Israel. Parental understanding of the diagnosis and the nature, frequency, and duration of the recommended treatment were assessed by comparing their parental recall on the questionnaire to the staff notes on the ED chart. The study found that 20% of parents did not demonstrate understanding of discharge instructions, with the biggest barrier being the use of medical terminology by staff.

Although, Waisman et al. (2003) study adds to current knowledge of parents' understanding of discharge information following a visit to the ED, it has number of limitations. Surveys were presented to parents at discharge when the information provided to them was very recent. Exact questions within the survey were not provided however, a three-point scale of comprehension was used to score responses. Parents responded with the support of a research assistant where necessary, but the proportion of parents needing assistance and nature of this assistance was not described.

In the second phase of the study (Waisman et al., 2005), researchers used a quantitative method approach to examine the impact of diagnosis-specific discharge information sheets on Israeli parents' comprehension of the discharge instructions. A convenience sample was taken to obtain data from 95 parents of children discharged home from an ED at an urban tertiary care paediatric department. All parents received a disease-specific information sheet, at discharge, to complement the physician's discharge instructions. Subsequently, the parents

were invited to complete the same questionnaire used in the first phase study, including demographic data, level of anxiety, and quality of physician's explanation. In addition to this data, parents were also asked to describe, in their own words, their child's diagnosis, and treatment instruction, as well as to indicate their preferred method of obtaining the discharge information. The data were compared with the first phase study group (n = 287) who were not given the disease-specific information sheet. The findings demonstrated that a complete understanding of the diagnosis was held by 73% of the parents who received the information sheet and 72% of the parents in the first phase study who did not. Rates of understanding of the treatment instructions were 92% for the information. Parents' understanding of the treatment instructions were significantly enhanced by the diagnosis-specific information sheet (p = 0.025), but not for the diagnosis (p=0.54). However, the finding of comprehension of discharge instructions may have been different if the parents had been required to complete the survey within 24 to 36 hours of ED discharge.

To summarise, parents' understanding of discharge information has not been extensively researched. However, from the existing literature it appears that an improved understanding of discharge information was obtained using a number of strategies: questionnaires for parents (Al-Harthy et al., 2016; Bloch & Bloch, 2013; Camp et al., 2014; Nibhanipudi, Chirurgi, & Hammad, 2015; Waisman et al., 2003; Waisman et al., 2005 ), video recorded, observations (Curran et al., 2017) and telephone interviews with parents (Considine & Brennan, 2007). The optimal timing for capturing data about parents' understanding of discharge information remains unclear, largely due to the small number of studies. However, Waisman et al., 2003 and 2005 obtained data on parents' understanding of discharge information immediately post discharge, while others have telephoned parents within two days of their child's discharge from the ED (Bloch & Bloch, 2013).

## 2.3.2 Parents' health literacy

Evidence shows that health literacy is an important factor in parents' understanding of their child's discharge information. Health literacy is an all-encompassing term; referring broadly to the capacity of an individual to read, understand and apply knowledge and skills to manage health-related practices.

Health literacy is critical because it can determine the individual's capacity to access, support and gather resources about health and health services. Health literacy has both direct and indirect consequences for personal and community health. In an ED setting, health literacy will strongly influence an individual's capacity to effectively use information and resources provided at discharge (Herndon et al., 2011; Nutbeam, 2008; Samuels-Kalow, Hardy, Rhodes, & Mollena, 2016; Tran, Robinson, Keebler, Walker, & Wadman, 2008). Key contributors to inequities in health literacy include: low levels of education, low socioeconomic status (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Yin, Dreyer, Foltin, Schaick, & Mendelsohn, 2007) language and cultural diversity (Tran et al., 2008) and even poor eyesight (Wahl et al., 2011). The unfamiliar use of medical terminology may further confound health literacy (Waisman et al., 2003). A critical component of effective discharge information to parents of children leaving an ED, is the assumption that they have understood the information provided to them about their child's continued care (Waisman et al., 2003) and the importance of follow up appointments (Nibhanipudi et al., 2015). Yet, using a variety of questions and methodological approaches, many research studies appeared to identify a lack of understanding of the discharge information among adults (Engel et al., 2012; Gignon et al., 2014; Hastings et al., 2011b; Waisman et al., 2003; Waisman et al., 2005; Zavala & Shaffer, 2011). Of particular relevance to this thesis is the parents' capacity to effectively understand the nature of medications and prescriptive information and any symptoms of side effects that are counterproductive to continued care.

Literacy competence and diligence around the literacy of parents can profoundly affect a child's care and outcomes following ED discharge. For example, patients/parents might be quite literate, but fail to read instructions around medication administration (Engel et al., 2012) or they may be simply unaware of their low level of understanding (Engel et al., 2009). Although readability is perhaps more about general literacy rather than health literacy per se, competence in reading could have a significant impact on health literacy. Given that the average reading ability of patients leaving an ED was identified to be as low as a sixth-grade standard, and that the materials provided were pitched at an eleventh-grade standard of literacy, difficulties in comprehending instructions will present many challenges (Herndon et al., 2011; Spendorfer et al., 1995).

Incomplete secondary school education was also identified as a contributing factor to the 28% of a group of 153 adult patients who could not understand discharge instructions (Logan et al., 1996). Similarly, around 50% of 36 ED patients had difficulties in understanding the clarity of instructions on the prescribed medication provided on discharge (Gignon et al., 2014). The purpose of the prescribed medication can also be unclear (Zavala & Shaffer, 2011). Moreover, confusion around general discharge information after ED treatment, independent of medication, results in poor adherence to instructions Subsequently, ED patients may be less likely to adhere to instructions provided at discharge (Wahl et al., 2011).

Information delivery should use simple language and visual aids either written or verbal, and a focus on patient comprehension and recall should be a priority (Spendorfer et al., 1995). The targeted educational standard of readability within documents can also be assessed. Depending on the nature of the resource, an information sheet summarizing instructions may improve parents' understanding (Waisman et al., 2005). To support effective patient care and satisfaction with services, it appears prudent that ED staff seek confirmation of understanding of instructions around care management prior to a patient's discharge (Samuels-Kalow et al., 2012).

Low health literacy has a negative influence on patients' adverse outcomes and poor health (DeWalt et al., 2007; Yin et al., 2007). Some investigations have used cultural diversity as a potential risk factor for compromised health literacy. A high prevalence (89.5%) of limited health literacy was observed in English-speaking parents or guardians of paediatric patients assessed in the ED (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005).

Overall, health literacy appears to complicate the ED discharge processes because, for a plethora of reasons, parents may not fully understand verbal instructions and existing written resources. It is clear that the communication between parents and providers may be more complicated for parents with limited health literacy, or a limited English-language proficiency.

### 2.3.3 Promoting understanding of discharge information

The literature review identified evidence based strategies to promote understanding of discharge information, including use of simple language, and ensuring readability of printed materials and specific take home written instructions.

In Australia, a prospective pre/post-test design was used to examine the effect of an educational intervention on discharge advice given to parents leaving the ED with a febrile child (Considine & Brennan, 2007). Data were obtained via structured telephone with parents of febrile children discharged from the ED. The 22 families were during the pre- test period and 18 families were recruited during the post-test period. The intervention for the study was an educational intervention for ED nursing staff that consisted of two tutorials. Pre-test data were collected in June 2005 and post-test data were collected after 2 months. Results showed that parents leaving the ED with no advice decreased by 48%. Reports of written advice increased by 69.7% and there was a 38.4% increase in reports of verbal advice. Parents leaving the emergency department with both written and verbal advice increased from 0 to 55.6%. Reports of parents receiving advice from nursing staff increased by 52% and there were significant increases in specific information related to oral fluid administration and use of antipyretic medications. Evidence-based education of ED nurses improved both the amount and quality of discharge advice for parents of febrile children and provided additional support for parents to care for their febrile children at home.

Another study, conducted in the USA, researchers used a quantitative method approach to determine if adding video discharge instructions affects caregivers' understanding of their child's ED visit, plan, and follow-up (Bloch & Bloch, 2013). Caregivers whose child was diagnosed with fever, vomiting or diarrhoea, and wheezing or asthma were randomized into written or video discharge instruction groups. In the ED, caregivers read standard written discharge instructions or watched a 3-minute video based on their child's diagnosis. After watching the video or reading the written discharge instructions, each caregiver's demographic information, including relationship to the patient, age, and level of highest education, was verbally obtained from each caregiver. They were given a 5-question, 20-point questionnaire, addressing key issues regarding the diagnosis, treatment, and follow-up for their child. For example, the questionnaire for fever included the following items: "1. What temperature is considered a fever? 2. What are signs of fever that you could see in your child? 3. How do you treat fever in your child? 4. How long should you expect your child to have a fever? 5. When should your child return to the ED or to their doctor?" All patients, regardless of study group, received routine discharge from the ED, and standard written discharge instructions were given to all participants to take home. No participants were sent home with

the video discharge instructions. After completing questionnaire, standard discharge procedure was followed. Caregivers were contacted by phone two to five days after discharge for a follow-up questionnaire.

Results showed that 436 participants, 220 received written and 216 received video discharge instructions. The follow-up questionnaire was completed by 341 caregivers. The group receiving video discharge instructions scored significantly higher in the ED and 2 to 5 days after discharge. At follow-up, 29% of the written and 42% of the video groups rated their discharge instructions as being extremely helpful. Brief video discharge instructions improved caregiver understanding both in the ED and after discharge compared with receive only written discharge information. Many children are discharged from the ED with fever as a significant component of their illness; therefore, it is important that ED staff provide accurate and reliable information about children's fever care at home.

Swiss-based researchers (Kaestili et al., 2016) investigated the impact on parental knowledge of providing with leaflets with customised drug information for 10 commonly prescribed paediatric medications. Telephone-based semi-structured interviews occurred 72 hours after discharge from the ED. The interviews focussed on parents' correct understanding of the medication's dosage, frequency, and duration as well as the purpose and relevant side effects of specific drugs. Results from the intervention demonstrated that both the distribution of the leaflets and being able to access the drug through their local pharmacy contributed significantly to improved parents' knowledge of the prescribed medication and care of their child at home.

In addition to printed resources, the impact of access to different modalities of interpreter services for parents has also been investigated. Specifically, Lion (2015) conducted a randomised controlled trial of telephone verses video-based interpreter services to improve communication with 208 parents of limited English-speaking capacity in Seattle, USA, and assess the impact of parents' understanding of their child's diagnosis. Although it was more expensive, video-based interpreter services were more effective than telephone-based support in improving parents' understanding of their child's diagnosis. However, assessment did not extend to parents' understanding of discharge information.

Another USA randomised controlled trial (Ismail et al, 2016) examined the effects of adding video-based discharge information on paediatric fever and closed head injuries in the ED, to standard care. The researchers had a goal of improving parents' understanding of their child's diagnosis, likely progress of the condition, and discharge information. Compared with standard care of written and verbal information, when parents were given additional access to the video, an improved understanding of the diagnosis and disease progression was evident.

Although limited in number, the existing interventions show possibilities for promoting parents' improved understanding of key information in paediatric EDs. However, a diversity of approaches, including staff education, modalities of interpreter services, and additional resources are only recently emerging as targets for intervention and evaluation.

# 2.4 Summary

This chapter has presented the literature review that highlighted the lack of published Australian studies and global interventions on parents' understanding of discharge information. The search methods and review process presented are linked to analysis of key papers. The review found that most studies investigating patient/ parents' understanding of discharge information have been conducted in the USA, Israel, and Europe where the characteristics of the population, health services, and the culture are often quite different from Australia. Few researchers have specifically targeted parents' understanding of discharge instructions following their child's presentation to an ED.

Previous research found that there is potential for some patients, even adults to experience difficulties in understanding their prescription of medications, and general discharge instructions. Although an important issue, there is limited published research on the impact of low health literacy among parents and their understanding of key discharge information regarding their child's home care after discharge.

Therefore, research aims, and questions of this thesis are supported, because though the topic is important, it has not been examined in Australia in this way before. Approximately three to five domains about understanding discharge information have been identified that can be further explored in this thesis. The proposed thesis will investigate the provision of discharge information to parents before their child leaves an ED. The next chapter presents the conceptual framework which was used to guide this thesis, that investigated the provision of discharge information to parents who presented their child to an ED.

# **Chapter 3: Conceptual framework**

# **3.1 Introduction**

The purpose of this chapter is to present and justify the conceptual framework, which was used to guide this thesis of the provision of discharge information to parents who have presented their child to an Emergency Department. The Donabedian Model of Quality of Care is a conceptual model that provides a framework to evaluate quality of care in clinical practice. This framework has been selected to guide this thesis because the provision of discharge information (the basis of this thesis) is an important component of quality in discharge planning. In this model, information about quality of care can be drawn from three interconnected domains: Structure, Process, and Outcome and integrated to inform recommendations for quality improvement (See Figure 2).



# Figure 2: The Donabedian Model of Quality of Care (Donabedian, 1988)

The three domains of the model are connected, and create a chain of causality that can be conceptually helpful for understanding the health system and for highlighting failures in the provision of quality care. Although many other quality of care frameworks have been developed such as the Six Sigma, Total Quality Management (TQM), Deming PDSA Cycle in health care (Višnjić, Veličković, & Jović, 2012), the Donabedian Model continues to be the main model for evaluating the quality of care in clinical practice (Ayanian & Markel, 2016; Moore, Lavoie, Bourgeois, & Lapointe, 2015). Through this model, enhancements in the structure of

care should lead to enhancements in clinical processes that should in turn improve patient outcomes (Moore et al., 2015).

In the past 10 years, the Donabedian Model has been used 195 times in health-related research. In this time, the application of the model has markedly varied including descriptions of innovations with nurse practitioners (Gardner, Gardner, & O'Connell, 2014), rehabilitation care for patients with spinal cord injury (Qu, Shewchuk, Chen, & Richards, 2010) and to describe problems in counselling on nutrition and child growth in a primary care setting (Palombo, Fujimori, Toriyama, Duarte, & Borges, 2017).

Within the adult literature, the Donabedian Model has been used to study of the quality of care of boarded patients in the emergency department (Liu, Singer, Sun, & Camargo, 2011). The American College of Emergency Physicians (ACEP) defines a "boarded patient" as "a patient who remains in the emergency department after the patient has been admitted to the facility, but has not been transferred to an inpatient unit" (The American College of Emergency Physicians, 2017). Marsden et al. (2017) applied this model to present the research protocol for a study that will evaluate the structures, processes, and outcomes of an ED-focused model of care aimed at improving care for older people living in the community or residential aged care facilities, who present to the ED with an acute illness.

Collectively, citations have linked the Donabedian model of care to emergency medicine 21 times in the past 10 years, yet only one study has directly addressed paediatric emergency care (Alessandrini et al., 2011). This published article was a review of current measures of performance relating to paediatric emergency care (Alessandrini et al., 2011). In the single study with an experimental design, 405 measures relating to routine paediatric emergency care were classified into structure, process, and outcome. As such, discharge information was not a strong focus of this article. Despite wide applicability, the Donabedian model has some limitations. These include that process is easier to measure than outcomes because outcomes such as quality of life and long-term independent function can be difficult for researchers to capture in time-limited studies. Another strong criticism has been that the model of care is neither complete nor concise (Gardner et al., 2014). Moreover, the model may be disadvantaged by not accounting for the possibility that human sociodemographic and environmental factors can alter even the best quality of service (Coyle & Battles, 1999). Also,

some health researchers have criticised an implicit linear direction of the model (Mitchell et al. 1998); failing to consider multi-directional influences and overlapping between structure, process, and outcome. Therefore, an implied chain of causality from structure to process to outcome cannot be assumed within the model; interactions and directionality within the model should also be considered (Figure 2).

Nonetheless, a recent article (Ayanian & Markel, 2016) asserted that the Donabedian concepts of structure, process and outcomes remain the foundation of investigations into quality of care. Within the acknowledged limitations, using the Donabedian Model of Quality of Care in this thesis assists in understanding the nature of the problems associated with the provision of discharge information to parents, and in answering the defined research questions with potential solutions to address the three domains of quality of care.

# 3.2 Domains of the Donabedian Model of Quality of Care

### 3.2.1 Structure

The domain of *Structure* refers to relatively static characteristics of the settings where health care is delivered. These characteristics include: material resources, such as the adequacy of the facility's physical space, equipment, and budget; human resources, such as the staffing ratio of nurses and doctors to patients and the experience and qualifications of the individual care providers; as well as organisational characteristics, such as the administrative structure and the financial management rules and procedures (Donabedian, 2005).

These factors influence the way providers and patients behave in a healthcare system, and are also measures of the average quality of care within this system. Information about *Structure* can be gathered via direct observation and supervisory checklists (Liu et al., 2011). For example, *Structure* was evaluated in a study of patients treated in a Canadian provincial trauma system by transposing on-site accreditation visit reports onto an evaluation grid according to American College of Surgeons criteria. Results recommended improvements in the structure of care should lead to improvements in clinical processes that should, in turn, improve patient outcomes (Moore et al., 2015). Also, Tvedt, Sjetne, Helgeland, and Bukholm (2014) used an observational study to determine the correlations between hospital-aggregated, nurse-assessed quality and safety, and estimated probabilities for 30-day survival in and out of hospital.

### 3.2.2 Process

The domain of *Process* denotes all the activities taking place during the delivery of care to the patients or their families, such as diagnosis, treatment, and prescription processing. *Processes* can be further classified into aspects of delivery such as the technical or inter-personal processes, and other characteristics of the way in which care is provided. In the Donabedian Model, a measurement of *Process* is considered to be almost equivalent to a measurement of overall quality of care, because *Process* includes all aspects of healthcare delivery. Information about *Process* can be gathered from health records (Gardner et al., 2014) such as laboratory testing, other diagnostic testing, patient and practitioner interviews, and direct observations (Liu et al., 2011). For example, Gardner et al. (2014) evaluated *Process* related to the safety and quality of nurse practitioner practice using interviews with nurse practitioners and patients.

### 3.2.3 Outcome

The domain of Outcome includes all the consequences of patient healthcare, embracing changes to health status, behaviour, knowledge, and satisfaction (Kajonius & Kazemi, 2016), as well as the patients' approval of the health care received and their related quality of life. The Outcome domain was evaluated for patients treated in a Canadian provincial trauma system. Outcome performance was measured using risk-adjusted rates of mortality, complications, readmission, and hospital length of stay. Correlations were observed between structure and process and process and outcome (Moore et al., 2015). Outcomes may be considered a significant gauge of the quality of healthcare, because improvement in patient health status is the principal goal of healthcare. However, an accurate measure of outcomes, ascribed solely to healthcare, is very difficult to achieve. Outcomes should not be measured without also considering Structure and Process (Gardner et al., 2014). Determining associations between Process and Outcome often necessitates large sample populations, amendments by case mix, and long-term studies, as outcomes may take a very long time to become obvious (Liu et al., 2011). For example, Kajonius and Kazemi (2016) measured the satisfaction with care of the elderly, as perceived by the elderly themselves, using a national survey of 95,000 older persons living in 324 municipalities and districts in Sweden and this was a useful measure of outcome to improve quality of health care in elderly care particularly the focus on process variables.

# 3.3 Application of the conceptual framework to this research

This thesis applies the Donabedian Model of Quality of Care to examine the *structure, process* and *outcomes* associated with the provision of discharge information to the parents of children discharged from the ED. This model provides direction in exploration of how certain structural issues, inherent in providing care to paediatric patients and their parents, can influence processes and lead to less than optimum outcomes. This thesis focusses on a quality indicator: an understanding of the required care of the child at home following discharge from an ED. The key characteristics for each of the three domains, as applied in this thesis, are presented in Figure: 3, and described below.



Figure 3: Conceptual framework

The conceptual framework guides the research design including selection of data sources, methods of data collection, data analysis, and interpretation, and the recommendations, which might lead to quality improvement.

#### 3.3.1 Structure in the Children's ED

In this thesis, structures within the children's ED have been identified as being: (i) the organisational structures; (ii) the staff mix; (iii) the demographics of the families using the service; (iv) the trends in presentation data; and (v) the features of the physical environment.

Organisational structures include policies, procedures and clinical guidelines and resources from the hospital, which may also be hospital-specific. Staff mix includes the number, types, and roles of staff (nurses, doctors, administration). Demographics refers to the socioeconomic status ascribed to the families presenting to the ED. Trends in presentation data refer to the number of patient presentations at an ED. In this thesis, the physical environment comprises the waiting time, the extent of crowding, the number of available consultation rooms, and the types of visible resources.

Structural elements may influence parents' understanding of discharge processes and materials. For example, parents' anxiety (Zemek et al., 2013) may be exacerbated by their unavoidable exposure to other patients in the ED who may have behavioural, cognitive, and mental health conditions, or distressing physical conditions. Also, the physical structure may lack the capacity to support good listening from parents when there is overcrowding, excessive noise, and perhaps other distressed patients (Graneto & Damm, 2013). The complexities of the ED can also make discharge planning difficult.

Data on structural characteristics of discharge information for paediatric patients leaving the ED, is examined to identify links with processes and outcomes.

### 3.3.2 Processes of providing and receiving discharge information in the ED

In this thesis, quality care within *Processes* of providing and receiving discharge information in the ED is explored using five indicators: (i) delivery of discharge information; (ii) parental background; (iii) health literacy; (iv) family experience with EDs; and (v) severity of the child's condition at presentation to ED. However, is it possible that some overlap in aspects of structure and process may occur when local demographics (seen in the structure domain of Figure 2) strongly influence parental background and family experiences (seen within the process domain of Figure 2). Examples of overlap may occur when families share local services, participate in similar community activities, and even strategically ch4oose to live among families from similar cultural backgrounds. This overlap is recognised in Figure 2 with a dashed line.

In this thesis, delivery of discharge information is defined as the information given by the ED staff to parents including diagnosis, medication, home care, follow-up, and return instructions based on signs and symptoms of potential concern (Engel et al., 2012), and the manner in which the information is provided. Resources may include verbal and handwritten information, pictures, printed pamphlets, CDs and DVDs and information accessed via websites and emails (McCarthy, Engel, Buckley, Forth, Schmidt, Adams, & Baker, 2012). The information and the way it is delivered can influence parents' understanding of discharge information. For example, the complexity of words selected by staff, the pace at which the words are delivered, the use of visual materials to support the verbal information and the opportunity to ask questions may be pivotal to parents' capacity to understand discharge information about the continued care of their child (Engel et al., 2012; Hoppa & Porter, 2011; Samuels-Kalow et al., 2013). Staff in the ED setting, (nurses and physicians), ideally provide multiple forms of discharge communication to ensure patient safety at home (Engel et al., 2012; McCarthy, Engel, Buckley, Forth, Schmidt, Adams, & Baker, 2012; Samuels-Kalow et al., 2013).

Family experience in the ED refers to whether this is a first-time visit, or whether parents of patients or the child patient have attended the ED on previous occasions, for management of chronic conditions. For example, the nature of the previous visit and the perceptions of this experience are also relevant as they may also impact on understanding of discharge information. Severity of the child's condition at presentation to the ED refers to the assigned triage score.

Data on process characteristics of provision of discharge information for parents of paediatric patients leaving the ED, are examined to identify links with structure and outcomes.

### 3.3.3 Outcomes

In this thesis *Outcome* performance is measured using two indicators: (i) parents' understanding of discharge information; and (ii) parents' satisfaction with the provision of discharge information. Examining the structure and process is important because these

ultimately can influence the *outcome* of parents' understanding of discharge information. An understanding of discharge information in this thesis is defined as parents' ability to recall the diagnosis, medications prescribed by ED staff, follow-up instructions, and symptoms necessitating a return to the ED. A further *outcome* of quality of care in this thesis is the level of parents' satisfaction with the care they received in the ED. Parent satisfaction in this thesis was assessed for two variables: how useful the discharge information was for them; and how the information was provided in the ED (as this can also influence parents' understanding of information).

# 3.4 Summary

This chapter described the Donabedian Model of Quality Care that was used to guide this thesis. The chapter also explained the *Structure, Process*, and *Outcome* domains of this model, and how they are applied in the context of a children's ED. Through this model, this thesis might identify improvements that could be made in the structure of ED discharge care, which may lead to improvements in relevant processes that should in turn improve patient outcomes following discharge form the ED.

# **Chapter 4: Methodology and methods**

# **4.1 Introduction**

This chapter presents:

- an overview of, and justification for, the mixed methods design used in this research, and the rationale for its use;
- an outline of the four studies developed to achieve the aim of the research and answer the four research questions;
- a description of how the overall design aligns with the Donabedian Model of Quality of Care and mixed methods approach, all underpinned by the philosophy of pragmatism;
- an outline of the generic attributes shared by the four studies: the setting, populations, and samples; and
- a discussion of the ethical considerations and processes involved in the conduct of the research.

This thesis aimed to explore the provision of discharge information for parents to assist in managing their child's care following their discharge from the ED. In Chapter 2, the literature review analysed studies related to this research aim, and identified gaps in knowledge about this area of research in Australia and internationally. Chapter three presented the Donabedian Model of Quality of Care that provides a theoretical basis for approaches to address the thesis aim, objectives and research questions and understanding more about the gaps in the literature. These gaps led to the generation of the following research questions, which underpin the research.

# **Research questions**

The research was designed to respond to the following research questions:

- 1. What protocols, procedures, guidelines, and resources are used to inform and support the provision of discharge information in the ED?
- 2. What are the current practices in the provision of discharge information in the ED?
- 3. What are ED nurses' perceptions of factors that influence the provision of discharge information to parents?
- 4. What are parents' perceptions of the quality of discharge information received in the ED?

The research questions guided selection of the research methodology selected to support the overall aim, with each decision in the planning of the thesis being supported by the philosophy of pragmatism.

# 4.2 The philosophical stance of pragmatism

Pragmatism has a strong philosophical place for researchers selecting mixed methods research designs. A school of philosophy founded in the USA around 1870, pragmatism underpins practical consequences in thinking, planning, and resolving problems (Dewey, 1998). Pragmatic thinking offers consequences that can be derived using any one of a number of approaches. The focus on practical consequences gives researchers the freedom to choose the methods, techniques, and procedures (Creswell, 2014a) necessary to best answer research questions, and solve real-world problems.

Taking a pragmatic approach can present challenges for the mixed methods researcher because it is deemed to be somewhat eclectic, lacking a strong focus on any given method. It is very important for the mixed methods researcher to acknowledge these criticisms and rigorously defend pragmatic approaches and adaptations (Cameron, 2011). The strength of pragmatism lies in researchers remaining open to both qualitative and quantitative data, in order to obtain the most insightful solution to a research problem (Creswell, 2014a). Pragmatism also accepts a values-oriented approach, and presents results within the context of provisional certainty. Considering practical consequences for research problems ensures results maintain relevance, and offer recommendations for actions with logical solutions in real life settings (Cameron, 2011).

Using a pragmatic approach to inquiry (Morgan, 2014) for this study, a clear link between the set of methods and research questions benefits from the combination of strengths of quantitative and qualitative approaches and a plan for integrating the results. Therefore, the purpose and the procedures in the mixed methods research drive the inquiry process in the goal of integration. Reflection on the nature of the problem and potential solutions and likely actions and outcomes in real life settings informs future research questions and research methods for the area of inquiry (Morgan, 2014).

The Donabedian model Quality of Care applied in this thesis assists to understand the nature of the problem (parents not understanding discharge information) and answer the four research questions by providing potential solutions to address the three domains of quality of care (structure, process, and outcome). This thesis explores solutions for the real-world setting; for example, while nurses aim to give the best quality of care, real-world issues such as nursing workload, can affect the quality of care and patient safety. Thus, the selection of mixed methods in this thesis was underpinned by a philosophical stance derived from pragmatism, and aligns with the Donabedian model.

## 4.3 Mixed methods approach

Mixed methods research designs describe studies that collect and analyse qualitative and quantitative data, culminating in the integration of findings to draw meta-inferences (Creswell, 2014a; Polit & Beck, 2017a). This type of design encompasses more than just collecting and analysing both kinds of data; the mixed methods design uses both approaches in conjunction with each other to generate greater strength in studies than exists in either qualitative and quantitative research alone (Creswell, 2009; Patton, 2015; Richardson-Tench, Taylor, Kermode, & Roberts, 2014).

For this thesis, a mixed methods approach was deemed more appropriate to address the research aim than either quantitative or qualitative methods alone. A quantitative approach can provide a general understanding of the problem. However, an in-depth understanding of the problem, typically obtained from more qualitative approaches could be lost. Hence, the strength of one method was used to balance the limitations of the other, thus providing a more complete understanding of the research problem than could be gained from either approach alone. In addition, the design provides the researcher with the freedom to select a variety of methods to address the problem (Weathington, Cunningham, & Pittenger, 2010); in this case to answer multiple research questions.

There are three basic designs for mixed methods approaches (Creswell, 2014a, pp. 219-227). First is the convergent parallel mixed methods approach, where qualitative and quantitative data are collected simultaneously, but analysed separately. Data are then collectively compared and explored for relationships that can be confirmed or challenged. Second is the explanatory sequential mixed methods design, which has two phases. Quantitative data such as a survey are first collected. Results are analysed, and the findings inform the second qualitative phase of data collection. The third design is the exploratory sequential mixed

methods design, which also uses two phases. The first phase explores and analyses qualitative data, and the findings are used to inform the next quantitative phase of data collection.

The mixed methods design selected for this research is the convergent parallel design (Creswell, 2014a). The selection of this design allowed the researcher to collect and analyse both quantitative and qualitative data during the same phase of the research process, and the overall analysis leads to an integration of the findings and interpretation. Another strength of a convergent design lies in the efficiency and flexibility of parallel data collection that can subsequently be analysed, either separately or together. The convergent parallel design is a "triangulation" design, in which multiple methods are used to verify results about a single topic or research question. Researchers use this convergent design when triangulation of methods requires direct comparison and contrast of quantitative statistical results, in combination with qualitative findings for validation purposes (Creswell, 2014a; Patton, 2015).

Despite its advantages, some limitations apply to the mixed methods approach. Acknowledged limitations include the necessity for a high volume of data to be collected, timeintensive demands associated with analysing data, and the familiarisation and competencies required of the researcher for qualitative and quantitative data analyses, integration, and meta-inference development (Creswell, 2014a). A mixed methods approach is helpful because many complex issues and systems exist that can be comprehensively investigated with a multitude of methods and the inclusion of multiple perspectives (Creswell, Klassen, Clark, & Smith, 2011).

The flow chart shown as Figure 4 outlines the convergent parallel design used in this thesis, and highlights that three of the four studies included both quantitative and qualitative data collection methods. By using the convergent design, the researcher combined the divergent strengths and weaknesses of quantitative methods (such as trends and generalisations) with those of qualitative methods (such as small samples, details, and focus group discussions) (Creswell, 2014; Kumar, 2014). The data from each of these methods were analysed separately and integrated, to consolidate and confirm the findings.



# Figure 4: The convergent parallel, mixed methods design (Based on Creswell, 2014)

# Alignment with the Donabedian Model

This thesis applies the Donabedian Model of Quality of Care to examine the structure, processes and outcomes associated with the provision of discharge information to the parents of children discharged from the ED. This model provides direction in exploring how certain structural issues, inherent in providing care to children and their parents, can influence processes and lead to less than optimum outcomes. Figure 5 shows alignment of the research methods with the Donabedian Model of Quality of Care for each of the four studies. Each study addresses at least one domain, with two studies addressing all three domains.



Figure 5: Alignment of the Donabedian model domains with the four research studies

## 4.4 Research studies and methods

This section presents and justifies the four studies and research methods used to conduct the research: (i) document analysis; (ii) non-participant observation; (iii) focus groups; and (iv) parents' survey.

### 4.4.1 Analysis of Emergency Department Documents

The document analysis study design used both qualitative and quantitative methods of data collection and analysis. Document analysis is a method to collect data by reviewing or existing documents. The analytic process involves finding, selecting, appraising, and synthesising data contained in documents. Robust data collection methods and the documentation of the research procedure are needed in qualitative research (Bowen, 2009). Document analysis studies typically collate and analyse information from internal or external sources. Sources external to a hospital may include government or profession organisations or other hospitals while internal sources may include documents from within the hospital department sources such as policies, guidelines, and related resources (pamphlets) (Department of Health & Human Services, 2009). The purpose of reviews is to generate findings that will benefit patients and the programs of care for them (Shankar, Shankar, & Praveen, 2011). Various tools are used to evaluate the quality of patients' resources (Luk & Aslani, 2011). Traditionally document analyses in health focussed on readability or the presentation of materials (Luk & Aslani, 2011). However, the reader's perceptions of the information and the comprehensiveness of the document in providing useful information should also be considered. For example, multiple tools exist for readability and vary in length from 100 words (Flesch-Kincaid Grade Level score) assessing syllables and sentence length (Hendrickson, Huebner, & Riedy, 2006), to similar metrics graphing syllables and sentence length from three passages of 100 words (Wallace et al., 2008). Also consecutive sentences can also be assess, simply investigating the number of words with three or greater than three syllables (SMOG) with the advantage of a strong predicatability of comprehension of the written documents, despite not accounting for sentence, grammar and vocabulary (Wallace et al., 2008). The quality of written health care information can also be analysed (Shepperd, Charnock, & Gann, 1999) to ensure the information provided is as accurate and comprehensive as possible.

However, this type of checking requires the user obtaining a high level of expert knowledge to assess quality (Mullan, Crookes, & Yeatman, 2003).

Thus, audit tools are used to identify particular content or text within the patient resources. There are benefits for the researchers are the ability to access data at a convenient time, as documents are in a written form which saves time and costs of transcribing. Also, document analysis can be less costly to obtain empirical data, documents are unobtrusive and used without impacting on participants. Moreover, documents can be checked and re-checked for reliability. Document analysis can less time consuming than the other methods (Bowen, 2009). A limitation of document analysis may be that information is protected and unavailable or private access (Creswell, 2014b).

The document analysis study was designed to identify key structural elements in the ED (current protocols, procedures, guidelines for ED staff, and resources available for parents relating to the provision of discharge information in the ED), and determine how documents inform and support the provision of discharge information.

Descriptive statistics are used to describe features of the documents in this study. Content analysis was applied to analyse written text such as pamphlets.

To evaluate parent resources, factors such as readability and comprehension need to be examined. Comprehensibility can be considered as a measure that merges readability of the material and health literacy of the patients and parents (Luk & Aslani, 2011).

Therefore, this study assessed the parents' resources (fact sheets) for readability using the SMOG formula (Mc Laughlin, 1969), which estimates the level of education required to understand the text in fact sheets.

### 4.4.2 Non-participant observation

The non-participant observation study design used both qualitative and quantitative methods of data collection and analysis. Observation is a suitable method of data collection when the researcher is interested in learning about the interactions of a group (Creswell, 2013). In qualitative research, the observer takes field notes to record and interpret the activities observed (Helleso, Melby, & Hauge, 2015). Four different strategies have been proposed to address the inherent challenges of researcher bias in observational recording; (i) simply noting all events, (ii) recording non-events such as expected behaviours that did not occur, (iii) noting paradoxes (that have been subjected to the researcher's interpretation) and (iv) noting potential problems within the observation (Peshkin, 2001). An alternative approach involves two strategies: a 'salience hierarchy'; recording events of significance or atypical behaviour and comprehensive note taking that includes non-events (Wolfinger, 2002). Taking notes however, takes time and could inadvertently result in participant reactivity (Holloway & Wheeler, 2010). Checklists can also be used in less time with potentially less distraction, to guide observations and ensure the same criteria for observation are applied to each participant. In this study, the researcher used fieldnotes that combined all four strategies in note taking, while the researcher remained as quiet and unobtrusive as possible during observations.

Quantitative method uses tools for counting observations of particular variables and can consider several strategies, as listed in the previous paragraph. Non-participant observation occurs when a researcher remains distant, and ideally unobtrusive, from the activities of the group or participant being observed. In this capacity, the researcher takes on the role of being a passive observer, witnessing the group's or participant's activities and making conclusions from the activities observed (Kumar, 2014).

Acknowledged limitations to non-participant observation studies include: the risk of altered behaviour in the presence of the researcher/observer, the researcher's ethical obligations not to report any data that may be considered either confidential or identifiable, the need for the researcher to have quality observation skills, and the time-consuming nature of data collection (Asan & Montague, 2014; Creswell, 2013). Ethical challenges can arise in non-participant observation studies when lapses in standard care or practices are observed. Medical researchers and or, staff are encouraged to consider the harm and benefits of speaking up promptly when issues arise (Pavlish, Brown-Saltzman, Hersh, Shirk, & Rounkle, 2011) and ethical committees may be particularly helpful in these situations.

The non-participant observation study was designed to identify current practices in the provision of discharge information to parents of children presenting to the ED, which reflected both process and outcome according to the theoretical framework in the Donabedian model. Observation also provides an opportunity to directly view structures in the ED.

Before analysis, all variables were examined through SPSS version 22. Descriptive statistics were used for analysis.

## 4.4.3 Focus group

The focus group study design used qualitative research methods for data collection and analysis. Focus groups explore a selected point of discussion through group interaction, in an in-depth and open-ended way (Kumar, 2014). Focus groups are considered to be helpful when the aim of the research is to explore the perceptions, experiences and understanding of a group of people who have some experience in common with regard to a situation or an event (Kumar, 2014). Focus groups build direct data showing both consensus and diversity by giving participants an opportunity to contemplate and respond to the views of others (Kumar, 2014). Also, the interactive nature of data collection found in a group discussion enables this method to generate more insights on the research issues than a series of in-depth interviews with the same number of individual participants (Hennink, Hutter, & Bailey, 2011). Focus groups are generally comprised of six to eight participants (Hennink et al., 2011) because this number of participants is recommended to allow all to contribute, allows for ease of group management, and encourages adequate participation within the group participants (Papastavrou & Andreou, 2012).

Focus groups also have limitations. Well-conducted focus groups need a skilled moderator to conduct the group and manage group dynamics (Hennink et al., 2011; Patton, 2015). Participation in focus groups can be of limited value if group members perceive a lack of freedom to speak openly and confidentially (Scholfield & Forrester-Knauss, 2014, p. 59). Researchers can have difficulties in recruiting appropriate focus group participants (Goodman & Evans, 2010b); ideally, participants should have a diversity of experiences in order to provide differing perspectives from within and between the focus groups, sufficiently rich sources of data for analysis and integration (Richardson-Tench et al., 2014).

The focus groups study was designed to identify ED nurses' perceptions of factors that influence parents' understanding of discharge information. By enhancing data richness and depth of inquiry, the focus group method permitted reflection on the structure, process, and outcome domains of the Donabedian Model of Quality of Care.

Qualitative content analysis was used to analyse data. Data were recorded by using audiorecorded digitally and fieldnotes, transcribed verbatim, and reread to identify key themes, independently coded by the researcher and supervisor, and analysed thematically.

### 4.4.4 Survey

The survey study design used quantitative and qualitative research methods. Surveys are beneficial to obtain information that is not directly observable, and for gathering data without direct contact with participants or retrieving information from people who are difficult to reach (Scholfield & Forrester-Knauss, 2014). Surveys can provide a quantitative description of attitudes or opinions of participants and qualitative data from text responses to open ended questions (Creswell, 2014a), and are often used by researchers for data collection (LoBiondo-Wood & Haber, 2010, p. 275). Surveys are useful when there is a limited set of questions. Each item in a survey should be clearly written, and the purpose of each questions clear to the respondent (LoBiondo-Wood & Haber, 2010).

The two most common types of survey questions are closed-ended questions and open-ended questions. Open-ended and close-ended questions are different in several characteristics, but especially in the role of respondents when answering such questions. Close-ended questions limit the respondent to the set of alternatives being offered, while open-ended questions allow the respondent to express an opinion without being influenced by the researcher (LoBiondo-Wood & Haber, 2010). There are several consequences for the quality of survey data. The advantages of open-ended questions include the possibility of discovering the responses individuals give spontaneously, thus avoiding the bias that may result from suggesting responses to individuals; a bias, which may occur in the case of close-ended questions. Open-ended questions also have disadvantages including the need for extensive coding, and they tend to result in more missing data in surveys than close-ended questions (Kazi & Khalid, 2012).

There are seven ways to administer surveys (Scholfield & Forrester-Knauss, 2014). First is the self-completion survey, where respondents are required to the complete the survey tool and instructions are given. Second is the group self-completion questionnaire, where the researcher administers a survey to a group, and respondents complete their own survey. Third is the mail self-completion survey, where participants are asked to complete a survey and return it by post, using a stamped addressed envelope provided by the researcher. Fourth is

the internet-based self-completion survey, where participants are asked to complete an internet-based survey and the web-link access is provided. Fifth is the face-to-face interview, where the researcher may collect data during a face-to-face interview by using an interview list of questions. Sixth is the telephone interview, where the researcher may collect responses to the survey items by using an interview question list over the phone. Seventh is the internet interview, where the researcher interviews research participants by using voice and video across the internet via software such as Skype or msn messenger.

A self-report study was designed to identify parents' perceptions of the relevance and quality of discharge information received in the ED. The extent to which parents understood the discharge information provided by the ED staff, the usefulness of this information in managing their child following discharge from the ED, and parents' satisfaction with this discharge information are outcomes explored in the survey. The survey was administered in one of three ways: (i) Mail self-completion, with a stamped addressed envelope provided; or (ii) Internet base self-completion (using Survey Monkey<sup>™</sup>); or (iii) A telephone interview.

All data were entered Survey Monkey<sup>™</sup>, which was then used to analyse the data. Survey Monkey<sup>™</sup> was selected as it is a well-recognised online survey platform and because results are easily transferred to the statistical software program SPSS Version 22. Descriptive analyses were applied in this study. For the purpose of this thesis, additional exploratory analysis using generalised estimating equations (GEEs) were used to understand more about correlations within the repeated measures of parents' perceptions of presentation and departure times in the ED within the survey. An exchangeable working covariance matrix was used to account for correlation and dependence between repeated measurements on the same individual over time (Hin & Wang, 2009; Liang & Zeger, 1986).

Integration of the findings of the four studies involved thematic analysis of qualitative data and descriptive statistical analysis of survey data. The triangulation of textual data included document analysis, observation field notes, focus group transcripts, and as well as questionnaires of parents' survey results.

# 4.5 Research setting

The setting for data collection was in a children's ED at a tertiary referral hospital in Brisbane, the capital city of Queensland, Australia. The hospital is located in the north of the Brisbane central business district. Data collection for the four studies was conducted on weekdays (starting at 9 am and continuing through to 5 pm) from July 2015 to September 2016. The bias of collecting data at the same time may limit the generalisability of cases occurring at other times of the day. However, the staff within the department agreed to the data being collected only at this time of day on week days (not weekends). The demographic profile of the area surrounding the hospital included predominantly Australian-born residents (73.2%). The most common other countries of birth were New Zealand 4.1%, England 3.4%, India 1.9%, Philippines 1.4%, and Italy 0.7%. Overall, 83.4% of people spoke only English at home. Other languages spoken at home included Italian 1.3%, Cantonese 0.8%, Mandarin 0.7%, Hindi 0.7%, and Punjabi 0.6%. Children under the age of 15 years represented 18.1% of the population of this local government area in Brisbane (Australian Bureau of Statistics, 2011).

The hospital is a 630-bed major tertiary referral hospital, and includes the relatively recently introduced child health services, which commenced in 2012. The child health services include a dedicated children's emergency department to make health care more convenient and accessible for families living in a large catchment area within the northern suburbs and outer metropolitan area close to Brisbane. The children's emergency department has a separate entry and waiting room, includes 12 dedicated paediatric treatment rooms and outpatient clinics for specialist paediatric services. The median waiting time in this paediatric ED in March 2016 was 14 minutes (Queensland Health, 2016); this is a slightly lower waiting time than the 2015-2016 national average of 19 minutes (Australian Institute of Health and Welfare, 2016).

## 4.6 Population and sample

The target populations for this thesis were nurses and other ED health care providers who worked with children and provided discharge information to parents in the ED, and parents who presented to the ED with a child. For the purpose of this research, the term "parents" is inclusive of guardians. Purposive sampling (Kumar, 2014) was used to recruit participants for the three studies involving parents who had taken their child to the ED and ED staff. Specifically, ED nurses were selected for the focus groups, and both parents and ED staff were invited to take part in the non-participant observation.

Previous studies have used parent surveys following visits to paediatric emergency departments with participant numbers ranging from 40 (Considine & Brennan, 2007) to 630 parents (Bucaro & Black, 2014). However, without information on response rates and limited time for data collection, probability sampling was difficult to support. This was compounded by the observation that the only previous study on paediatric discharge information in Australia had the smallest sample size of 40 parents (Considine & Brennan, 2007). Given the uncertainty of estimating how many parents in Australia, would typically consent to providing responses to surveys about their experiences in the children's ED, and that randomly selecting parents in this setting would be problematic (Rubin & Babbie, 2010), recruitment of parents for the survey involved non-probability sampling. While a strategy to include maximum variation sampling in securing a diverse range of parents would have been ideal (Patton, 2015), the research assistant targeting parents for recruitment into this survey study was time restricted and inclusion criteria for parents of children leaving the ED also had to be considered.

Inclusion criteria for parents of children presenting to the ED were: the child (patient) had a triage score ranging from three to five (Australasian College of Emergency Medicine, 2016); the child was subsequently discharged from the ED to home; and the parents understood spoken and written English.

Exclusion criteria included: (i) parents for whom there was a suspicion regarding the cause of their child's injury; (ii) children with a cognitive or neurological deficit; or (iii) children taking analgesic medication on a regular basis. Each of the selected exclusion criteria mask greater complications for medical care, and may not be regarded as typical emergency care treatment in a children's ED. For example, situations of child abuse may necessitate additional specialist services from child psychologists, social workers, and even legal authorities in child protective services. Cognitive or neurological deficits in children presenting for emergency medical care may exacerbate the level of care required and specific specialised level of information provided to parents. Habitual analgesic medication in children may alter typical pain reflexes
and again, alter the care and information normally provided to children and their parents in an emergency setting.

### 4.7 Ethical considerations

Ethics approval for this research program was sought and gained from the Research Ethics Committee of the hospital (HREC/15/QPCH/70) and the Research Ethics Committee of Australian Catholic University (HREC Register number 2015-124R) (See Appendix 2 for Ethics approval). The data collection procedures covered all aspects of human rights protection. The computer on which data were stored was password-protected, and a lockout screensaver was installed. All data were saved onto two USBs at the completion of data entry, and printed as a hard copy; the USBs and hard copy were stored in a locked filing cabinet, only accessible to the research team. Key ethical issues for this thesis included informed consent, confidentially and beneficence (Australian Government National Health and Medical Research Council, 2007).

### 4.7.1 Informed consent

Parents' consent for themselves and their child to participate in non-participant observational study or survey

All parents who met the inclusion criteria over the period of data collection were invited to participate in the observation study. An invitation and an information sheet about the study were provided at the point of initial contact with parents. Parents who consented for themselves and their child to participate in the observation study consented to their interactions with the ED staff being observed by the researcher, from admission to discharge. Consent was also obtained from the ED staff for these observations, which included staff interactions with parents. The parents and staff were not given full details of the study's focus on parents' understanding of discharge information, in order to minimise any potential bias in reporting their interactions with the ED staff.

Parental consent generally provides additional protection when a young person is not able to understand or appreciate what research entails, or the young person is not willing to properly consider information (National Health and Medical Research Council, 2015). Thus, parents were given the opportunity to respond on their child's behalf (Queensland Health, 2011). Participants were informed their participation in the study was voluntary, and refusal to participate or a decision to withdraw at any time did not involve a penalty or loss of the benefits to which the participant would otherwise be entitled. (See invitation information and consent form, Appendices 9 and 11).

Parents, who chose to participate in the survey, were provided with an invitation and an information sheet about the study. The consent of parents choosing to complete the survey, either online or by post in a reply-paid envelope was implied by return of the survey. (See information sheet, Appendix 9). However, a further group of parents, who agreed to participate in the telephone survey, were invited to sign a consent form in the waiting room by a research assistant who was a registered nurse employed at the participating hospital. Parents were given an information letter, and a consent form was signed at this time. (See information sheet and consent form, Appendix 9).

#### ED staff consent to engage in non-participant observation and focus groups

ED staff who volunteered to participate in the non-participant observation and the focus groups studies were provided with written information describing the research study. They were invited to sign a consent form prior to data collection. (See information sheet and consent form, Appendix 10).

#### 4.7.2 Beneficence

There were no likely benefits for the ED staff and parents who participated in studies within this thesis. However, the findings may improve the outcomes of children returning home from the ED in the future. In addition, there was a minimal perceived risk for parents, children, and staff from participating in studies for this thesis; the time taken to complete the survey could cause some inconvenience for the participants.

#### 4.7.3 Confidentiality

The steps were taken to ensure that confidentiality was maintained were: collecting only nonidentifiable demographic information about each participant; omitting any identifying information on the data collection forms; and focus group records only reported the overall collated data, with the names and experience of participants remaining obscure to the researcher. Consent forms were stored separately from the data for both the focus groups and participant observations. Participants were assured all results would be reported as group findings, and these findings would be reported in the nursing literature and in communitybased reports; only group results would be presented in these reports, and responses from focus groups would be written in a way that would not identify individual nurses. The data were stored using strategies that maintain confidentiality and security at all times. All data will be stored for a minimum of five years in accordance with the current NHMRC guidelines. After that time, data will be destroyed. In order to protect the data from corruption, three copies of data are being kept: an electronic copy saved to the principal researcher's notebook computer, a backed-up version on a separate external hard drive, and a hard copy stored in a locked filing cabinet. A security code was installed on the researcher's notebook computer, so that only the researcher and the supervisors could access the files on the computer.

#### 4.8 Assurance in rigour and validity

By using both qualitative and quantitative methods, the rigour and validity of mixed methods research present many challenges.

Trustworthiness and data integrity are key to rigour in qualitative research (Polit & Beck, 2017b; Scholfield & Forrester-Knauss, 2014), and can be addressed by maintaining credibility, dependability, confirmability, and transferability of the research (Polit & Beck, 2017a). Credibility in data refers to the strategies used to ensure results are believable in nature and accurately reported; such as providing several quotations from nurse's perspective on the same concern. Also, analysis of documents with largely nation-wide availability in paediatric emergency care may provide some confidence in their credibility of the available resources. Dependability refers to the reliability of data standing the test of time; such as understanding tensions in national policy, on-going issues with time-restrictions for treatment in the ED (NEAT). In the focus groups, a challenge was whether ED nurses would feel able to speak openly if their manager or other senior staff were in the same group. On the other hand, the participants were experienced ED nurses with a range of experiences at the site of data collection and other children's medical emergency settings, making their responses and dependable and therefore relevant to this thesis. Multiple approaches (document analysis, non-participant observation, focus group and survey) to understanding parents' perceptions were used in this research to improve the confirmability of the emerging themes. Thus, multiple sources of data and the capacity for triangulation of key agents or resources may also support the depth of data and enhance validity in the methods (Holloway & Wheeler, 2010) For example, having nurses confirm their confidence in the usefulness of resources available for parents would support the trustworthiness in the quality of the document analysis. Another example may lie in the capacity to compare observations of parents interacting with staff with nurses' perceptions of how they support parents' understanding of discharge information. Transferability was supported in providing a depth and breadth of data to profile the understanding of parents' receipt and response to discharge information from a number of perspectives. Also, strategies to support the trustworthiness in the qualitative aspects of data collection included the independence of the researcher and focus group leader from the ED staff.

Independence and objectivity of quantitative data remain a high priority, and a number of strategies are needed to maintain internal and external validity. Internal validity refers to the rigour of testing exactly what was planned to be assessed, gathering information on potential confounders and minimising potential sources of bias (Polit & Beck, 2017a). Three key strategies for avoiding bias of quantitative data are checking for internal validity and external validity as well as minimising selection bias (Schneider, Whitehead, LoBiondo-Wood, & Haber, 2014). To first address internal validity, a pilot test of the parents' survey was conducted. Face and content validity of the parents was distributed to (1) approximately four university-based paediatric nursing staff for critical comment (2) approximately 3 parents of primary school children and (3) a health-based epidemiologist. On the basis of this feedback, changes were made to the wording of some questions and the design of the survey. These changes included instructions on how to complete the survey and resulted in the survey being divided into five sequential and logical sections. All reviewers were asked to ensure that the survey would be readily understood by a range of parents, would provide the data required to profile the provision of discharge information to parents and had a visual design appealing to parents. Feedback on the duration of time required to complete the survey requested.

To support external validity, the literature from previous surveys was rigorously reviewed for questions to parents relating to paediatric emergency care (Waisman et al., 2003; Waisman et al., 2005), or questions to adult ED patients about understanding discharge information (Engel et al., 2012; Engel et al., 2009; Hastings et al., 2011; Logan, Schwab, Salomone, & Watson, 1996; Spendorfer, Karras, Hughes, & Caputo, 1995; Zavala & Shaffer, 2011). Section

2.3.1 on the measurements of understanding of discharge information and Table 3 of the literature review describe some specific questions previously used to assist in understanding discharge information. Also for demographic data, some questions were incorporated from the largest ongoing longitudinal study of Australian children (LSAC) (Yu & Daraganova, 2017). Thus, external validity for the parents' survey was supported by the use of previously used and relevant questions.

Minimising selection bias involves an in-depth description of potential explanatory factors. Therefore, the survey included information on the education of parents, post-code based socio-demographic background, years in Australia, language spoken at home, and the number of previous visits to a children's ED. Also, a number of questions linked to relevant parent attributes were included in the survey: parents' confidence in home-based management of the patient (Engel et al., 2009) parents' satisfaction with their ED experience (Curran et al., 2014), and parents' perceptions of their own anxiety levels before and after their visit to the ED (Bucaro & Black, 2014; Holm & Fitzmaurice, 2004; Zemek et al., 2013).

Inclusion criteria are also considered part of the construct validity of profiling parents' understanding of discharge information and understanding English language. For example, selection only included parents with children receiving triage scores of three to five and who also understood English language. This selection strategy excluded parents whose perceptions of their child's emergency condition could be deemed to be extreme, where in fact they were not (presentation triage scores of 1 to 2). It also removed atypical cases such as presentations with suspected links to child abuse, children with cognitive or neurological deficits, and children regularly using analgesic medication (potentially masking pain responses). Selection bias is often difficult to remove, and thus a challenge for external validity. If selection bias is potentially problematic and/or unavoidable, it is important for the researchers to examine the study's design and find ways to adjust and acknowledge these issues in their study results (Polit & Beck, 2017a).

Bias of results can also be addressed in quantitative research by removing identifiable participant details prior to data analyses, employing research assistants who were not going to be involved in data analyses to gather data, and doing random checks of data spreadsheets with original data.

# 4.9 Summary

This chapter presented the philosophy of pragmatism, the concept of mixed methods research design, the research methods used in this thesis, as well as the ethical considerations related to this research program which was undertaken in the real world setting of a children's ED. The research design used to conduct the research for this thesis is underpinned by the Donabedian Model of Quality of Care framework; gathering informative and in-depth data on structures, processes and outcomes surrounding the quality of care provided in the discharge information to parents about their child's care at home, after leaving the children's ED. The data were gathered and analysed in four studies: review of documents; non-participant observation-of parents and ED staff; focus groups with ED nurses; and a survey of parents. Specific details of the methods used in each of these studies are presented in chapters six to eight of this thesis and the integration of the findings of the four studies are presented in the chapter nine.

# **Chapter 5: Analysis of Emergency Department Documents**

# **5.1 Introduction**

This chapter presents the research design, findings, and the strengths and limitations of the first of the four studies, the Analysis of Emergency Department Documents in this thesis, and answers the first research question:

*Question1: What protocols, procedures, guidelines, and resources are used to inform and support the provision of discharge information in the ED?* 

A review of emergency department documents was used to answer this question, and examined all relevant protocols, procedures, guidelines for ED staff, and discharge information resources for parents. The data collection and analysis undertaken in this study addresses the first domain of the Donabedian Model of Quality of Care, namely, *Structure*.

The findings from the Document analysis were later integrated with the observed experiences of parents in the ED, along with the survey and focus groups findings, in order to compile a well-connected profile of discharge planning and provision of discharge information for parents to assist in managing their child post discharge from the ED.

# 5.2 Research design and methods

# 5.2.1 Research design

A document analysis was conducted in the Children Emergency Department using a purposedesigned audit tool, informed by the Donabedian Model of Quality of Care (1988) and key findings from the literature review. The tool is included as Appendix 3. The purpose of the document analysis is to add objective evidence to this research, and permit triangulation of the data. The next section is comprised of a description of the sampling of the documents for review, data collection procedures and analysis.

# 5.2.2 Sampling

This review sought to identify documents with information relating to support for parents of children discharged home from internal and external sources ED. Formats of the documents could include hand written notes, printed resources, on-line material, digital material, images, or any other format.

#### 5.2.3 Data collection

The researcher conducted the data collection, assisted by an ED nurse. The data collection questions in the audit tool were initially answered in consultation with an ED nurse. The audit tool was comprised of five questions. Each question was to be answered with either "yes" or "no"; when the answer was yes, copy of documents or extracts of text from the document(s) were selected, and coded according to source, title, date, and type for subsequent analysis. The questions were:

(1) Does the hospital have any protocols, procedures, and guidelines on discharge planning, and in particular providing discharge information in the ED?

(2) Do the documents include recommendations on categories of discharge information to be provided in the ED?

(3) Do the documents include recommendations on staff training for providing discharge information?

(4) Do the documents include recommendations on which ED staff should provide discharge information in the ED?

(5) Do the documents include recommendations on how to deliver discharge information to parents or guardians?

Documents were identified through discussion with an experienced ED nurse using the audit tool and a search of the hospital's web based database. More specifically, the analysis of the identified documents aimed to detect any reference to patient diagnosis and treatment, individualised patient self-care information and/or instructions, community resources available to support children discharged from the ED, follow-up and/or return to ED instructions, and referrals to other community healthcare providers. The audit sought documents with information including recommendations on ED staff training relating to discharge information, such as, addressing issues of quality information sharing, engaging with parents, and communicating with non-English speaking parents and or, with parents under stress.

The search also sought evidence of structural dimensions relating to discharge information. For example, documents were explored for descriptions about staff roles in the provision of discharge information. Despite a thorough search and audit process, no relevant protocols, procedures, or guidelines were identified. However, a number of online and printed resources to support provision of discharge information to parents were identified and retrieved for analysis.

### 5.2.4 Data Analysis

The resources to support provision of discharge information were retrieved from hospital and government websites, and also from the wall display in the children's ED in July 2015 and analysed. Analysis first involved identifying the target audience for the resources- parents or staff and summarising parent-focussed resources according to the title and source of the material. The literacy standards (that is, the level of reading difficulty, or level of readability) of these resources for parents were assessed using the SMOG formula (Mc Laughlin, 1969). Finally, each resource was compared against a checklist of expected domains of content identified in the literature review, including (i) patient status and treatment, (ii) self-care information, (iii) community resources, (iv) follow-up/return to ED instructions and (v) relevant community referral

# 5.2.4.1 Simple Measure of Gobbledygook (SMOG)

The SMOG tool (Mc Laughlin, 1969) was used to assess the level of reading difficulty of the documents.

# SMOG grade = 3 + Square Root of Poly-syllable

Used previously in health settings for the promotion of materials, the SMOG readability level results range from 1-2 (basic elementary) to 14 (tertiary education) (Kondilis, Akrivos, Sardi, Soteriades, & Falagas, 2010). Recommendations for the readability level of health information material are that it should be written at a level of 5-8 (Albright et al., 1996; Badarudeen & Sabharwal, 2010; Cotugna, Vickery, & Carpenter-Haefele, 2005).

# 5.3 Findings

A major finding of this document review was that despite the availability of some resources for parents (fact sheets), other ED documentation lacked information on discharge policies and practices. The findings in relation to the online resources for parents and staff are presented according to type, sources, literacy level and content.

#### 5.3.1 Types and sources of the online resources

Online resources were available for the ED staff to download via the Queensland Health intranet (QHEPS: Queensland Health Electronic Publishing Service) website; resources could then be printed, displayed, given to parents, and/or used exclusively by ED staff. These resources were written between 2008 and 2013. QHEPS provided 49 resources on conditions that may relate to a child presenting to a Children's ED, 46 resources (on 41 conditions) for parents (See Table 4), and three resources designed specifically for staff. The three staff resources included:

- 1. An asthma action plan
- 2. A departmental guideline for the management of return to sports after head injury
- 3. A dehydration assessment tool

The asthma action plan was designed for doctors to help a child with asthma and/or their parents to recognise when the condition was worsening; it also gives clear instructions on what to do after discharge from the ED. An online form was available to fill in the information and print three copies of the generated action plan (one for the family, one for the notes, and one for the General Practitioner [GP]). This resource was not analysed because it was not retrieved from either the wall displays or website of the specific hospital setting. The Health Departmental guideline for the management of return to sports after head injury, and the dehydration assessment tool were not analysed because they were not intended for parents. Thus, three resources relating to possible parental understanding of information about caring for their child after discharge from the ED were excluded from subsequent analyses.

Other resources for parents and staff were obtained from three different sources: 29 from the Royal Children's Hospital, Melbourne (RCHM); 11 from Queensland Health; and 9 from the study site, including the three staff resources (Table 4). Multiple resources were available for some specific health conditions. For example, resources on asthma were available from all three sites, but each targeted a slightly different purpose; one provided information about asthma, one provided instructions on how to use a spacer, and the third was an asthma action plan for doctors to provide information on asthma preventer and reliever medication (dose and frequency), instructions to manage prednisolone for acute exacerbations, information for the current episode, and instructions for what to do if symptoms are induced by sport.

Resources for four health conditions were supported by similar guidelines from two sites: epistaxis, febrile convulsions, influenza, and pulled elbow.

|     | RCHM                        |    | Study site               |     | QLD Health           |
|-----|-----------------------------|----|--------------------------|-----|----------------------|
| 1.  | Asthma use of spacers       | 1. | *Asthma action plan      | 1.  | Asthma in children   |
|     |                             | 2. | Febrile Convulsion       | 2.  | Febrile Convulsions  |
| 2.  | Pulled elbow                | 3. | Information for patients |     |                      |
|     |                             |    | with pulled elbow        |     |                      |
| 3.  | Epistaxis (Nosebleeds)      |    |                          | 3.  | Nosebleed in         |
|     |                             |    |                          |     | children             |
| 4.  | Influenza                   |    |                          | 4.  | Viral illness        |
|     |                             | 4. | Information for patients | 5.  | Minor Head Injury in |
|     |                             |    | with post-concussion     |     | children             |
|     |                             |    | syndrome                 |     |                      |
| 5.  | Chicken pox                 | 5. | *Dehydration             | 6.  | Abdominal pain.      |
| 6.  | Colic, Crying, and          |    | ,<br>Assessment Tool     | 7.  | Accidental poisoning |
|     | unsettled babies            | 6. | Fever in children        | 8.  | Bronchiolitis        |
| 7.  | Conjunctivitis              | 7. | Information for carers   | 9.  | Constipation         |
| 8.  | Cough                       |    | of children with plaster | 10. | Croup                |
| 9.  | Eczema                      |    | and fracture             | 11. | Gastroenteritis      |
| 10. | Glue ear                    | 8. | Procedural sedation of   |     |                      |
| 11. | Hand, foot, and mouth       |    | children and discharge   |     |                      |
|     | disease                     |    | advice                   |     |                      |
| 12. | Henoch Schönlein            | 9. | *Departmental            |     |                      |
|     | Purpura                     |    | guideline for the        |     |                      |
| 13. | Herpes Simplex              |    | management of return     |     |                      |
| 14. | Impetigo                    |    | to sports after head     |     |                      |
| 15. | Lumbar puncture             |    | injury                   |     |                      |
| 16. | Meningers and infection     |    |                          |     |                      |
| 17. | Migraine backache           |    |                          |     |                      |
| 10. | Nappy rash                  |    |                          |     |                      |
| 20  | Atitis media                |    |                          |     |                      |
| 20. | Penis and foreskin care     |    |                          |     |                      |
| 22. | Pneumonia                   |    |                          |     |                      |
| 23. | Reflux                      |    |                          |     |                      |
| 24. | Respiratory syncytial virus |    |                          |     |                      |
| 25. | Roseola Infantum            |    |                          |     |                      |
| 26. | Scabies                     |    |                          |     |                      |
| 27. | Slapped cheek (Fifth        |    |                          |     |                      |
|     | syndrome)                   |    |                          |     |                      |
| 28. | Care of wounds after use    |    |                          |     |                      |
|     | of stitches and/or glue     |    |                          |     |                      |
| 29. | Threadworms                 |    |                          |     |                      |

Table 4: Queensland Health Electronic Publishing Service's online resources

Note: \* = resources for staff only; RCHM= Royal Children's Hospital, Melbourne; QLD Health = Queensland Department of Health; Study Site = site of current research project

### 5.3.2 Readability levels within resources for parents

In order to understand more about the suitability of resources for parents to assist post discharge care of their child, a literacy rating scale was applied to the contents of each of the 46 resources listed in Table 5.

All resources from QHEPS (comprising the three separate sources of the Royal Children's Hospital, Queensland Health, and the Study site) were only available in the English language. The SMOG readability formula, detailed in section 5.2.4.1, presents the results of the estimated readability for specific school year levels of the resources. To reiterate, the score of nine should be easily readable to a student in year nine.

Within the resources analysed there were inconsistent literacy levels, with some information sheets using simple words and diagrams, and others providing complex explanations. Three resources targeted standards expected of year 8, and 4 targeted year 12. Year 10 readability was the most common score across all documents, with the study site documents scoring highest at 100%, Queensland Health documents at 82% and RCHM documents at 68%.

| SMOG score |   | Condition                                   |                                |
|------------|---|---|--------------------------------|
|            | RCHM  | Study Site                                  | QLD Health                     |
| 8          | Hand, foot, and mouth<br>disease<br>Lumbar puncture<br>Penis and foreskin care  | _   | -                              |
| 9          | Asthma use of spacers<br>Colic, Crying, and unsettled<br>babies<br>Epistaxis (Nosebleeds)<br>Glue ear<br>Respiratory syncytial virus<br>Threadworms |   | Bronchiolitis<br>Viral illness |
| 10         | Chicken pox<br>Cough<br>Eczema  | Fever in children<br>Information for carers | Asthma active<br>plan          |

### Table 5: Resource and site-specific readability levels

|    | Henoch Schönlein Purpura  | of children with plaster                                     | Febrile  |
|----|---|--|--|
|    | Herpes Simplex  | and fracture   | Convulsions  |
|    | Impetigo  | Information for patients                                     | Nosebleed in   |
|    | Nappy rash  | with pulled elbow  | children   |
|    | Aligraine headache Procedural sedar<br>ulled elbow children and disc<br>eflux advice<br>oseola Infantum<br>cabies<br>lapped cheek (Fifth<br>yndrome)<br>are of wounds after use of<br>titches and/or glue | Procedural sedation of<br>children and discharge<br>advice   | Minor Head<br>Injury in<br>children<br>Abdominal<br>pain<br>Constipation<br>Croup<br>Gastroenteritis |
| 11 | Conjunctivitis<br>Meningococcal infection<br>Otitis media   | Febrile Convulsions  | Accidental<br>poisoning  |
| 12 | Influenza<br>Meningitis<br>Pneumonia  | Information for patients<br>with post-concussion<br>syndrome |  |

Note: RCHM = The Royal Children's Hospital, Melbourne; SMOG = Simple Measure of Gobbledygook; QLD Health = Queensland Department of Health.

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Average SMOG

10

The literacy competencies of some parents could make these resources difficult to understand because the readability was quite high, beyond the recommended sixth to eight grade level (Badarudeen & Sabharwal, 2010). Figure 6 shows readability most frequently matched standards expected at tenth grade level.

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#### 5.3.3 Information within resources for parents

Twelve types of information were extracted (where available) from the resources: (i) the definition of each disease/condition/illness/common injury; (ii) the likely causes of each diagnosis; (iii) signs and symptoms; (iv) appropriate first aid; (v) prevention; (vi) treatment; (vii) what to expect during the course of the condition; (viii) when to come back to the hospital; (ix) home care; (x) follow-up; (xi) key points to remember; and (xii) where to find help for additional information. For the purpose of reviewing all of the resources, 12 categories of information were reduced to 5 categories (See Table 6). The reduction of categories was informed by the studies discussed in the literature review in Chapter 2, and the first domain of the Donabedian Model, namely *structure*.

| Reduced categories of information        | Original types of information   |
|--|---|
| (i) patient status and treatment         | <ul> <li>(i) the definition of each</li> <li>disease/condition/illness or common injury,</li> <li>(ii) the likely causes of each diagnosis,</li> <li>(iii)signs and symptoms</li> <li>(vi) treatment</li> <li>(vii) what to expect</li> </ul> |
| (ii) self-care information,              | (iv) first aid<br>(v) prevention<br>(ix) home care<br>(xi) key points to remember   |
| (iii) community resources                | (xii) where to seek help for additional information   |
| (iv) follow-up/return to ED instructions | (viii) when to come back to the hospital<br>(x) follow-up   |
| (v) relevant community referrals         | (xii) where to find help for additional information   |

Table 7 provides specific comparisons of each resource's capacity to the address five fundamental issues in child emergency care: (i) patient status and treatment; (ii) self-care information; (iii) community resources; (iv) follow-up/return to ED instructions; and (v) relevant community referrals (Engel et al., 2012; Samuels-Kalow, Stack, & Porter, 2012).

| Resources on<br>childhood conditions<br>for parents | Information provided to parents       |  |  |   |   |  |
|---|---------------------------------------|--|--|---|---|--|
|   | Patient<br>status<br>and<br>treatment | Patient<br>self-care<br>information<br>and<br>instructions | Information<br>about<br>community<br>resources | Follow- up<br>instructions<br>& return to<br>ED<br>instructions | Referrals<br>to<br>community<br>health<br>providers |  |
| Abdominal pain                                      | ✓                                     | ✓  | ✓  | ✓   | ✓   |  |
| Accidental poisoning                                | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Asthma  | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Bronchiolitis                                       | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Chicken pox   | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Colic, crying, and unsettled babies                 | ✓                                     | ✓  | $\checkmark$                                   | ✓   | $\checkmark$  |  |
| Conjunctivitis                                      | $\checkmark$                          | $\checkmark$   | ×  | $\checkmark$  | $\checkmark$  |  |
| Constipation  | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Croup   | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Eczema  | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Epistaxis<br>(Nosebleeds)                           | $\checkmark$                          | $\checkmark$   | ×  | $\checkmark$  | $\checkmark$  |  |
| Febrile convulsions                                 | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Fever in children                                   | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Gastroenteritis                                     | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |
| Glue ear  | $\checkmark$                          | $\checkmark$   | ×  | $\checkmark$  | $\checkmark$  |  |
| Hand, foot, and<br>mouth<br>Disease                 | √                                     | $\checkmark$   | ~  | $\checkmark$  | √   |  |
| Henoch Schönlein<br>Purpura                         | $\checkmark$                          | $\checkmark$   | ×  | $\checkmark$  | ×   |  |
| Herpes Simplex                                      | $\checkmark$                          | $\checkmark$   | ×  | $\checkmark$  | ×   |  |
| Impetigo  | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | ×   |  |
| Influenza   | $\checkmark$                          | $\checkmark$   | $\checkmark$                                   | $\checkmark$  | $\checkmark$  |  |

# Table 7: Review of resources using the criteria adapted from the literature

| Information for<br>patients with post-<br>concussion syndrome           | √            | ✓            | ×            | ✓            | ✓            |
|---|--------------|--------------|--------------|--------------|--------------|
| Information for<br>carers of children<br>with plasters and<br>fractures | ✓            | ✓            | ✓            | ✓            | ✓            |
| Lumbar puncture   | $\checkmark$ | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ |
| Meningitis  | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Meningococcal infection   | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Migraine headache   | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Minor Head Injury in<br>children  | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Nappy rash  | <b>√</b>     | <b>√</b>     | $\checkmark$ | ✓            | <b>√</b>     |
| Otitis media  | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Penis and foreskin<br>care  | <b>√</b>     | <b>√</b>     | ×            | <b>√</b>     | <b>√</b>     |
| Pneumonia   | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Procedural sedation<br>of children and<br>discharge advice              | ~            | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Pulled elbow  | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Reflux  | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Respiratory syncytial<br>virus  | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Roseola Infantum  | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | $\checkmark$ |
| Scabies   | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Slapped cheek (Fifth<br>syndrome)                                       | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |
| Care of wounds after<br>use of stitches and/or<br>glue                  | ✓            | $\checkmark$ | ×            | ✓            | ✓            |
| Threadworms   | $\checkmark$ | $\checkmark$ | ×            | $\checkmark$ | ×            |
| Viral illness   | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ | $\checkmark$ |

After the removal of duplicate resources, it was found that all 41 QHEPS resources available online for parents, relating to childhood conditions (i) addressed patient status and treatment,

(ii) provided information on patient self-care, and (iii) included follow-up and return to ED instructions. Of the 41 resources, 28 provided information about community resources. All but four of the reviewed resources referred children and/or their families to community health providers, such as paediatric dietitians, physiotherapists, or sports medicine practitioners. The four conditions about which the relevant resources lacked information about referrals to community health providers were herpes simplex, Henoch Schönlein Purpura, impetigo, and threadworms.

None of the resources specifically addressed discharge processes. The resources were more likely to contain generic information, which may or may not have been useful for quality processes in the care of children by parents after leaving the ED. However, two of the existing pamphlets extended generic information into tips for children's care at home. Specifically, pamphlets about plaster casts used for bone fractures, and the care of wounds after use of stitches and/or glue, contained additional information perceived as useful for parents following their child's discharge from an ED. For example, specific home-based care for stitches included keeping the wound area dry for 24 hours, avoiding picking at the wound, and returning to the ED should the wound re-open within less than 48 hours. Similarly, parents caring for a child at home with a plaster cast were advised to keep the limb elevated in the first few days after discharge from hospital, care for the skin under the plaster by avoiding the natural response to itchiness (for example, using a knitting needle, ruler or pen/pencil to scratch the skin under the plaster) and care for the plaster by keeping it dry without any pressure or artificial heating. The plaster care pamphlet also asks parents to observe their child for excessive pain, signs of poor blood supply and excessive swelling.

Analysis of the resources, using the suggested standards for Children's Emergency Care from the International Federation for Emergency Medicine (2012), provided generally positive findings about information for parents. Specifically, all 41 resources provided to parents contained some information relating to the progress of their child's condition and requirement for care at home, including recognition of important adverse changes. One resource on reflux, lacked advice on medications, and only the resource on threadworms did not have advice on what to do if the condition worsened. It appeared that all resources had been strategically designed as an integral part of the discharge information because the resources could also assist parents with care of their child at home.

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There were three major findings in this study.

- No policies directly addressed discharge information for parents of children leaving the ED. Only two of the available protocols and resources for staff were inclusive of discharge information in the paediatric ED setting.
- 2. There was inconsistency in the framework and design of resources available for parents to take home, despite information coming from three separate sources. There were also specific inconsistencies relating to referrals to community healthcare providers; in 15 of the 41 resources lacked information about referring parents to community resources, and four specifcally lacked links to community health providers.
- 3. The variability of literacy levels used within the resources that parents could take home to support their child's care following discharge from the ED was mostly pitched at to high a level (at a year 10 readability standard).

# 5.4 Discussion

The document analysis study aimed to identify the structures (protocols, guidelines and resources) to support the provision of discharge information to the parents of children leaving the ED. The first major finding that there was an overall absence of documentation on discharge planning in the children's ED to guide staff practice is concerning. Given that this ED is a learning environment for health professionals such as nurses and doctors, having some wiritten guidelines on discharge processes for children and their parents would be useful, rather than assuming that all staff are well informed of the differences in this aspect of care for sick or injured children.

The second major finding was inconsistency in the framework, language and design of resources available for parents to take home. The inconsistencies may be due to resources coming from three different sources. However, even within the same source, a diversity of types of information could be found; the diversity constitutes a potential risk of confusion for users of these resources.

Previous studies have recommended the types of information to be provided to parents, including individualising patient self-care information and instructions (Gozdzialski et al., 2012), referring patients and ensuring patients or carers comprehend the support and have

the capacity to provide care in the home setting (McCarthy, Engel, Buckley, Forth, Schmidt, Adams, & Baker, 2012; Samuels-Kalow et al., 2012; Zavala & Shaffer, 2011).

Inconsistencies in discharge information pose risks to patients' health (Curran et al., 2014). Specific concerns about the risks of inadequate discharge information in the paediatric ED include parents' potential confusion about the diagnosis, medications and advice about care at home. Even the 2012 International Standards of Care for Children in Emergency Departments (ISCED) (International Federation for Emergency Medicine, 2012) makes limited reference to the discharge process for children. Only one paragraph on discharge information was found in this 94 page document. The ISCED standards refer to the need for parents to understand: (i) how a condition can progress; (ii) how parents can care for their child at home; (iii) information on medications; (iv) the need to observe signs and symptoms of a condition's progression; and (v) advice on how to act if the condition worsens, or if parents are overly concerned about their child. Additional standardised information could include contact telephone numbers when parents are seeking more advice, and where appropriate, information on multiple on-going follow-up appointments (International Federation for Emergency Medicine, 2012).

The third major finding was the marked differences in readability levels used within the resources for parents. Using the SMOG readability formula may have some limitations in terms of representing more holistic health literacy, but readability formulas including SMOG remain useful for at least part of the analysis of health resources (Sanghvi, Cherla, Shukla, & Eloy, 2012). Findings showed the majority of resources were mostly pitched at a year 10 readability standard. With the complex written language in some resources, there is the risk of poor understanding by parents of the children's needs once they are discharged from the ED. In a previous investigation into the readability standards of parents leaving a paediatric ED, approximately 50% of parents showed a lack of capacity to understand paediatric emergency department information (Chacon, Kissoon, & Rich, 1994). More recently, the SMOG readability score was applied to Australian paediatric oral health education materials (Arora, Lam, Karami, Do, & Harris, 2014). Similar to the findings in this thesis, readability varied widely; with disadvantaged communities perhaps likely to experience the most difficulties reading this material (Arora et al., 2014).

The limitations of readability formulae were recently reviewed by the Australian Government's Department of Health (Australian government, 2013). Although the review acknowledged the wide use of readability formulae including SMOG for assessing an extensive range of patient information materials, the formula's reliance on scores for polysyllabic words was seen as problematic. For example, a polysyllablic word such as diabetes is a commonly used medical term that cannot be avoided in some materials targeting diabetes and its use inflates readability scores. This review of patient formation resources called for greater scrutiny of visual or design components of materials to improve readability where polysyllabic words are unavoidable(Australian government, 2013). Common resources used in paediatric emergency care include polysyllabic words such as meningitis, meningococcal and gastroenteritis that could require additional support from visual or design considerations.

Nonetheless, several healthcare organizations have targeted the readability of health information for patients and parents suggesting it should be no higher than sixth to eighth grade level (Badarudeen & Sabharwal, 2010); materials pitched at an eleventh-grade standard of literacy (SMOG) may present difficulties in comprehending, and therefore following instructions, and potentially compromise outcomes (Spendorfer et al., 1995).

The printed resources reviewed in this study may be appropriate for most parents in Australia, given that approximately 74% of the population complete high school (Mitchell Institute, 2015). The literacy standards also assume competencies in English language, independent of school completion, although this may not always apply because 28.2% of Australia's estimated resident population were born overseas (Australian Bureau of Statistics, 2016). Greater considerations for the literacy and language competencies of parents would also comply with the model of quality of care recommended by Donabedian.

### 5.5 Strengths and limitations of the study

#### 5.5.1 Strengths

Consistent with the Donabedian model of Quality of Care, this study was able to provide evidence of the structure or setting in the ED. The assistance of an ED staff member ensured the search for documents was thorough and not limited to documents visible in the ED. Copies of the documents were able to be taken away for analysis. The study identified and analysed all of the resource materials for parents from the various sources against expected standards.

#### 5.5.2 Limitations

Reviewing documents is largely limited by the information available. It is possible that organisation-wide policies regarding preparing and delivering education material existed. Documents of this nature were extensively sought at the national, state, and local hospital level but such policies could not be identified. Also, this document analysis was limited to the resources available from the paediatric emergency department for parents. Different guidelines that include follow-up instructions may exist elsewhere, but they were beyond the scope of this document analysis. When a paucity of documents is evident, document analysis becomes very limiting. Document analysis can also be limited even when available documents describe what should be happening (assuming the information sought is available) because the documents are unable to support an understanding of what may be happening in practice. In this study, there was no documentation on how discharge information resources for parents should be prepared or used. The limitation of using readability as an index, but not a surrogate of health literacy is acknowledged. However, readability formulae continue to be useful along with other measures in understanding more about the quality of available documents.

#### 5.6 Summary

This chapter presented the research design, methods, qualitative data analysis and findings of the Document analysis study. Overall, many of the documents reviewed provided inconsistent discharge information for parents of children leaving the ED; however, their use and effectiveness remained unclear. Hence the following chapter presents the findings of observations of parents, children and their interactions with staff in the ED to further explore the provision of discharge information, and identify current practices in the provision of that information.

# **Chapter 6: Observation of Practice in the ED**

### 6.1 Introduction

This chapter presents the research design, methods, data analysis, findings, and discussion of the second of the four studies, Observation of Practice in the ED in this research program. This non-participant observation study aimed to identify current practices in the provision of discharge information to parents of children presenting to the ED, from admission to discharge and parents' perceptions of that information. The data collection and analysis undertaken in this study addresses all three domains of the Donabedian Model of Quality Care, namely, *structure, process, and outcome*.

The two research questions addressed in this study are:

Question 2: What are the current practices in the provision of discharge information? Question 4: What are parents' perceptions of the quality of discharge information received in the ED?

### 6.2 Research Design and Methods

This section explains the methods used for sample selection and recruitment, and data collection and analysis. The researcher, the non-participant observer, witnessed the interactions between the ED staff and the parent/child dyad. Non-participant observation has the strength of providing a snapshot of many interactions and experiences in the ED setting. It is not limited to participant opinion or recall, and includes actions, the use of resources, and the engagement of multiple individuals within the setting (Watson, Booh, & Whyte, 2010). An ED nurse from the hospital, who was familiar with the ED processes, was a research assistant during data collection, enabling the researcher to remain in an observer role.

### 6.2.1 Sampling and recruitment

Non-probability sampling was used to recruit parents and children attending the paediatric ED. Limitations of selection bias and the inability to broadly transfer this information as "representative" of the whole population of parents attending this ED are acknowledged. However, non-probability sampling provided in-depth observations for exploratory research. More specifically, non-probability sampling supported the objective of providing a snapshot

of parents willing to be observed with their child throughout their visit to the ED, as well as staff interactions with parents. Recruitment of relatively small samples sizes is common in qualitative research and supports the required depth of research (Creswell, 2012). The participants in this observation study were thirteen parent(s)/child dyads and the ED staff involved in their care while in the ED, and those who provided discharge information. The inclusion criteria for the parent/child dyad were the parent(s) understood spoken and written English, the child was assessed at a triage score of three to five, and treatment for the child had not commenced. The exclusion criteria for the parent(s)/child dyad were: discharge from the ED to the paediatric short stay unit or paediatric wards of the hospital; parents for whom there was a suspicion regarding the cause of their child's injury; children with a cognitive or neurological deficit; and children taking analgesic medication on a regular basis. Of the thirteen parent/child dyads initially observed for this study, three children were not discharged home from the ED but transferred to an acute ward; their observation data sets were therefore removed from analysis, as the. Ten observation data sets are reported in the findings (Table 8).

#### 6.2.2 Data collection

The researcher collected data using a combination of visual observation, an observation checklist and field notes. The observation checklist covered the three domains of the Donabedian Model of Quality of Care framework of *structure, process* and *outcome,* and relevant findings from the literature review. The observation checklist is presented in Appendix 4, and Figure 7 presents the data collection process for the non-participant observation study.

The researcher undertook non-participant observation in the ED on 10 days, 4-6 hours each day, at various times throughout the morning shift in July 2015. At the study site, a triage nurse recruited the parents in the waiting room while they were waiting for their child's treatment in the ED. On behalf of the researcher, the research assistant requested, and was given, the parents' permission for the researcher to observe the child while in the ED.

In the role of a non-participant observer, the researcher followed the parents with their child on their journey through the ED. The researcher observed the participants in all aspects of their management from the waiting room through to discharge from the ED. Data were obtained by observing the structure in the ED, communication between ED staff and each parent/child dyad, and observing the outcome of each case. The first data collection phase involved observations in the waiting room prior to the child's consultation in the ED. The researcher sat on the opposite side of the parent(s) with their children in the waiting room until the process of consulting and treatment started; the researcher then followed the participants from the waiting room to the treatment room or children's ED X-Ray room or children's ED plaster cast room.



### Figure 7: Steps in data collection process

Although Donabedian's *process* domain includes all activities that take place during the delivery of care, this study specifically explored the process of providing and receiving discharge information, collectively described as being 'communication between ED staff and parents and their child'. The researcher collected data on the *process* characteristics of the discharge information for parents. The researcher observed, using a checklist to guide observations, and took field notes to collect relevant data relating to parents and their child: delivery of discharge information, parental background, health literacy (researcher's observations of how well parents appeared to understand the discharge information provided such as facial expressions, repetition of key words or any questions asked), family experience with EDs, and the child's pain scale and severity of presentation. The researcher assessed the children's pain levels by using Wong- Baker FACES® pain rating scale (Wong & Baker, 1988); a score of 0 (no pain) to 10 (worst pain). These characteristics were collected and examined to

address the research questions and points of comparison of observations of parent's anxiety, parents' confident and parents' satisfaction. *Outcomes* included ratings of parents' anxiety using a score of 0 (calm) to 10 (panic) based on parents' behaviour when they were presenting to the ED and a face scale to rate parent's satisfaction before their child discharged from the ED.

#### 6.2.3 Data analysis

The researcher wrote down a brief case description of each parent/child dyad including the ED layout, staff present and common activities to assist with the analysis. In addition, the researcher noted impressions of the children's ED, including an opinion of how and if any interactions between each parent/child dyad and ED staff took place. The researcher reflected on the participants' behavior, and how the data could answer the research questions. Data were discussed with the researcher's supervisors.

Analysis of the qualitative visual (observational) data, recorded as field notes, was undertaken. Observations were predicted to capture data on the three domains of structure, process, and outcome within the theoretical framework of the Donabedian Model for understanding quality of care in health settings such as an ED. Observation checklists (Appendix 4) included a column on comments for the researcher's fieldnotes. Overall, there were five pages of checklists for each patient; with observations taking as long as 4 hours. Data reduction involved aggregation to provide tables profiling a "snapshot" of parents, their child, and their interactions with ED staff. Data analysis was largely descriptive. The statistical software program SPSS version 22 (Pallant, 2016) was used to analyse the quantitative data according to structure, process, and outcomes. More specifically, data analysis first involved a profile of total waiting time, and the time to spent waiting to see the consultant. Next child presentations were reviewed to profile the age and sex of the child; whether the presentation appeared to be an illness or injury; the triage score; which and how many parent/s accompanied the child; and the researcher's perception of the child's pain scale. Data were then sorted to describe the observations of parents' interactions with staff: the frequency of interactions, who provided the discharge information, the number and type of resources given to parents and the description of information provided to parents. The final component of data analysis largely involved the researcher's perceptions of parents' anxiety, understanding,

and satisfaction of services for their child in the ED, as well as observations of any questions asked of the staff.

### 6.3 Findings

This section first presents findings on the *structure* of the ED environment, followed by findings associated with the *process* of communication between ED staff and each case of parents with children in relation to the provision of discharge information, are presented. Finally, the findings related to the *outcome*, that is, the parents' satisfaction with the ED service they received from arrival to discharge, including discharge information, are presented.

### 6.3.1 Structure of the ED environment

For the purposes of this thesis, the *structure* of the ED environment was considered to be its physical structure, the number and type of ED staff, any resources available for parents in the ED, and any support services that may impact on the process of parents receiving and understanding discharge information in the ED setting.

### 6.3.1.1 Physical structure

Features of the physical structure in the ED setting included the waiting room, consultation rooms, an x-ray facility, and a "plaster" room. Short stay spaces were not allocated within the Paediatric ED.

The waiting room comprised 12 seats placed in three rows in front of the triage counter, and banquette seating in a corner; all seats had good visibility of two large television screens. The televisions featured cartoons or children's animation movies. Staff in the triage area worked within a glass enclosure. The waiting room also had a play space for children, separate from the allocated seating. A water bubbler for public use and small paper bags for use in vomiting episodes were always readily accessible in the waiting room, in addition to male and female toilet facilities.

Twelve clinical rooms provided space for consultation and treatment in this dedicated paediatric ED setting. Two fast track rooms were also available. Each of these fourteen rooms had a communication board for parents to see the name of the treating staff.

Although each consultation room had a communication board primarily for parents to see the name of the staff members during treatment, these boards were not always updated, nor were they accurate. In only two observed cases, were these boards updated with the name of staff members. A second purpose of the board was for interactive written communication between parents and ED staff. There were spaces for staff to write what parents were waiting for, such as Ventolin (bronchodilator medication) dosage, or how far the administration of the dose has progressed. Additional space on this communication board was made available for both patients and or parents to write comments and or questions. Parent's engagement in this form of communication was only observed once despite active encouragement by the ED staff. An observed parent with their child was suggested to write down questions about the child' treatment on the communication board after the nurse wrote the name of doctor and nurse on the board. Mother said *"It is a good idea because some of doctors just come and give medication and go. So, this board can help me to communicate with the doctor"*. However, no observed patient or parent wrote any questions on the board.

An x-ray facility with a dedicated radiographer was connected to the Paediatric ED. This space had a small area with play materials for children to use while waiting for an x-ray. In addition to the 14-clinical consultation/treatment rooms, there was a 2-bed "plaster" room to assist in the management of fractures.

### 6.3.1.2 ED staff

From the researcher's observation, the typical ED staffing for a morning shift consisted of four medical staff, three nurses, one nurse unit manager, and one clerical support worker. Specifically, within the triage area of the ED, each morning shift allocated one triage nurse and one clerical support worker. On one occasion, two physiotherapists and a medical student were observed to apply a plaster cast and fit crutches for a patient with a fracture.

#### 6.3.1.3 Resources

The "Emergency Department Children's Early Warning Tool" (Queensland Government) was used initially as part of the triage record for the child's conditions. This form was then completed by the consulting doctor and the attending nurses. Four versions of the form were available depending on the age of the child (0 to 4 years, 5 to 9 years, 10 to 14 years and over

15 years). The form also provided a section for staff to tick; showing which of the four options for discharge information had been given to patients: (i) a discharge letter (ii) patient information fact sheets (iii) whether a prescription had been provided and (iv) whether followup arrangements were made and communicated. This form was the official and confidential record of patients and their treatment in the ED.

There were two different types of resources on display for visitors to the ED. One was a poster on the wall of the ED showing how to use a spacer for asthma. The other resource comprised English language clinical information pamphlets covering 16 topics, which were printed as Fact Sheets, and which patients/parents could take. The 15 medical topics covered were: croup, asthma, bronchitis, viral infection, fever, febrile convulsion, stiches and glue care, wound care, plaster care, crutches, ankle sprain, gastroenteritis, and procedures involving sedation, immunisation, and constipation. The other pamphlet "topic" was a parent feedback form relating to their experiences in the ED. The pamphlet stand was labelled for each of these conditions so that parents could see what was available, even if there were no pamphlets left. Pamphlets were plentiful on each day of observation, except on the first day when there were no pamphlets on fever.

#### 6.3.1.4 Support services for parents

Support in the form of interpreter services, via an "on-call" booking service, was available for parents or guardians for whom English was not the preferred language for communication. However, no observations of the use of the interpreter services were made; this may have been due to the selection criteria for this study that required parents to understand written English.

There were no other support services available for parents in the ED of this hospital.

#### 6.3.1.5 Waiting times

In this study three specific waiting times periods were observed and timed: presentation to consultation, consultation to discharge, and presentation to discharge. There were long waiting times for some of children to be seen and for treatment to begin. Yet, the NEAT time policy did not seem to interfere with the provision of discharge information, with no observations of patient waiting times or number of patients waiting mentioned as being

stressful by staff, and staff were not observed to be rushed. The median waiting time from presentation to consultation was 24 minutes. However, this waiting time ranged from 17 to 76 minutes. Longer durations were involved in the time spent waiting from the start of the medical consultation to ED discharge. Specifically, the median time from consultation to discharge was 73 minutes with a range of 21 to 223 minutes. The total median time from presentation to discharge in observations from this children's ED was approximately 100 minutes. All of the observed children were discharged within the NEAT target times (four-hour rule). Table 8 presents observations of children's' time in the ED.

| Time                      | Male        | Female       | All          |  |
|---------------------------|-------------|--------------|--------------|--|
|                           | (n=5)       | (n=5)        | (n=10)       |  |
| Waiting time in minutes   |             |              |              |  |
| before consultation       |             |              |              |  |
| Median                    | 23.0        | 26.0         | 24.5         |  |
| Mean (SD)                 | 36.0 (24.4) | 34.2 (23.7)  | 35.1 (22.7)  |  |
| Range                     | 58 (17-75)  | 58 (18-76)   | 59 (17-76)   |  |
|                           |             |              |              |  |
| Consultant to discharge   |             |              |              |  |
| time in minutes           |             |              |              |  |
| Median                    | 57.0        | 96           | 73.5         |  |
| Mean (SD)                 | 66.8 (34.3) | 112.8 (80.3) | 89.8 (63.1)  |  |
| Range                     | 89 (21-110) | 188 (35-223) | 202 (21-223) |  |
|                           |             |              |              |  |
| Total median time from    | 80          | 122          | 98           |  |
| presentation to discharge |             |              |              |  |
| in minutes                |             |              |              |  |
|                           |             |              |              |  |
|                           |             |              |              |  |
|                           |             |              |              |  |

#### Table 8: Description of children's time in the ED

Of the 10 children observed in this study, seven children presented with injuries and three children presented with an illness. Two of the children were given a triage score of 3 (potentially life-threatening, or situational urgency), four children were given a triage score of 4 (potentially serious or situational urgency or significant complexity or severity), and four children were given a triage score of 5 (less urgent or clinico-administrative problems). These

triage scores were based on the Triage Scale of the Australasian College of Emergency Medicine (2016) (see Table 1).

Details of the children observed in the ED, and which parent(s) accompanied them, are reported in Table 9. The median age of children observed in this study was 10 years in both boys and girls, with a range of 1.7 - 15.1 years. Triage scores for the observed cases were most frequently either 4 or 5 (n = 4 for each of these scores), and two cases were given a triage score of 3. Six of the ten cases observed presented with their mother, two with their father, and two with both parents. More girls were accompanied by their mother than boys. The median pain score on admission for the children was 2.5.

| Characteristics        | Male           | Female          | All             |
|------------------------|----------------|-----------------|-----------------|
|                        | (n = 5)        | (n = 5)         | (n = 10)        |
| Age in years           |                |                 |                 |
| Median                 | 10.1           | 10.0            | 10.0            |
| Mean (SD)              | 9.6 (2.5)      | 8.3 (5.6)       | 8.9 (4.1)       |
| Range                  | 6.1 (5.7-11.8) | 13.4 (1.7-15.1) | 13.4 (1.7-15.1) |
| Type of presentation   |                |                 |                 |
| Illness                | 0              | 3               | 3               |
| Injury                 | 5              | 2               | 7               |
| Triage                 |                |                 |                 |
| 3                      | 0              | 2               | 2               |
| 4                      | 2              | 2               | 4               |
| 5                      | 3              | 1               | 4               |
| Accompanying the child |                |                 |                 |
| Mother                 | 2              | 4               | 6               |
| Father                 | 2              | 0               | 2               |
| Both                   | 1              | 1               | 2               |
| Pain score (0 – 10)    |                |                 |                 |
| Median                 | 2              | 1               | 2.5             |
| Mean (SD)              | 2.4 (1.1)      | 2.6 (2.2)       | 2.0 (1.6)       |
| Range                  | 6 (0-6)        | 8 (0-8)         | 8 (0-8)         |

#### Table 9: Details of children observed in ED

#### 6.3.3. Processes from arrival to discharge from ED

Processes observed included interactions with ED staff and parents' responses as they received discharge information for the care of their child. On presentation to ED, a clerical staff member took demographic details from the parent. A triage nurse then conducted an initial assessment of the child. The triage nurse took the child's temperature, body weight,

and asked the parent or child about the presenting problem. The child and parent were then asked to wait in the waiting area until a doctor or an ED nurse called their name for further assessment. The length of this wait was dependent on how sick the child was, and the number of other patients presenting to the ED at a similar time.

When called, the child and the parent(s) proceeded to the consulting room where they were seen by either a doctor or an ED nurse. Eight of ten parents experienced an interaction with one doctor, and two interacted with two doctors. Four of the ten parents communicated with either one or two nurses in addition to the doctor. Two cases had interactions with three nurses; one relating to a child with pain, and one to a child with a fever. In both cases involving three nurses, communication occurred with one triage nurse, one nurse who administered the pain relief medication, and another nurse who re-checked the dosage prior to administration of the medication.

From the observation process that occurred between presentation of the patient to their discharge, the researcher noted that all parents received their discharge information from medical staff. However, two of the observed cases received discharge information from a doctor, physiotherapist, and a medical student. Doctors provided all the verbal information for all observed cases. No parents received discharge information from nurses. Parents whose children were suffering with gastroenteritis, or fever or whose child had a plaster cast applied, received both verbal information and pamphlets. These pamphlets were the same as those available in the ED waiting room.

Three specific types of information provided by staff were common to all parents of children being discharged. Consistently, parents received verbal information about patient status and treatments, individualised patient self-care, and follow-up and return to ED instructions. Two of ten parents also received verbal information about referrals to community health providers. However, none of the parents were verbally provided with information about additional community resources that may have been useful to their child's health care. Based on their facial expressions, and other nonverbal communication such as nodding their head, all parents appeared to understand the information provided by staff when the child was discharged. Doctors also provided opportunities for all parents to ask questions. Table 10 presents the researcher's observations of parents' interactions with staff. Treatment rooms remained relatively quiet and parents did not appear to have other distractions such as other children to care for during their visit to the ED. Moreover, parents refrained from using their mobile phone during the consultation phase of the ED visit. Thus, minimal distractions to parents theoretically increased the opportunity to ask questions of ED staff. Even when two parents accompanied the child, interactions between parents did not occur in the presence of ED staff.

| Relevant descriptors for this observation                                    |  |  |  |  |
|--|--|--|--|--|
| Medical registrar/<br>doctors/medical<br>student for each of<br>the 10 cases | Nurses<br>(including the<br>triage nurse) for<br>each case   | X ray staff /<br>physiotherapist<br>for each case  |  |  |
| 0<br>8<br>2<br>0   | 0<br>4<br>4<br>2   | 4<br>5<br>1<br>0   |  |  |
| Medical registrar/<br>doctors<br>8   | Nurses<br>0  | Other<br>(doctors PLUS<br>physiotherapist)<br>2  |  |  |
| Verbal<br>7  | Verbal &<br>Pamphlets<br>3   | No resources<br>provided<br>0  |  |  |
|  | Relevant deso<br>Medical registrar/<br>doctors/medical<br>student for each of<br>the 10 cases<br>0<br>8<br>2<br>0<br>Medical registrar/<br>doctors<br>8<br>Verbal<br>7 | Relevant descriptors for this obsMedical registrar/<br>doctors/medical<br>student for each of<br>the 10 casesNurses<br>(including the<br>triage nurse) for<br>each case00842402Medical registrar/<br>doctorsNurses<br>o802402Medical registrar/<br>doctorsNurses<br>Pamphlets173 |  |  |

| Table 10: Observations of parents interac |
|---|
|---|

| Type of information provided to parents | patient status and treatments                 | 10 |
|---|---|----|
|   | individualised patient<br>self-care           | 10 |
|   | information about<br>community resources      | 0  |
|   | follow-up & return to<br>ED instructions      | 10 |
|   | referrals to<br>community health<br>providers | 2  |

### 6.3.4 Outcome

In this study outcome, performance is measured using two indicators that were derived from the researcher's perceptions: (i) parents' understanding of discharge information; and (ii) parents' satisfaction with the provision of discharge information.

Findings from observations of the researcher's perceptions of parents' understanding of information in the ED when the child was discharged are outlined in Table 11. The researcher's perceptions of the level of parents' anxiety was estimated using a score of 0 (calm) to 10 (panic). The mean score allocated to parents was 3.8, which represented non-extreme levels of anxiety. All parents appeared to have had previous experience presenting a child to the ED. Despite parents being consistently offered opportunities to ask questions, only three parents did so, with one or two questions. Specifically, one parent asked the doctor about how to use pain relief medication at home, one was concerned about the need to consult with their family GP, and one asked about the results of their child's x-ray.

Of the three parents who received pamphlets, none appeared to read the information in the pamphlet during their time in the ED; parents put the pamphlet into their bags soon after receiving it from the staff. At the time of the child's discharge, the researcher used a six-point scale based on faces to rate a perception of parental satisfaction. From the researcher's perspective, all observed cases were either 'extremely satisfied' or 'very satisfied' with information received at discharge. Specifically, the mean score from the researcher's

observations and perceptions showed parents' apparent satisfaction was 5.4 (range five to six), with a score of 6 being 'extremely satisfied' and 1 being 'extremely dissatisfied'

| Observation   | Selected so          | oring of observa                            | ntions |  |
|---|----------------------|---|--------|--|
| Parents anxiety (perceived using a scale of                                     |                      |   |        |  |
| 0 (calm) to 10 (panic)  |                      |   |        |  |
| Median  |                      | 4.0   |        |  |
| Mean (SD)   | 3.8 (1.3)<br>4 (2-6) |   |        |  |
| Range   |                      |   |        |  |
| Number of parents appearing to have   | Yes                  | No  | D      |  |
| previously been to the ED   | 10                   | 0   |        |  |
| Parents' perceived understanding of   | Yes                  | No  | )      |  |
| information provided by staff when their child was discharged                   | 10                   | 0   |        |  |
| Number of questions asked by parents  | 0                    | 1-2   | 3 +    |  |
| before leaving the ED   | 7                    | 3   | 0      |  |
| Topics of questions asked by parents when                                       | Medications          | Other                                       |        |  |
| the child was discharged  | 1                    | 1 consult with GP and<br>1 results of X-RAY |        |  |
| Perceptions of parents' satisfaction using 6 faces on visual scale with 1 being |                      |   |        |  |
| extremely satisfied and 6 being extremely                                       |                      |   |        |  |
| dissatisfied  |                      |   |        |  |
| Median  |                      | 5.0   |        |  |
| Mean (SD)   |                      | 5.4 (0.5)                                   |        |  |
| Range   |                      | 1 (5-6)                                     |        |  |

Table 11: Observations of parents in the ED when the child was being discharge

Findings emerged from this non-participatory observation study of ED staff and parents with children presenting to the ED, which aligned with each of the Donabedian framework domains of *structure*, *process*, and *outcome*. In *structure*, there were long waiting times for the child to be seen and for treatment to begin, and there was inconsistency in the type of information provided by staff. In *process*, nursing staff in the ED did not engage themselves in the provision of discharge information; the task was viewed as a responsibility of the medical staff. In

*outcome*, parents appeared to be satisfied with the discharge information and services provided to their child in the ED.

Key findings of this second study were: (i) the four-hour rule was achieved and did not seem to generate pressure on staff; (ii) printed resources were a secondary, and less preferred form of discharge information for parents; and (iii) at discharge, parents appeared satisfied with the mostly verbal discharge information they received from their treating doctor in this children's ED.

### 6.4 Discussion

Three major findings emerged from this non-participatory observation study of ED staff and parents with children presenting to the ED. Results were reviewed within the context of the Donabedian model domains of structure, process, and outcome. Within the structural domain waiting times emerged as factor that may impact on both staff and the parents and their children. Within process, the staff providing discharge information to all parents and in the outcome domain, parental satisfaction with discharge information provided. There was inconsistency in the type of information provided by staff. Second, nursing staff in the ED did not engage themselves in the provision of discharge information, the task was viewed as a responsibility of the medical staff. Finally, parents appeared to be satisfied with the services provided to their child in the ED.

#### 6.4.1 Structure: Waiting times

#### 6.4.1.1 Waiting times

Despite a median waiting time of 24 minutes before children were provided with medical care within the ED, the median time between first consultation and discharge was approximately 74 minutes. The results matched with the Australian triage system guidelines (Australasian College of Emergency Medicine, 2016). The treatment time (74 minutes) may be explained by shortages in medical staffing, the complexity of the individual treatment required, the need to consult with specialist paediatric services, or the need for additional care from physiotherapists, radiographers, or pathologists. Some services such as physiotherapy and pathology were shared with the larger hospital and as such, may have resulted in prolonged periods of waiting following the initial medical consultation. Even with the dedicated
children's ED X-ray facilities, there could be extensive waiting times. In addition, some presentations such as asthma resulted in multiple tests and treatment with nebuliser; hence a prolonged waiting period was noted. Prolonged observation times were also prevalent in children who presented with gastrointestinal concerns. Thus, extended time spent by parents and children in the ED could represent the quality of care provided by ED staff prior to the child's discharge to home.

An important finding from the researcher's time in the ED was that staff did not appear to be rushed or under any time pressures. Previous studies have demonstrated time-related pressures in EDs in Taiwan and Australia, where a non-supportive work environment, resulting from heavy workloads and inadequate nurse-patient ratios, was directly related to the provision of inadequate patient care (Han, Barnard, & Chapman, 2009a; Johnston et al., 2016). Time pressures may create more stress in the ED depending on which type of medical staff lack the time to provide individual care during busy periods. Time restrictions may also impose higher levels of stress and anxiety on ED patients and their families (Ozel, 2001).

Previous reports of time pressure in ED settings were not supported by the observations in the current study. It is possible the observed ED staff were accustomed to working in the ED, and therefore did not feel the pressure of time. Another possible explanation may be staff numbers and ratios were adequate. Alternatively, it is also possible the observed staff appeared to lack awareness of time restrictions because they were well experienced, efficient in their services, and clearly understood their role.

#### 6.4.2 Process: Staff provision of discharge information

In this study, all parents received verbal discharge information and individualised patient care advice from an ED doctor. Also, doctors consistently asked parents if they had any questions about the information they received. Only three of the ten parents asked questions of doctors. Only one parent's question referred to their child's care at home. None of the observed parents received any discharge information from ED nurses.

Besides asking the parents and patient if they had any questions, staff involved in discharge processes did not demonstrate any other strategies, such as asking parents to repeat the verbal information given to them and determining if there were any potential barriers to implementing the advice provided. A previous study (Samuels-Kalow et al.,2016) revealed that parents felt that teach-back would help confirm learning, avoid forgetting key information, as well as improve the communication between doctor and parent/patient.

Only three of the parents were given information pamphlets concerning their child's condition. Even when information resources for parents existed, the resource display in the ED waiting room was not readily visible. The lack of interest in resources has been reported previously in children's EDs; with one study concluding that parents preferred to read the written resources at home rather than delay their child's discharge from the ED with explanations about additional resources (Verma & Byrne, 2010). In agreement with the previous research, parents in the current study (section 6.3.3) showed a lack of interest in receiving additional resources, even though information resources could potentially better inform quality of care at home following discharge. Parents' familiarity with their child's condition or possibly a perception of adequacy in the information provided by the medical staff may have decreased the parents' need for additional resources.

## 6.4.3 Outcome: Researcher's perceptions of parents' satisfaction with discharge information provided

Parents largely appeared satisfied with the discharge information received in the ED. The observed satisfaction in the current study is in contrast to a previous report of patients' experience in an ED (Gignon et al., 2014). In this French study, interviews with patients following discharge showed substantial confusion with medications and dosages, and insufficient confidence to ask questions. However, the French study was not conducted in a paediatric setting like the present study, where staff consistently asked parents if they had any questions, and the use of a communication board was encouraged if parents thought of questions while their child was waiting for treatment. There was, however, a significant point of difference between the two studies; one was observational and the other used interviews. Therefore, it appears important for a researcher to supplement observations with questions, interviews, or surveys to help clarify conclusions made during less direct data collection strategies.

#### 6.5 Strengths and limitations of the study

#### 6.5.1 Strengths

This study was undertaken in the real world setting of a Children's ED. Because the method involves direct observation of one patient at any given time, it was relatively easy to compile a depth of data for subsequent analysis under the three domains of the Donabedian model. Ten parents with their child were followed through the ED journey. Also, seeing firsthand the environment- noise, busyness, how children were distracted while waiting all factors that may contribute to parental responses including anxiety (Heilbrunn et al., 2014; Holm & Fitzmaurice, 2004) and satisfaction with services.

#### 6.5.2 Limitations

During prolonged (1 to 3 hours) observation, the sense of observer to monitor may decrease. Nonetheless, the researcher was guided by more than 10 years of clinical nursing practice with children and careful development of observations occurred in collaboration with supervisors. Key attributes of parents such as understanding, anxiety, and satisfaction were assessed from the researcher's perception rather than the perceptions provided more directly from parents. Thus, bias of the researcher's perceptions must be acknowledged, and results interpreted cautiously within this limitation. The researcher's perceptions of parents' attributes were never intended to be a diagnosis or a strongly confirmed status. The attributes simply provided part of the in-depth observations of parents' experiences and interactions in the ED. The facebased scale that the researcher used to score the perceptions of parents' satisfaction was also an adaptation from existing health and psychological literature (Elfering & Grebner, 2010; Lorish & Maisiak, 1986; Yoshihara et al., 2015), but may require additional rigour to use elsewhere.

#### 6.6 Summary

This chapter identified the research design, methods, and qualitative data analysis and findings of the non-participant observations used to identify current practices in the provision of discharge information to parents of children presenting to the ED. The observations made during this study informed the focus group discussions in the third study of this thesis, detailed in Chapter 7.

# Chapter 7: Nurses' perspectives of the provision of ED discharge information

#### 7.1 Introduction

This chapter describes the third study of the four studies, nurses' perspectives on the provision of ED discharge information given to parents when their children are discharged from an ED. The data collection and analysis undertaken in this study address the second domain of the Donabedian Model of Quality of Care, namely, *process*. This focus group study aimed to explore ED nurses' perceptions of factors that influence parents' understanding of discharge information.

This chapter presents the research design, focus group data collection method and qualitative data analyses used for this study followed by the findings and discussion.

The research questions addressed in this study are:

- *Question 2:* What are the current practices in the provision of discharge information?
- *Question 3:* What are ED nurses' perceptions of factors that influence the provision of discharge information to parents?

Nurses comprise a point of consistency in a children's emergency setting where patients and their parents may be asked to engage with several doctors while being "treated" in the ED. Nurses provide the first line of healthcare contact when they assign triage scores, and arguably have the most opportunities to engage with, and provide support to, parents and their child during their time in the ED. Therefore, experienced ED nurses were deemed to be well placed to comment on factors that might influence parents' understanding of the information provided to them for their child's care at home following discharge from the ED.

#### 7.2 Research Design and Methods

Focus groups were conducted in the Children's ED at the study site. Analysis of focus group data aim to identify ED nurses' perceptions of enablers and barriers to parents' understanding of discharge information.

Traditionally, focus groups allow rich data to be gathered. A semi-structured format was used to prompt discussion (Tod, 2010). Questions to trigger discussion were informed by the *process* and *outcome* domains of the Donabedian Model of Quality of Care framework.

This section describes the overall strategy in conducting the focus groups using three components: (i) a description of sampling and the recruitment of the focus group participants; (ii) a description of the data collection procedures; and (iii) a description of how the data was analysed.

#### 7.2.1 Sampling and recruitment

The target population for this study was ED nurses who worked in a children's ED setting in which discharge information was routinely provided to parents. The ED nurses were recruited by purposive sampling (LoBiondo-Wood & Haber, 2010); the researcher selected the participants who were considered to be typical of the population.

The researcher and a research assistant first contacted the ED nurse manager to explain the purpose, timeframe, and general procedures of the focus group discussions. With this support, the recruitment strategy commenced. (Of note, the research assistant (RA) in this study, differed from the RA who assisted with the parents' survey study).

The ED nurse manager provided confidential advice on who to recruit, how best to recruit them, as well as when and where to conduct the focus groups. For example, following advice from the ED nurse manager, staff new to the ED were excluded prior to recruitment for the focus groups; the optimal place for recruitment was identified as the staff room and the best time to approach nurses about being involved in the focus group was advised to be between the morning and afternoon shifts. To maximise recruitment several strategies were employed; the researcher explained the purpose and requirements of the study at a staff meeting, a poster about the research was displayed in the staff room and information sheets and consent forms were placed in the staff room. The poster and letter of information provided the researcher's details for any questions nurses may have had about the project.

Potential participants in the study setting were eligible for inclusion in a focus group if they were experienced (more than three months) and currently working in the Children's ED.

#### 7.2.2 Data collection

The focus groups were conducted after the observation of parents and children receiving treatment in the ED had been completed, so that selected observations could be explored during the semi-structured discussion in the focus groups. The ED nurse manager arranged times for the focus groups so that staff could attend during their shift. Two days before the scheduled group, the researcher went to the ED, introduced herself to the ED nurses, explained the study to them using the "Participant Information Sheet" (Appendix 10), answered any questions, and left a copy of the information sheet in the ED. Reassurance was given to the ED nurses that any information they provided would not be linked to them as individuals in any subsequent report. This confidentially was important, as the ED nurses needed to feel assured they could talk freely during the discussion.

The ED nurses who were interested in participating in a focus group were asked to provide written consent (Appendix 10). During this information session, the researcher, and the research assistant reiterated the confidentiality of their comments and absence of anticipated risks inherent in ED nurses' participation. ED nurses who agreed and provided written consent invited to participate in the focus groups that occurred in the meeting room.

The researcher and research assistant conducted the focus groups on 5 and 6 August 2015. Three focus groups, each with two participants, were conducted at a convenient time after the completion of a morning shift or prior to the commencement of an afternoon shift; usually around 2.30 to 3.00 pm. To comply with the inclusion criteria, the six registered nurses who took part in the focus groups were currently working in the children's ED. Although it would have been ideal to have more nurses in each group, no more than two nurses were available and willing to participate at any given time from this very busy ED. Arguably, one group of six participants would have provided richer data than three groups of two participants but availability of ED nurses varied greatly; making it impractical to organise one group instead of three. At the change of shift some nurses remained with patients, while others believed they

had insufficient time to commit to a focus group that could have lasted approximately 20 minutes. One to one interviews were considered, but the richness of possible interactions between experienced nurses, even with small numbers was deemed preferable. During the focus group discussions, pre-planned open-ended questions were used to trigger discussion with the nurses. These trigger questions, and other discussion prompts, were drawn from the research questions underpinning for this thesis, as well as from the findings of the non-participatory observation study of the ED detailed in Chapter 6. During the discussions, the researcher also encouraged the participants to speak freely, emphasised there were no right or wrong answers, and stated that all participants were to respect each other's opinions, and maintain the confidentiality of all the discussions (Burns & Grove, 2005). All focus groups concluded by the researcher asking the participants whether there was anything else they wished to discuss; this was to minimise any constraints they may have experienced during the focus groups.

The trigger questions guiding the discussion included:

- What are your views on the provision of discharge information to parents in the ED that works well?
- 2. What are your views on the resources provided to parents?
- 3. What happens when parents do not seem to understand?
- 4. What challenges are there in the provision of discharge information to parents in the ED?
- 5. Is there anything else you would like to share with us on this topic?

The researcher took field notes, while a research assistant facilitated the discussion. These sessions were recorded digitally and transcribed verbatim within one week by the researcher and confirmed by the research team. All identifying information, such as names and institutions, were removed from the transcripts.

#### 7.2.3 Data analysis

Content analysis was used to analyse data obtained from the three focus groups. Content analysis is defined as a research method for the systematic analysis of texts (interview transcript, diaries, or document) (Patton, 2015), while the core ideas found through content analysis characterise the patterns and themes that emerge from the data (Patton, 2015). Text data for qualitative content analysis can be obtained from focus group transcripts.

There were several reasons for the selection of qualitative content analysis as part of the data analysis of the focus group data. First, qualitative content analysis is seen as an accepted approach to analyse the focus group interview transcriptions (LoBiondo-Wood & Haber, 2010; Patton, 2015). This method enables the production of detailed and core constructions from the text data throughout the process of reduction and analysis. Furthermore, qualitative content analysis goes beyond merely counting recurring words. It also examines and classifies text data into an efficient number of categories that represent similar meaning. These categories can represent explicit communication or inferred communication. Finally, qualitative content analysis is relatively inexpensive to perform; in terms of both the analysis itself and the generation of findings (Patton, 2015).

Data analysis used four main principles. First, the researcher analysed the data from the three focus groups separately, and then integrated the results in order to produce the findings. This allowed examination of the data from each group, and comparison of data between groups, as is desirable with focus group data analysis (Patton, 2015). The Donabedian model guided the approach taken to coding. The researcher read the transcriptions and identified categories. Discovering themes is the basic task when analysing text. The first pass at generating themes often comes from the questions of the interview. Hence, the researcher categorised the responses into two themes, barriers, and enablers; informed by the structure, process and outcome domains of the Donabedian theoretical framework. This approach brought clarity to the data. Finally, content analysis was used because it offers an interpretative process. Thus, the researcher identified, coded, and categorised the transcribed data, using all of the coded categories emerging from text data. The researcher checked with members of the supervisory team in the process of coding for validation purposes. Furthermore, as discussed in section 4.8 on the Assurance in rigour and validity (pages 74 to 75), minimising bias of reporting was important. Therefore, the independently transcribed records from the focus group discussions were initially checked by the researcher. Then, a member of the supervisory team received the same transcriptions and confirmed the accuracy of the researcher's original check.

#### 7.3 Findings

This section presents the findings from the three focus groups aimed to identify ED nurses' perceptions of factors that influence the provision of discharge information to parents. Barriers and enablers were identified as themes within the *structure* and *process* domains (Table 12). Two themes were identified for *outcomes* were explored for markers of effectiveness and ineffectiveness: parents' understanding of, and their satisfaction with, the discharge information they were given (Table 13). Some concepts were identified as both barriers and enablers of parents' understanding of, or satisfaction with, discharge information. These themes are described in detail and explained below, supported by extracts from the focus group data.

| Enablers   |
|--|
| some ED staff (i) Interpreter services<br>(ii) Access to the other sources |
| based resources<br>rices   |
| viours (i) Multiple sources of<br>h literacy information                   |
| s (ii) Ensuring parents<br>ition of the understanding                      |
| al media (iii) Follow up   |
| l<br>v<br>l<br>f<br>f<br>r   |

| Table 12: Summar | y of themes ir | n the <i>structure</i> | e and proces | s domains |
|------------------|----------------|------------------------|--------------|-----------|
|------------------|----------------|------------------------|--------------|-----------|

#### Table 13: Summary of themes in the *outcome* domain

| Theme   | <ul> <li>Parents' understanding of discharge<br/>information</li> </ul>   |  | Parents' satisfaction with discharge information                                       |   |
|---------|---|--|--|---|
|         | Ineffective   | Effective  | Ineffective  | Effective   |
| Outcome | <ul> <li>(i) Inaccurate and<br/>incomplete<br/>information</li> <li>(ii) Time policy</li> <li>(iii) Parents'<br/>characteristics</li> </ul> | <ul> <li>(i) Professional</li> <li>experience</li> <li>and</li> <li>confidence</li> <li>(ii) Providing</li> <li>useful</li> <li>resources</li> </ul> | <ul><li>(i) Inconsistent</li><li>communication</li><li>(ii) Parents' beliefs</li></ul> | <ul><li>(i) Professional confidence</li><li>(ii) Ensuring parents understanding</li></ul> |

#### 7.3.1 Structure

The *structure* domain of the Donabedian model refers to relatively static characteristics of the settings in which the health care is delivered, which in this study was a children's ED. The focus group participants identified four barriers and two enablers to parents' understanding of discharge information in the structural features of the ED.

#### 7.3.1.1 Barriers

Four structural barriers in the provision of discharge information were identified: (i) the inexperience of some ED staff that resulted in inconsistencies with the discharge information provided to parents; (ii) time limits imposed by the NEAT policy operating within Australian EDs (Geelhoed & Klerk, 2012; Sullivan et al., 2016); (iii) the absence of locally-developed resources to support the provision of discharge information; and (iv) the procedures involved in accessing interpreter services.

#### 7.3.1.1.1 Inexperienced ED staff

Focus group participants commented on the inexperience of some doctors who worked in the ED as being a potential barrier because they may not be able to provide adequate and/or appropriate information for parents to understand how to care for their child after discharge. For example, in the following extracts, the participants described three situations of the inexperience of some doctors that could be a barrier to parents' understanding the discharge information:

Doctors ... come to emergency ... on rotations and maybe haven't done paediatrics before and they've been trained at different places. (Focus group 1)

Yeah, I mean even ... um ... some of the doctors who have not worked with children before, will be keen to give them a Panadol, Nurofen ... If they've got a fever just for the sake of getting the fever down and then we have ... (to say to parents) ... you don't have to do that. That's fine (not giving medication) if they've got a fever and they are looking happy. (Focus group 2) That's not to say that we're blaming them (Medical staff). When they do their training, they don't do a lot of paediatrics. So, it might be more so that they are unfamiliar with how to treat children and what to do and how to handle them. (Focus group 3)

Thus, inexperienced ED staff were seen to be a potential barrier to parents' understanding and following discharge information provided in the ED.

#### 7.3.1.1.2 Time Policy

ED staff can be constrained by the need to be time efficient. Some participants commented on how the four-hour rule imposed by the NEAT policy is a significant impediment to their work; specifically, in providing discharge information to parents in the children's ED. For example, achieving the NEAT target, which in turn, generates other challenges to this working environment.

Time ... Is a big one (barrier) because having the time ... to explain, um ... we work against the clock because we have a four- hour limit. (Focus group 3)

All ED nurses in the focus groups shared concerns that time was a significant constraint to their work in the ED. For example:

*Time; it's busy and you don't have as much time as you want, you know, to be able to explain to them. (Focus group 2)* 

So, that (time) is one barrier as we've been getting busier. (Focus group 2)

Thus, time appeared to be a common source of concern to the nurses in the ED. Achieving the NEAT target and managing the other complexities of the ED can make discharge planning difficult, particularly when overcrowding is an ever-present factor.

7.3.1.1.3 The absence of locally-developed web based discharge resources

Nurses participating in the focus groups identified limitations of existing resources available for parents to support care of their child following discharge. The participants described two examples of how the absence of locally-developed web-based discharge resources could be a barrier to understanding discharge information: ... Sometimes, like, um, the resource provided ... for the parents on our QHEPS website isn't enough and you have to actually go outside, um, to other sources to get some information. (Focus group 3)

So, we are still in the process of updating all those guidelines and making them ours and using them, you know, freely. (Focus group 3)

Although it may have been ideal to develop locally-based resources, the nurses discussed avoiding duplication and the amount of time that may be required to develop and update quality local resources.

If we develop our own, then we have to review it. We have to update it. Whereas if they've got a unit that does all of that, that's their job, that's the only job that they have. (Focus group 3)

Ideally, the ED nurses perceived that resources available to parents required accurate, consistent, and local information to support quality of care in discharge information. However, providing such resources would have limited benefit for parents with compromised English literacy, particularly without the availability of interpreter services; information resources were only available in English.

7.3.1.1.4 Interpreter services

The focus group participants shared concerns about the lack of immediately accessible interpreter services in the ED for parents with limited verbal and or written English fluency. If ED staff needed an interpreter, they had to contact the interpreter centre service by telephone.

Sometimes it's... after hours and you can use phone calls (for interpreter services). (Focus group 1)

Also, bilingual ED staff members, who are able to interpret, may not be on shift at the appropriate time.

So sometimes, we use, uh, if there's a doctor or someone that speaks, like, Farsi or Quran or something ..., if we're having trouble getting an interpreter, ... we might have to use them. (Focus group 3) A further source of information in the ED for parents with limited English language literacy was a basic communication card system comprising key healthcare words with accompanying pictures, and an English-based suggestion for pronouncing each word. These cards have been translated into numerous languages for use in the hospital, but with a lack specificity for the children's ED. As such, nurses did not perceive these cards to be useful for the communication of discharge information in the ED.

We have gotten some basic um, interpreter cards, but they're not really for explaining medical conditions. They're more like basic communication like food, drink, toilet ...that kind of thing. (Focus group 2)

However, when interpreter services were accessible, they could also be seen as an enabler for parents to receive quality discharge information, as described in the next section.

#### 7.3.1.2 Enablers

The two structural enablers considered as enhancing the understanding of discharge information for parents were: (i) interpreter services; and (ii) access to other available resources

#### 7.3.1.2.1 Interpreter services

Structural arrangements for interpreters have already been discussed as a barrier (Section 7.3.1.1.4); however, there was also some more positive discussion from the participants about the successful use of interpreters in the ED. Discussion within the focus groups included the benefits to parents' understanding of health care when a bilingual ED staff member was available to act as an interpreter. Focus group participants were generally positive about the existing structural facilities for interpretation, and the cultural staff-mix available to them to support provision of discharge information for non-English speaking parents, as reflected in the following quote.

We do use (the) interpreter service, but yeah sometime(s)... (it) is probably the phone service (rather than having an interpreter available on site) ... which works very well. (Focus group 2)

If it's language, we have interpreters and we use the interpreter system.

#### (Focus group 3)

Perceptions of the quality of the discharge information provided by the nurses were clearly supported by the availability of informal (staff) or formal interpreter services.

#### 7.3.1.2.2 Access to the other resources

The focus group participants discussed the multiple sources of available information (for example, their own hospital's information, and resources from their home state government and other Children's Hospitals) as being useful for parents to access and enhance their quality of care when children were discharged to home. Access to, and convenience of, electronic and readily available health information through the Health Department website was a valuable resource. The ED nurses identified the ease with which they could obtain health information from this website, as reflected in the quote:

It's all on the website... which I've found has worked for myself in particular, probably everybody, is that having it all displayed there and then knowing that you can just go and get some and then, you know, print some off and make sure that there's enough there for the week. (Focus group 3)

ED nurses reported the benefits of interpreters and other resources in improving their confidence that parents understood important information about their child's care.

#### 7.3.2 Process

The *process* domain of the Donabedian Model refers to the relatively dynamic characteristics of engagement and influences in a healthcare setting, which in this thesis is linked to providing and receiving discharge information in the ED. In this thesis, processes are dynamic because influences and situations perceived by ED nurses can be altered by the context, such as parents bringing a child to the ED for the first time or having a child re-present to the ED with a more severe condition than on previous occasions.

#### 7.3.2.1 Barriers

Five specific barriers affecting the processes experienced by parents receiving discharge information for children were identified from the focus group data: (i) parents' health behaviours; (ii) parents' health literacy; (iii) parents' beliefs and expectations about their

child's management; (iv) social media; and (v) conflicting discharge information provided to parents.

#### 7.3.2.1.1 Parents' health behaviours

Parents' health behaviour was discussed in the focus groups as how parents could have different understandings of the information provided by ED staff, which would potentially result in a variety of responses to the same information.

The participants described two categories of observed parental behaviour that could be a barrier to understanding discharge information:

(i) parents who appeared disinterested, as reflected in the following excerpt:

I think that there are some parents that just ...don't want to know everything, they just ... want to come here and have you fix their child and then they'll take them home. They're not interested. (Focus group 1)

(ii) parents who were perceived to be too well informed to actually listen to the discharge information, as reflected in the following quote.

Some of them really know their stuff and you know, .... they know everything (and are uninterested in hearing more). They've got books with them that have gotten everything that's happened in the last few weeks. (Focus group 1)

Parental behaviours (actions taken to acquire knowledge) could subsequently sometimes become a major barrier to the provision of discharge information to parents in the children's ED. Parental health behaviour as stated previously is complex and may be strongly influenced by their competencies in health literacy as well as their cultural, family and or individual beliefs around specific issues in health as shown in the following section.

#### 7.3.2.1.2 Parents' health literacy

Nurses in the focus groups discussed sub-optimal health literacy of parents as a barrier that potentially decreased the parents' understanding of home care information provided during the discharge of a child from the ED.

The ED nurses discussed how they would respond when they were uncertain whether parents understood the information they were being provided by the ED doctors. The participants described they would first sort out issues such as health literacy that were perceived to be among possible barriers to understanding the advice provided in the ED.

Why don't they understand? Mm-hmm ...So are we looking at language? .... There are lots of reasons why. Um ... They, there might be problems with them understanding. (Focus group 3)

#### 7.3.2.1.3 Parents' beliefs

The focus group participants also discussed any pre-existing beliefs of parents as potentially impairing the process of understanding discharge information. Nurses shared an understanding that parents' beliefs can be informed by multiple factors such as previous experiences, access to information, culture, family and/or individual beliefs relating to specific issues in health, and that these beliefs may actually be misconceptions, and therefore be a barrier to parents' understanding and following discharge information.

... People think just to put people on antibiotics as soon as they get a runny nose and a cough. (Focus group 1)

They just still have that underlying fear of fevers for whatever reason, cultural, previous experience or whatever. (Focus group 1)

Some cultures are very, very worried about fevers and they have parents, like grandparents who come in with them who don't want to listen to the doctors and nurses because they are so entrenched in the ...(notion) that (it is) a dangerous thing. Because if they are very concerned, why are we not doing blood tests, why aren't we doing this, why aren't we doing that? And even after an explanation, they are still not very happy because that's just kind of what they've been used to. (Focus group 2)

7.3.2.1.4 Parents' assumptions about information in social media

ED nurses' discussion on the impact of parents' assumptions of the accuracy of social media information on parents' care of children identified the difficulties arising when parents had already accessed health information via health and parenting websites, such as "Dr Google". Some ED nurses expressed concern that information acquired from these types of sites may have been misleading or inaccurate. Parents do definitely do their research before they come in. like Google....I think everyone's a little bit of a ... Um ... like can do that cause a doctor Google doesn't necessarily ... Wikipedia, like, you know, I think that's kind of the first thing people click on and they read all these things, those side effects or all the possible ... Um ... Like, worse case scenarios and they are sort of just freaking out in their heads. (Focus group 1)

I think they are kind of self-diagnosing ... and there are a few websites as well that don't give accurate advice or a few parenting websites that I've looked on that have given wrong advice about fever and I think make people (overly) concerned about febrile convulsions and brain damage and that kind of thing. (Focus group 2)

Parents' assumption of the accuracy of all web-based resources was therefore perceived by nurses to be a major barrier to quality health care in the children's ED. In contrast, ED nurses discussed the positive processes that occurred when they were able to deliver or recommend resources and information from trusted sources.

7.3.2.1.5 Conflicting Information

The participants identified that conflicting information provided by ED staff could negatively impact on parents' understanding of discharge information. Nurses from the ED expressed their concerns for parents when ED staff, including staff other than nurses, provided conflicting information to parents of children being discharged from the ED. Two examples of this concern involved nurses reporting on inconsistencies and confusion that arose when ED staff recommended the medication for a child that varied from advice already provided by other ED staff including ED nurses:

*I think part of that reason for (conflicting information) sometimes ...(is) because of an inconsistency with the advice ... given by doctor(s). (Focus group 2)* 

I think probably inconsistency in, ... treatment ... it's a little bit confusing for parents as well, if they're told one thing by one doctor and another thing by another doctor. (Focus group 2)

Thus, the participants reported that inconsistent information may impact on parents' understanding of discharge information.

In contrast, the processes in the ED that nurses perceived as enablers rather than barriers for parents to receive quality discharge information are presented in the next section.

#### 7.3.2.2 Enablers

Focus group participants considered enablers to the process of effectively providing discharge information for parents to be: (i) multiple sources of information; (ii) ensuring parents understood discharge information; and (iii) nurses having a capacity to follow-up some patients.

7.3.2.2.1 Multiple sources of information

Nurses valued having multiple sources of discharge information available to share with parents.

We give a lot of um, .... patient handouts to parents who present, if it's the first time. For example, with croup or if they have gotten any misconceptions about fevers. So, a lot of people think that fevers are dangerous then we usually give them verbal advice and then give them a fever handout afterwards. (Focus group 2)

I think that having a properly written medical handout is much more useful for them ... even if they don't look at it. At least we can feel like we've tried to give them the right information. (Focus group 2)

We give out information sheets, you know, depending on what their diagnosis has been. (Focus group 3)

Thus, quality discharge information for some of the nurses in the focus groups required the availability of multiple resources. However,

7.3.2.2.2 Ensuring parents understanding of information

Nurses in the focus groups acknowledged uncertainties as to whether parents understood the information provided. The participants considered having opportunities to confirm parents' understanding was a useful strategy support quality of discharge information.

I think it's good to just go in there and double check that they're aware of what's going on and that kind of stuff. (Focus group 1)

If I'm concerned that somebody doesn't understand then, I'll ask them to repeat it back to me, or ask if they've got any questions or try and explain things in more simplistic layman's terms rather than using medical kind of jargon. (Focus group 2)

If they're just not really understanding but want to understand, we go out of our way to give them extra information, to sit down and explain, to get them (information) for asthma, for example, we want them to show us how ... they're doing it, tell us what their understanding is, of, you know, what they're doing, when they're doing it. So, that we find out or work out what the barriers are to then be able to troubleshoot, um, and assist them. (Focus group 3)

The participants expressed some pride in their capacity to better support parents by knowing when they required additional information to properly understand the information provided.

#### 7.3.2.2.3 Follow-up

The ED nurses valued the opportunity to provide additional quality in discharge care by being able to follow up particularly vulnerable patients, such as refugee families, through community-based case managers.

We do try and follow up with, um, so refugees, having a (case) manager. The manager might not have come in with them. Um, we want to make sure that the manager knows... is aware of, of what has happened with them. (Focus group 3)

Nurses in the focus groups could see the follow-up processes for vulnerable families as a strong enabler of understanding discharge information.

#### 7.3.3 Outcome

The *outcome* domain of the Donabedian Model refers to the results of the quality of care. Findings from the focus groups identified some effective and ineffective factors influencing nurses' perceptions of: (i) parents' understanding of discharge information: and (ii) parents' satisfaction in the quality of care provided.

#### 7.3.3.1 Ineffective outcomes in parental understanding of discharge information

The participants in the focus groups identified three factors that may compromise parents' understanding of discharge information: (i) the provision of inaccurate and/or incomplete information; (ii) time policy; and (iii) parental characteristics.

7.3.3.1.1 Inaccurate and/or incomplete use of information

The participants were concerned about the potential confusion to parents' understanding of how to manage their child at home when they observed inaccurate and/or incomplete information being provided by some ED staff.

The asthma plan hasn't been explained to them appropriately, so they've given one puff instead of the six puffs even though they've been given an asthma plan. I feel from that point of view we haven't actually educated them well enough to um ... But once again we do leave that up to the medical staff here at the xxxxx hospital. (Focus group 2)

Sometimes the instructions aren't necessarily clear because you can read, even if you are English speaking, you can read what's written one way or another, so it will need (to be) interpreted. Um, you know, because maybe the grammar isn't brilliant or the, you know. Just how it's, it's, it's been written (in a confusing way). (Focus group 3)

Some concerns were expressed that not all ED staff were aware of the extent of available resources dedicated to children in this ED. There was a suggestion that if the ED staff had a more complete awareness of all the available resources, they could provide the appropriate resources to support verbal information, and thus help parents have a better understanding of the discharge information.

Doctors need to know that ... that's available. So, our doctors working both EDs, and in our adults, doesn't have freely available, um, guidelines printed. (Focus group3)

#### 7.3.3.1.2 Time policy

The NEAT time policy, which sets a finite time for an admission to ED at four hours, has already been discussed as a potential structural barrier. However, time constraints emerged as a

concern also within an outcome context. Specifically, nurses discussed that time constraints could potentially lead to a compromised understanding of discharge information by parents.

*Um, sometimes they ... um, because they want to ... get home quickly, ....don't want to wait. (Focus group 3)* 

You know, leaving without medical advice or against medical advice, that sort of thing. ...it's because of time, they need to get out because they have other children, they've got other concerns. (Focus group 3)

The participants agreed that time constraints resulted in both parents demonstrating a sense of urgency to leave the ED, and insufficient time for nurses to check that parents had understood the information they were given:

Sometimes you just get too busy. To give people adequate information and before you can get back to the bed you're looking after, they've already been discharged. (Focus group 2)

Time, it's busy and you don't have as much time as you want, you know, to be able to explain to them. (Focus group 2)

It appeared nurses were not only aware of their own time constraints, but also seemed sensitive to parents' perceptions of the time already spent in the ED. Time clearly had the potential to reduce the effectiveness discharge information outcome from both the parents' and nurses' perspectives.

7.3.3.1.3 Parents' characteristics

The ED nurses recognised a diversity of parent's backgrounds in their discussion of behaviour of parents as potentially decreasing the effectiveness of their understanding of home care information provided during the discharge of a child from the ED.

I think that there are some parents that just ... That don't want to know everything, they just ... They just want to come here, and have you fix their child and then they'll take them home. They're not interested. (Focus group 1) The diversity of parents' background also provided challenges to ED nurses who agreed that language, previous experiences, and/or the cultural diversity of parents could alter how well they cared for their child at home.

*Cause sometimes if it is a language barrier, that's probably the hardest one to educate because they just don't know and understand why they are, what's actually wrong with the child. (Focus group 3)* 

I don't think they've misunderstood what we're saying. They just still have that underlying fear of fevers for whatever reason. ...cultural... previous experience or whatever. (Focus group 1)

Therefore, independent of resources and how experienced the ED nurses were in helping parents understand information, parents' characteristics could make communication challenging, and have an undesirable impact on the child's home care.

#### 7.3.3.2 Effective outcomes in parental understanding of discharge information

Two factors were identified as being important to effectively providing discharge information to parents: (i) the professional experience and confidence of the ED staff; and (ii) the provision of useful resources.

7.3.3.2.1 Professional experience and confidence

Nurses from the focus groups discussed effective outcomes of care within the context of their clinical experience and confidence.

We go out of our way to give them extra information, to sit down and explain, to get them ...for asthma, for example, we want them to show us how to, how they're doing it, tell us what their understanding is, of, you know, what they're doing when they're doing it. Um. So, that we find out or work out what the barriers are to them being able to troubleshoot, um, and assist them. (Focus group 3)

I haven't noticed, like, any failure ... giving out education or information or anything like that. (Focus group 1)

Therefore, the ED nurses shared the perception that their training and their confidence was helpful to ensuring parents' understanding of discharge information. Sometimes nurses' verbal information was supported by the availability of appropriate resources to parents.

#### 7.3.3.2.2 Providing useful resources

Having additional resources, such as pamphlets, were considered important to complement the verbal information provided to parents. Such resources helped nurses feel effective about how they were supporting parents' understanding of their child's health and healthcare needs.

I think that having a properly written medical handout is much more useful for them than even if they don't look at it. At least we can feel like we've tried to give them the right information. (Focus Group 2)

We give a lot of um, patient handouts to parents who present, if it's the first time. For example, with croup or if they've got any misconceptions about fevers... So, a lot of people think that fevers are dangerous then we usually give them verbal advice and then give them a fever handout afterwards. So, they can read through that and be reassured that a fever doesn't cause a febrile convulsion and fever is not going to cause brain damage and all these myths. (Focus Group 2)

Therefore, participants believed having additional resources could reinforce the discharge information that they verbally provided parents, and help to improve parents' understanding of that information.

#### 7.3.3.3 Ineffective outcomes in parental satisfaction of discharge information

The ED nurses in the focus groups identified two factors that could result in parents being dissatisfied with the discharge information given to them: (i) inconsistent communication between ED staff and parents; and (ii) parents' beliefs.

#### 7.3.3.3.1 Poor communication

In the focus groups, ED nurses raised concerns about the provision of inconsistent information or poor delivery of this information by medical staff to parents. They considered poor communication could lead to parental confusion about details of the information provided, and consequently impair the overall quality of care, and their satisfaction with the discharge information given to them.

Communication with ... the medical staff. Absolutely, you know. They know in their head what's happening but often that doesn't get related to us, you know? And the next minute, the bed's empty and the child's gone home. So communication's a big thing with, um, ...with everyone. So, it's not just, um, doctor to patient or nurse to patient. It can be doctor to nurse. Um, and ... because everyone's, I guess, bedside manner isn't always the same. (Focus group 3)

... or you've just spent, ... 20 minutes trying to reassure a parent that what, their child's symptoms are okay, let's just not give a Panadol at all, and then the doctor comes in and says, oh they've got a fever, let's give some Panadol. So much I have just done the education and, they've just ruined it and the parents believe the doctor. (Focus group 2)

7.3.3.3.2 Parents' beliefs

Nurses discussed two cases in which parents' existing beliefs may have impaired their ability to be satisfied with the discharge information provided.

Someone who just wanted ... They'd been to (another) ... hospital already. They just wanted antibiotics for their child so. And they came ... Wanted their child here and (claimed) the child had a virus (but you wouldn't give antibiotics for a virus) ... he didn't ... The doctors over there (the other hospital) had taken the time to explain to them. We took the time to explain to them here and she was just adamant ... She didn't want to leave without getting antibiotics. (Focus group 1)

I don't know if it's necessarily that they haven't understood or whether it's still that they have their own beliefs and things like fevers, you know, you can have a very welllooking child come in with a fever and give them lots of education on fevers and ... But, we don't treat fevers, we treat the child. Or rest of it and give them the handouts on fevers and spend a fair amount of time trying to educate them on it and then they'll come back 12 hours later and say they've still got fevers and we'll say he has nothing else ... Has anything else changed in the child or is it just that they still have fevers. (Focus group 1)

The observations that nurses believed parents tried different hospitals or returned to the same hospital could demonstrate dissatisfaction with treatment and information provided.

#### 7.3.3.4 Effective outcomes in parental satisfaction of discharge information

Two factors were recognised by the focus groups as being important for ensuring parents were satisfied with the discharge information they were given: (i) professional experience and confidence of the ED nurses; and (ii) ensuring parents understood the information provided to them.

7.3.3.4.1 Professional experience and confidence

The nurses in the focus groups felt their professional confidence was important in the effectiveness of providing information, and may be linked to parents' overall satisfaction of that information.

...Yeah, sometimes they don't actually take it all in that they can go home and pull out a handout and um, see what symptoms require representation. (Focus group 2)

, um, because you want to ... feel comfortable that they do understand what needs to be done. That their understanding is ... clear. (Focus group 3)

7.3.3.4.2 Ensuring parents' understanding of information

The opportunity to verify parents' understanding of the information provided, also may contribute to parents' satisfaction with the quality of care provided. Nurses from the focus groups discussed effective outcomes of care that included having opportunities to ensure parents' understanding; this assurance was considered to be a useful strategy that supported quality of care.

*if I'm* concerned that somebody doesn't understand then, I'll ask them to repeat it back to me, or ask if they've got any questions or try and explain things in more simplistic layman's terms rather than using medical kind of jargon. (Focus group 2) I think some people will ... just kind of nod when the doctor is saying things ... and then you go in there and go, "Did you understand that?" And they go, "Oh, I do have a question about this." and then, I think it's good to just go in there and double check that they're aware of what's going on and that kind of stuff. (Focus group1)

Thus, effective communication to parents was a means of nurses perceiving they were providing effective discharge care for children and their parents. Nurses' communication involved strategies of double checking parents' understanding, avoiding medical jargon, and asking parents if they had any questions even after the parents had informed other ED staff that they understood what they had been told.

The findings of the focus groups conducted with ED nurses were aligned with the three domains of *structure*, *process* and *outcomes*, and informed data analyses.

Within the *structure* domain, barriers to the effective provision of discharge information were concerns about inexperienced ED staff, time policies, an absence of locally-developed resources for discharge information and procedures involved in accessing interpreter services. *Structure*-related enablers the value of interpreter services when they were available in the children's ED, and access to additional sources of information, such as pamphlets, from state or local health services.

The process-related barriers were concerns around parents' behaviour, health literacy and their beliefs that were sometimes at odds with the nurses' perceptions of quality of care. Nurses also expressed concerns about some parents' assumption of the accuracy of, and their use of, social media such as Dr Google, that was not always appropriate for individual cases. Another concern for the nurses in the focus groups was that parents received conflicting information from staff within the ED. *Process*-related enablers were considered to be accessibility to multiple sources of information, opportunities to ensure parents understood discharge information, and having a capacity to follow-up on some patients after discharge.

Nurses' perceptions of the causes of ineffective *outcomes* for understanding discharge information were some parents receiving inaccurate and incomplete information, pressures relating to time policies, and parental characteristics that limited their understanding, such as no previous experiences in a children's ED and/or cultural diversity. Nurses perceived effective

outcomes in quality of care were related to their own professional experience and confidence in being able to provide useful resources for parents.

#### 7.5 Discussion

Discharge information is an important part of high-quality care in the ED. Communication was discussed as a strength in the role of ED nurses that could significantly contribute to the provision of discharge information.

Despite the absence of direct reference to "discharge information" within standards for practice by registered nurses in Australia (Nursing and Midwifery Board of Australia, 2017) related expectations for strong communication appear in the words "education and advice". It could be argued that discharge information requires both education and advice and is therefore is well aligned to the role of the ED nurse. Furthermore, the International Standards of Care for Children in Emergency Departments use the term "ED care providers"; a term which does not discriminate between doctors and nurses. In advising these "providers" about discharge information, the three considerations were suggested: (1) the need to avoid using over medicalized words, (2) practical advice in caring for this child and (3) being sensitive of the family's cultural context (International Federation for Emergency Medicine, 2012). All three of these considerations were part of the ED nurses' discussion and perceived competencies.

Discourse provided by ED nurses included reflections on the process and outcome domains of the Donabedian theoretical framework. Paediatric health care settings often require nurses who as a result of additional postgraduate training and, extensive clinical experience with children, have competencies in the knowledge and skills in clinical practice to ensure specialist nursing care for children (Association for the Wellbeing of Children in Healthcare, 2015). The specialist paediatric nurses are expected to demonstrate self-direction and a high level of responsibility in their delivery of quality care (Australian Confederation of Paediatric and Child Health Nurses, 2006). Therefore, it was unsurprising that the nurses from the focus groups perceived a high level of competence in being able to promote understanding of discharge information by parents.

ED nurses also described concerns about the inexperience of other ED staff within the setting. Inexperience may be attributed to the ED rotational rosters that also supported a learning environment for doctors, who were yet to be independent practitioners. It is reasonable to expect a range of staff experiences in the ED. However, the impact of this in the children's ED was a concern to nurses who perceived the potential of professional inexperience as a barrier to parents' understanding of discharge information. The International Federation for Emergency Medicine notes that "more full-time dedicated ED staff members make departments run more smoothly, and thus maintaining good clinical care standards becomes easier. If ED staff numbers include many working on a temporary or occasional basis then staffing quality and skills levels becomes unpredictable and safe care is less likely" (The International Federation for Emergency Medicine, 2012 p.29). None of the ED nurses in the focus group were in training, temporary or occasional. This may explain some of the confidence to communicate with parents.

ED nurses discussed multipe factors that may contribute to improved understanding of resources provided to parents. They were concerned about the language, consistency and accuracy of information that some parents received. Similar concerns about information given to parents of children needing medical care have been previously described as unclear or deficient and may have resulted in decreasing parents' understanding of the information provided to them (Tait, Voepel-Lewis, Snyder, & Malviya, 2008). Thus, strategies are needed to minimise the risk of a poor understanding of information provided to parents.

Nurses in the current study believed in their capacity to help parents when they were afforded opportunities to follow-up with families after a child was discharged from the ED. The appropriate follow-up is essential to optimize outcomes after discharge from the ED when nurses perceive additional care may be required (Schatz, Rachelefsky, & Krishnan, 2009). Nurses in the focus groups were experienced in supporting many children with high needs, including children from refugee families. Refugee children are a vulnerable group who require culturally appropriate and trauma sensitive services (Garakasha, 2015). Continuity of care and a desire to follow up the child when they return to their family and community may also support parents' understanding of a child's health needs (Garakasha, 2015). Even though this type of follow up on discharge information appeared to be a rare opportunity for ED nurses, they perceived a lot of success in communicating with these vulnerable families.

#### 7.6 Strengths and limitations of the study

#### 7.6.1 Strengths

For the first-time discussions from focus groups with ED nurses have been framed within the Donabedian model and coded into barriers and enablers of the provision of discharge information. Findings strengthen the evidence of ED nurses' perceptions of how the specific domains of *structure*, *process* and *outcomes* affect parents' understanding of, and satisfaction with, the discharge information. These ED nurses' perceptions of competence in communication, their sensitivity to cultural diversity and their dislike of hearing others use medical jargon highlight professional practices well aligned to the International Standards of Care for Children in Emergency Departments (International Federation for Emergency Medicine, 2012).

#### 7.6.2 Limitations

For this study, the three focus groups were limited to two ED nurses in each group due to difficulties experienced in recruiting ED nurses. This limitation arose because only 4 to 5 nurses comprised a shift, and the pace of the work in the ED has its own pressures. Therefore, the small numbers in the groups may have limited the depth and breadth of the data; however, the participants were experienced ED nurses with a range of experiences at the site of data collection and other children's medical emergency settings, making their responses relevant and useful to this thesis. Also, focus groups did not target doctors or other ED staff such as physiotherapists and medical trainees (students). In this particular health service, it was found that discharge information was the primary role of the ED doctor, which is an acknowledged limitation of the focus group component within the thesis.

#### 7.7 Summary

This chapter has presented the research design, focus group data collection method, and qualitative data analysis for this study. The findings and discussion presented at the end of the chapter highlight strengths and limitations of the study. The next chapter presents the fourth and final study in this thesis (parents' survey).

### **Chapter 8: Survey of Parents**

#### 8.1 Introduction

This chapter presents the fourth and final study in this thesis, and it aligns with both the *process* and *outcome* domains of the Donabedian Model of Quality of Care. A survey was used to gather data from parents about their experience in the ED. The parents' survey aimed to identify the extent to which parents understood the discharge information provided to them by the ED staff, the usefulness of this information in managing their child at home after discharge from the ED, and their satisfaction with this discharge information.

The research question addressed in this study is:

*Question 4: What are parents' perceptions of the quality of discharge information received in the ED?* 

This chapter describes the research design; the methods used for the survey and data analysis, the results, and discusses results.

#### 8.2 Research design and methods

#### 8.2.1 Research design

The survey design used in this study was aligned to the three domains of the Donabedian Model of Quality Care framework. The parents' survey included six sections: (i) About you, (ii) About your child in the children's ED, (iii) Detail about your visit to the children's Emergency Department (iv) After visiting the Emergency Department, (v) The first week after you return home and (vi) your overall experience of the Emergency Department. The 66 questions (See Appendices 6 and 7) are used in the survey relating to demographic profile of parents, and questions which were largely based on the literature on discharge planning. Open-ended questions related to parental understanding, perceptions of resources and parental satisfaction with discharge information provided.

The survey was created to be self-administered, so the parents could complete the survey without assistance from the research team, and at a time and place most convenient to them (Dillman, Smyth, & Christian, 2009). Printed copies of the survey were provided in recognition that not all parents are able to access or have the skills to complete the survey electronically.

The telephone option for undertaking the survey served the purpose of prompting parents to complete the survey, and to minimise the possibility of literacy issues such as misunderstanding the meaning of questions, or being uncertain about how to answer any of the questions. Sampling of the participants, the data collection procedures, and the data analysis are described below.

#### 8.2.2 Sampling of participants

The participants in this study were parents of children who had presented to the ED and were subsequently discharged from the ED to home. The participants in this study were a different group from the participants of the non- participant observation study because the survey was conducted data after observation study is completed. Non-probability convenience sampling (Holloway & Wheeler, 2010) was used to recruit parents in the Children's ED. Although probability-based sampling would have been ideal, uncertainty surrounded the number of parents willing to participate in the survey. Moreover, access to the ED was restricted to a limited period of time, to minimise disruption to the ED. Therefore, non-probability sampling was selected, and vigilance in interpreting the results of statistical analyses was applied (Weathington, Cunningham, & Pittenger, 2010). Within non-probability sampling, convenience sampling maximises access to a population that closely aligns to the purpose of the study, and it supports an efficient and timely collection of data for an environment in which access is limited.

In this study, the convenience sample comprised parents of children treated and discharged home from the ED. Another inclusion requirement was that parents understood spoken and written English. Parents were excluded from the study if they: (i) were suspected of child abuse according to the triage nurse; (ii) had a cognitive or neurological deficit; and/or (iii) were taking analgesic medication on a regular basis.

#### 8.2.3 Data collection

This final study was conducted after the third study. Parents were invited by the research assistant to participate in the survey once they had seen the triage nurses and while they were waiting for treatment in the waiting area of the children's ED.

The data were collected over a twelve-month period in one of three survey formats: (i) a hard copy, which was to be completed and then returned by post using the stamped addressed envelope provided; (ii) an online survey tool (Survey Monkey<sup>™</sup>); or (iii) a telephone-based survey conducted by a research assistant to increase parent participation and convenience.

Parents were asked to complete the survey by nurses and doctors within the ED. Initially, parents were encouraged to complete a hard copy version of the survey and return it via a reply-paid envelope; they provided parents with the survey form before their child was discharged from the ED. Alternatively, the parents were asked to complete the survey on-line. Additional hard copies of the survey were available from a labelled box conveniently located near the exit of the ED, so parents could collect one when they were leaving the ED. ED volunteers also agreed to encourage parents to take a survey as they left the ED, if they had not already received a survey from the ED staff. Results from the pilot study on the survey showed that parents needed only 10 to 15 minutes to complete the survey, so this statement was included in the recruitment strategy when the RA approached potential parents. The expected duration of the survey was also included in the information sheet that described the study to parents (Appendix 9).

Despite these strategies there was a much lower response rate than expected to the parents' survey in the first 6 months of survey distribution. Although parents were taking the survey home, few completed and returned the survey in hard copy or online. Therefore, the research team sought, and was granted, ethical approval for a modification of the methodology to include an additional, telephone-based format for the survey. In this format, a research assistant called the parents of children 36-48 hours after their child had been discharged from the ED; this time-line was used to minimise the bias of poor recall (Bauer, Cheatham, Cary, & Abbema, 2002).

For parents agreeing to participate in the survey via a telephone call, a research assistant located in the ED, initially obtained written informed consent, before helping parents to complete the first section of the survey (which was asking about parent demographics), and before parents left the ED. During this discussion, the research assistant also obtained a telephone number and time that would be convenient to contact the parents to complete the remaining survey questions.

#### 8.2.4 Data analysis

All of the completed surveys were used in the data entry and analysis for this study. All data were entered into Survey Monkey<sup>™</sup>, which was then used to analyse it. Survey Monkey<sup>™</sup> was selected as it is a well-recognised online survey platform, and because results are easily transferred to the statistical software program SPSS Version 22 (Pallant, 2016).

Parents' self-reported levels of anxiety, confidence and satisfaction were modelled using a Generalised Estimating Equations (GEEs) approach (Armitage, Geoffrey Berry, & Matthews, 2002), while accounting for correlated data within the repeated measures study design in the survey. An exchangeable working covariance matrix was used to account for correlation and dependence between repeated measurements on the same individual over time (Hin & Wang, 2009; Liang & Zeger, 1986).

The multivariate model compared the repeated anxiety, confidence and satisfaction measures (on arrival to ED and on discharge) while accounting for key explanatory variables: parents' age, level of education, socio-economic status, years living in Australia, number of times being in a paediatric emergency department, age and sex of the child, the main reason of referral to the ED, time from arrival at the ED until being assessed by either a nurse or a doctor, and length of stay in the ED. Statistical significance was set at a p value of =< 0.05 (two sided). All analyses were conducted using IBM SPSS software, version 22. However, given the non-probability sampling strategy, this type of statistical treatment involving GEEs has acknowledged weaknesses and results require cautious interpretation.

As parents provided limited text responses to the open-ended questions in the survey, the planned qualitative analysis of text responses was not possible.

#### 8.3 Results

Seventy-nine surveys (hard copy, online, telephone, combined), completed by 79 respondents, were returned over a period of 12 months (August 2015 to September 2016), with the majority (72%) being returned in the 6-month period February to June 2016.

The findings from the parents' survey presented in this section are reported in several categories: the demographics of participants; parents' self-reports on their child's presentation and treatment in the ED; and their understanding of how they were advised to

manage their child at home. Descriptive analyses identified two factors (parental anxiety and confidence) that might impact on parents' understanding of how to manage their child, and parents' satisfaction with the discharge information provided to them in the ED.

#### 8.3.1 Demographic profile of parents and children (Questions 1-14)

Most parents who accompanied their child to the ED were older than 30 years of age and predominantly the mother. Parents were also from proportionally more middle-to-upper class than lower class ranked suburbs, and appeared to be well educated (with more than half being university graduates compared with 40.5% in the state of Queensland and 22% nationally (Australian Bureau of Statistics, 2016). Most (61.5%) of the parents had been born in Australia; proportionally more than state (46.9%) and national (47.3%) averages (Australian Bureau of Statistics, 2016). Again, a higher proportion of families speaking only English at home (92%) was identified in the parents responding to the survey compared with state (73.9%) and national averages (72.7%) (Australian Bureau of Statistics, 2016). Other languages spoken at home included Cantonese, French, Mandarin, Spanish, and Arabic. Almost three quarters of the parents responding to the survey had visited a children's ED on at least three previous occasions. Table 14 details the demographics of parents presenting to the ED.

| Characteristic                  | N (Percent)        | Queensland     | National Census     |
|---------------------------------|--------------------|----------------|---------------------|
|                                 | (Total: <i>n</i> = | Census Data    | Data (if available) |
|                                 | 79)                |                |                     |
| Age of the parent in years, (%) |                    |                |                     |
| 30 or younger                   | 11 (13.9%)         | Median age of  | Median age of       |
| 31 to 40                        | 36 (45.6%)         | mothers in in  | mothers in in 2015  |
| 41 +                            | 32 (40.5%)         | 2015 was 30.2  | was 31 years*       |
|                                 |                    | years*         |                     |
| Sex of parent, (%)              |                    |                |                     |
| Female                          | 74 (93.7%)         | n/a            | n/a                 |
| Male                            | 5 (6.3%)           | n/a            | n/a                 |
| Socio-economic status (based on |                    |                |                     |
| SEIFA), (%)                     |                    |                |                     |
| Lower SES                       | 22 (27.9%)         | Brisbane SIEFA | National SEIFA      |
| Middle SES                      | 32 (40.5%)         | score of 1,047 | score 1,002         |
| Higher SES                      | 11 (13.9%)         | (relatively    | (marginally         |
| Missing                         | 14 (17.7%)         | advantaged) ## | advantaged) ##      |

| Table 14: Demographic profile of | of parents presenting to the ED |
|----------------------------------|---------------------------------|
|----------------------------------|---------------------------------|

| Parent education, (%)              |            |       |        |
|------------------------------------|------------|-------|--------|
| High school or lower               | 11 (13.9%) | 28.9  | 40.3%  |
| TAFE certificate or diploma        | 23 (29.1%) | 18.2% | 24.6%  |
| University degree                  | 44 (55.7%) | 40.5% | 22.0%% |
| Missing                            | 1 (1.3%)   |       |        |
| Years lived in Australia, (%)      |            |       |        |
| All their lives                    | 48 (61.5%) | 46.9% | 47.3%  |
| 10 years or more                   | 19 (24.4%) | n/a   | n/a    |
| Less than 10 years                 | 11 (14.1%) | n/a   | n/a    |
| English language spoken at home,   |            |       |        |
| Yes (%)                            | 73 (92.4%) | 73.9% | 72.7%  |
| Other languages, (%) (Cantonese,   | 6 (7.6%)   | 26.1% | 27.3%  |
| French, Mandarin, Spanish and      |            |       |        |
| Arabic)                            |            |       |        |
| Non-indigenous Australian, Yes (%) | 78 (98.7%) | 98.9% | 97.2%  |
| Previous visit in an emergency     |            |       |        |
| department (ED), (%)               |            |       |        |
| First time in an ED                | 9 (11.4%)  | n/a   | n/a    |
| Second time                        | 12 (15.2%) | n/a   | n/a    |
| Third time or more                 | 58 (73.4%) | n/a   | n/a    |

Note: \* = from

http://www.abs.gov.au/ausstats%5Cabs@.nsf/0/8668A9A0D4B0156CCA25792F0016186A? Opendocument

## = from http://profile.id.com.au/brisbane/seifa-disadvantage-small-area

The characteristics of the children presenting to the ED are summarised in Table 15. Slightly more boys than girls were the patients treated in the ED, with an average age of 5 years or younger. Marginally (10%) more children presented with illness than injury and these conditions will be reported separately.

| Characteristic                             | N (Percent)            |
|--|------------------------|
|  | (Total: <i>n</i> = 79) |
| Child's sex, (%)                           |                        |
| Male                                       | 47 (59.5%)             |
| Female                                     | 32 (40.5%)             |
| Child age in years, (%)                    |                        |
| 5 years or younger                         | 33 (41.8%)             |
| 6 to 10                                    | 20 (25.3%)             |
| 11 or older                                | 15 (19.0%)             |
| Missing                                    | 11 13.9%)              |
| Main reason of presentation in the ED, (%) |                        |
| Illness                                    | 43 (54.4%)             |
| Injury                                     | 36 (45.6%)             |

#### 8.3.2 Children presenting with illnesses (Question 15)

#### 8.3.2.1 Classification by body system for symptoms described by parents

Table 16 presents a body system classification for symptoms of children's presentations to the ED that was described by parents. The range of symptoms children presented with at the ED, as reported by the parents were categorised according to a list of body systems. The two most common categories were the respiratory system (37.2%) and the oral / gastrointestinal system (34.9%). None of the parents reported children with symptoms involving more than one body system.

| Body system                    | Ν                      | %     |
|--------------------------------|------------------------|-------|
|                                | (Total: <i>n</i> = 79) |       |
| Respiratory                    | 16                     | 37.2  |
| Oral and Gastrointestinal      | 15                     | 34.9  |
| Inflammatory and Immune System | 3                      | 7.0   |
| Skin                           | 3                      | 7.0   |
| Renal and Urogenital           | 2                      | 4.7   |
| Eye                            | 2                      | 4.7   |
| Cardiovascular                 | 1                      | 2.3   |
| Ear                            | 1                      | 2.3   |
| Total                          | 43                     | 100.0 |

Table 16: Children's symptoms classified by body system

#### 8.3.2.2 Parent-reported diagnoses of their child's illness (Question 20)

Parents' recall of their child's diagnosis was reported following their response about their child's symptoms. Table 17 displays a relatively broad range of diagnoses reported by parents for their children's conditions. Approximately one in four parents (25.6%) reported their child had been diagnosed with a viral infection. The next most prevalent diagnoses were Croup / Bronchitis / Bronchiolitis / Upper respiratory tract inflection (collectively, 9.3%), and gastrointestinal illness that included diarrhea and vomiting (9.3%). The parent-reported diagnoses in the survey may not be a correct representation of the actual medical diagnoses made, but they demonstrate the parents' recollection of the diagnosis they were given for their child's condition.
| Diagnosis   | N<br>(Total: <i>n</i> = | %     |
|---|-------------------------|-------|
|   | 79)                     |       |
| Viral infection   | 11                      | 25.6  |
| Croup / Bronchitis / Bronchiolitis / URTI                     | 4                       | 9.3   |
| Gastrointestinal illness (diarrhoea, vomiting)                | 4                       | 9.3   |
| Lower limb cellulitis or inflammatory response / cellulitis / | 3                       | 7.0   |
| Infected molluscum wart                                       |                         |       |
| Eye irritation  | 2                       | 4.7   |
| Dehydration   | 2                       | 4.7   |
| Syncope   | 1                       | 2.3   |
| Asthma & LRTI   | 1                       | 2.3   |
| Allergic reaction   | 1                       | 2.3   |
| Urinary tract infection                                       | 1                       | 2.3   |
| Lymph node infection  | 1                       | 2.3   |
| Ear stud lodged in ear lobe tissue                            | 1                       | 2.3   |
| Mouth ulcer   | 1                       | 2.3   |
| Scabies   | 1                       | 2.3   |
| No diagnosis  | 6                       | 13.9  |
| No response from parents to survey question                   | 3                       | 7.0   |
| Total   | 43                      | 100.0 |

## Table 17: Child's diagnosis on discharge from the ED as reported by parents

Note: URTI = upper respiratory tract infection; LRTI = Lower respiratory tract infection

## 8.3.2.3 Parent-reported ED treatment for their child's illness (Question 21)

Parents described the nature of treatment their child received in the ED in response to an open-ended question. Table 18 shows the two most frequently described treatments were an examination of the body (20.9%), and some type of administered medicine (19.8%). Checks of vital signs (temperature, blood pressure, heart rate) and requests for a urine sample were the next two most common types of treatment described by parents, both having an incidence of 10.5%.

| Table 18: Parental | descriptions of | f the treatment | their child | received in | n the ED |
|--------------------|-----------------|-----------------|-------------|-------------|----------|
|                    |                 |                 |             | icecived ii |          |

| Parent-reported treatment for illness    | Ν                      | %    |
|--|------------------------|------|
|  | (Total: <i>n</i> = 79) |      |
| Examination of body                      | 18                     | 20.9 |
| Administration of medicine in the ED     | 17                     | 19.8 |
| Vital signs taken                        | 9                      | 10.5 |
| Urine test                               | 9                      | 10.5 |
| Blood sugar test / or another blood test | 6                      | 7.0  |
| Fluid intake / output record             | 4                      | 4.7  |
| Nasal swab                               | 3                      | 3.5  |

| Child monitoring                              | 3  | 3.5   |
|---|----|-------|
| Prescribed antibiotic                         | 3  | 3.5   |
| ECG   | 2  | 2.3   |
| Ultrasound                                    | 2  | 2.3   |
| Blood oxygen level test                       | 2  | 2.3   |
| Eye care                                      | 2  | 2.3   |
| Advised to return to the ED or other hospital | 2  | 2.3   |
| Consultation with allergy specialist          | 1  | 1.2   |
| Immunisation                                  | 1  | 1.2   |
| Neurological testing                          | 1  | 1.2   |
| No response from parents to survey question   | 1  | 1.2   |
| Total *                                       | 86 | 100.0 |

Note: \* = There could have been more than one treatment per child

8.3.2.4 Parents' understanding of how to care for their child's illness at home (Questions 22-35) Parents' understanding of how they were to care for their child at home was also captured in the survey. The results in Table 19 show more than one third (37.9%) (n = 22) of parents reported the care of their child at home involved instructions to monitor their child for key markers of health, such as sufficient intake of fluid or food, pain, and other relevant symptoms. However, more than one quarter of parents did not respond to the question asking them to describe the information provided at discharge to care for their child at home.

Table 19: Parental descriptions of how to care for their child's illness at home after discharge from an ED

| Parent-reported care at home instructions     | Ν                      | %     |
|---|------------------------|-------|
|   | (Total: <i>n</i> = 79) |       |
| Monitor child (intake of fluid or food, pain, | 22                     | 37.9  |
| symptoms)                                     |                        |       |
| Return to ED if child has not improved        | 5                      | 8.6   |
| Administration of medicine                    | 4                      | 6.9   |
| Rest / ice / compress / elevate               | 4                      | 6.9   |
| Personal hygiene                              | 3                      | 5.2   |
| Read about illness                            | 3                      | 5.2   |
| Follow up with GP                             | 1                      | 1.7   |
| No response from parents to survey question   | 16                     | 27.6  |
| Total *                                       | 58                     | 100.0 |

Note: \* = There could have been more than one treatment per child

About half (51.3%) of 76 parents who completed this survey item (n = 79) stated they received information pamphlets by the ED staff in addition to the verbal information they had been given. Parents stated printed resources included information on how conditions progress, how

parents can care for their child at home, how to observe signs and symptoms, advice on medications, advice on worsening of the condition, follow-up instructions, and advice on when to return to ED.

# 8.3.3 Children presenting with injuries

# 8.3.3.1 Parent-reported descriptions of their child's injury (Question 15)

A total of 36 (46%) (n=79) of the children presented to the ED due to injury. Table 20 summarises parents' descriptions of their child's injuries. Musculoskeletal injuries were the most prevalent injury presentation described (44.4%), followed by undefined cause of injuries (33.3%).

| Types of injury                          | Ν                      | %     |
|--|------------------------|-------|
|  | (Total: <i>n</i> = 79) |       |
| Musculoskeletal (bruise, swelling, pain) | 16                     | 44.4  |
| Head injury                              | 3                      | 8.3   |
| Skin injury                              | 3                      | 8.3   |
| Poisoning                                | 1                      | 2.8   |
| Eye injury                               | 1                      | 2.8   |
| Injury - undefined                       | 12                     | 33.3  |
| Total                                    | 36                     | 100.0 |

Table 20: Parental descriptions of why their child was taken to the ED

# 8.3.3.2 Parent-reported diagnoses of their child's injury (Question 20)

Parents reported a relatively broad range of injuries, as shown in Table 21. Approximately one in four parents (25.2%) reporting an injury to their child recalled the diagnosis was a fracture (buckle, arm, radius, radial head, wrist, and bone or collar bone). The next most prevalent injury diagnosis was attributed to skin bruises or lacerations (19.4%) (n = 7). Head injuries accounted for approximately 17% (n = 6) of presentations.

## Table 21: Parental descriptions of their child's injury diagnosis

|--|

|                            | (Total: <i>n</i> = 79) |       |
|----------------------------|------------------------|-------|
| Fracture                   |                        |       |
| - buckle                   | 2                      | 5.6   |
| - arm                      | 2                      | 5.6   |
| - radius                   | 1                      | 2.8   |
| - radial head              | 1                      | 2.8   |
| - wrist                    | 1                      | 2.8   |
| - whist                    | 1                      | 2.8   |
| - bone (site unstated)     | 1                      | 2.8   |
| - collar bone              | 1                      | 2.8   |
| total                      | 9                      | 25.2  |
| Skin bruises / lacerations | 7                      | 19.4  |
| Head injury                | 6                      | 16.7  |
| Sprained                   |                        |       |
| - ankle                    | 2                      | 5.6   |
| - foot                     | 1                      | 2.8   |
| - not specific             | 1                      | 2.8   |
| total                      | 4                      | 11.2  |
| Injury                     |                        |       |
| - eye                      | 1                      | 2.8   |
| - nail                     | 1                      | 2.8   |
| total                      | 2                      | 5.6   |
| Dislocation                | 3                      | 8.3   |
| Muscle strain              | 1                      | 2.8   |
| Haematoma                  |                        |       |
| - chin                     | 1                      | 2.8   |
| No diagnosis               | 3                      | 8.3   |
| Total                      | 36                     | 100.0 |

# 8.3.3.3 Parent-reported ED treatment for their child's injury (Question 21)

Following the question on injury diagnosis, parents were also asked a question about the treatment their child received in the ED for their injury. Table 22 lists the parents' descriptions of the various treatments provided. The most frequently described treatment provided for injuries in the ED involved X-ray (25%) (n = 17). The next most prevalent type of treatment described by parents comprised of the monitoring of "vital signs" and physical assessment (20.6%). Of note, medicine was administered to 15% of these children for pain relief.

| Table 22: Parental descriptions of injury treat | tment their child received in the ED |
|---|--------------------------------------|
|---|--------------------------------------|

| Injury treatment | N<br>(Total: <i>n</i> = 79) | %    |
|------------------|-----------------------------|------|
| X-ray            | 17                          | 25.0 |

| Vital signs / physical assessment / monitoring          | 14 | 20.6  |
|---|----|-------|
| Administration of medicine: Pain relief                 | 10 | 14.7  |
| Plaster / cast  | 6  | 8.8   |
| Bandage / sling   | 4  | 5.9   |
| Observation (neurological signs)                        | 4  | 5.9   |
| Physiotherapist review                                  | 3  | 4.4   |
| Manual manipulation and repositioning of dislocated arm | 2  | 2.9   |
| Rest / ice / compress / elevate                         | 2  | 2.9   |
| Eye glued   | 1  | 1.5   |
| Oxygen level  | 1  | 1.5   |
| Prescription of antibiotics                             | 1  | 1.5   |
| Blood test  | 1  | 1.5   |
| Intravenous fluid intake                                | 1  | 1.5   |
| No response from parent to survey question              | 1  | 1.5   |
| Total*  | 68 | 100.0 |

Note: \* = There could have been more than one treatment per child

# 8.3.3.4 Parents' understanding of how they were to care for their child's injury at home (Questions 22-35)

Parents reported the care of their child's injury at home involved instructions to monitor their child for key markers of care such as observing for signs of concussion, and more broadly, to keep checking on their child's health status (16.3%) (n = 7). A similar number of parents (14%) reported the next two most common types of injury care at home: (i) bandaging, ensuring the use of a prescribed sling; and (ii) dressing wounds. Approximately 16% (n = 7) of parents did not respond to this question on home care of their child's injury. Table 23 lists the parents' descriptions of what they were to do to care for their child after they had returned home from the ED.

| Home care                             | N | %    |
|---------------------------------------|---|------|
| Observe signs of concussion / monitor | 7 | 16.3 |
| Bandage and sling / dressing          | 6 | 14.0 |

## Table 23: Parental descriptions of caring for their child's injury at home

| Restricted activities at home               | 6  | 14.0  |
|---|----|-------|
| Rest / ice / compress / elevate             | 5  | 11.6  |
| Cast care                                   | 5  | 11.6  |
| Administration of medicine                  |    |       |
| Pain relief                                 | 2  | 4.7   |
| Antibiotics                                 | 1  | 2.3   |
| Observe pain / swelling/ colouring          | 2  | 4.7   |
| Return to ED if child has not improved      | 2  | 4.7   |
| No response from parents to survey question | 7  | 16.3  |
| Total *                                     | 43 | 100.0 |

Note: \* = There could have been more than one treatment per child

## 8.3.4 Parents' Anxiety (Questions 63 - 64)

Parents were asked to recall their level of anxiety on arrival to the ED and after their child was discharged from the ED. Anxiety was measured by the following questions: "How anxious were you when you arrived with your child at the emergency department?" and "When you left the emergency department, how anxious did you feel about being able to care for your child when you got home?" Both questions were scored using a five-point scale from "not at all anxious" to "extremely anxious". A ranking of three on this scale referred to "quite anxious" as shown in questions 63 and 64 of the survey.

The difference between parents' self-reported anxiety on arriving to and departing from the ED are presented in Table 24. The results show, on average, parents reported significantly less anxiety by the time their child was discharged from the ED.

| Anxiety level<br>(Levels 1 – 5) | Anxiety on<br>arrival to ED | Anxiety after<br>discharge from ED | Mean<br>difference | р       |
|---------------------------------|-----------------------------|------------------------------------|--------------------|---------|
|                                 | N (%)                       | N (%)                              |                    |         |
|                                 | (Total: <i>n</i> = 79)      | (Total: <i>n</i> = 79)             |                    |         |
| Not at all anxious (Level 1)    | 20 (25.3%)                  | 53 (67.1%)                         |                    |         |
| A little anxious (Level 2)      | 40 (50.6%)                  | 22 (27.9%)                         | -                  | -       |
| Quite anxious (Level 3)         | 11 (13.9%)                  | 3 (3.8%)                           |                    |         |
| Very anxious (Level 4)          | 7 (8.9%)                    | 1 (1.3%)                           |                    |         |
| Extremely anxious (Level 5)     | 1 (1.3%)                    | 0 (0.0%)                           |                    |         |
| Mean anxiety (SD)               | 2.10 (0.93)                 | 1.39 (0.63)                        | 0.71 (0.92)        | < 0.001 |

Table 24: Parents' self-reported anxiety on arrival to and discharge from the ED

## 8.3.4.1 Parents' Anxiety: multivariable analysis

Anxiety was assessed using a Generalised Estimating Equations (GEEs) approach, as described in Section 8.2.4. Results of GEE regression modelling are presented in Table 25.

| Covariates                                 | β            | Wald 95% CI          | р            |
|--|--------------|----------------------|--------------|
| Parents' age                               |              |                      |              |
| 30 years or younger (reference)            | 0.00         |                      |              |
| 31 – 40 years                              | 0.26         | -0.17 – 0.88         | 0.2          |
| 41 years or older                          | 0.36         | -0.22 – 0.73         | 0.3          |
| Parents' level of education                |              |                      |              |
| High school education or lower (reference) | 0.00         |                      |              |
| TAFE/Diploma/University degree             | <u>0.38</u>  | <u>0.01 – 0.75</u>   | <u>0.043</u> |
| Socio-economic status (defined by SEIFA)   |              |                      |              |
| Low SES (reference)                        | 0.00         |                      |              |
| Middle SES                                 | 0.02         | -0.35 – 0.38         | 0.9          |
| High SES                                   | <u>-0.38</u> | <u>-0.64 – -0.12</u> | <u>0.004</u> |
| Years living in Australia                  |              |                      |              |

Table 25: Parents' anxiety during their stay in the ED: A repeated measure multivariable Generalised Estimating Equations (GEEs) regression

| All their lives (reference)                             | 0.00         |                      |                  |
|---|--------------|----------------------|------------------|
| Ten years or more                                       | 0.04         | -0.27 – 0.34         | 0.8              |
| Less than ten years                                     | <u>0.32</u>  | <u>0.03 – 0.61</u>   | <u>0.032</u>     |
| Age of child (continuous)                               | -0.14        | -0.29 – 0.02         | 0.1              |
| Male sex of child                                       | 0.14         | -0.06 – 0.34         | 0.2              |
| First visit in a children ED                            | <u>0.39</u>  | <u>0.02 – 0.76</u>   | <u>0.037</u>     |
| Main reason of referral to the ED                       |              |                      |                  |
| Injury (reference)                                      | 0.00         |                      |                  |
| Illness   | <u>0.29</u>  | <u>0.06 – 0.53</u>   | <u>0.015</u>     |
| Time from arrival until examined by nurse               |              |                      |                  |
| Less than 10 minutes (reference)                        | 0.00         |                      |                  |
| Ten minutes or more                                     | <u>0.39</u>  | <u>0.00 – 0.78</u>   | <u>0.049</u>     |
| Time from arrival until examined by a physician         |              |                      |                  |
| Less than 30 minutes (reference)                        | 0.00         |                      |                  |
| Between 30 to 60 minutes                                | 0.11         | -0.24 – 0.45         | 0.5              |
| More than one hour                                      | <u>0.28</u>  | <u>0.04 – 0.53</u>   | <u>0.025</u>     |
| Length of time in the ED (continuous)                   | 0.02         | -0.07 – 0.11         | 0.7              |
| Time (post discharge anxiety versus anxiety on arrival) | <u>-0.52</u> | <u>-0.75 – -0.28</u> | <u>&lt;0.001</u> |

Results of the GEE regression modelling showed eight key independent predictors of parents' anxiety during their stay in the ED. Parents who had a higher education were more likely to report higher levels of anxiety than parents who had lower education ( $\beta$  = 0.38, 95% CI 0.01, 0.75, *p* = 0.043). Compared to the lower socio-economic class, parents coming from upper class ranked suburbs reported less anxiety ( $\beta$  = -0.38, 95% CI -0.64, -0.12, *p* = 0.004). Parents who had been living in Australia for less than 10 years were more likely to be anxious, compared to those who had lived all their lives in Australia ( $\beta$  = 0.32, 95% CI 0.03, 0.61, *p* = 0.032). Parents who were presenting to the ED for the first time were more likely to be anxious than those who had presented to the ED previously ( $\beta$  = 0.39, 95% CI 0.02, 0.76, *p* = 0.037), and those presenting with a sick child were more likely to report anxiety than parents who

had a child with an injury ( $\beta$  = 0.29, 95% CI 0.06, 0.53, *p* = 0.015). Any period of time from a child's arrival at the ED until the assessment by a triage nurse that was longer than ten minutes significantly increased parents' anxiety ( $\beta$  = 0.39, 95% CI 0.00,0.78, *p* = 0.049). Furthermore, parents who experienced a waiting time of more than one hour from arrival at the ED until a doctor assessed their child expressed increased anxiety ( $\beta$  = 0.28, 95% CI 0.04,0.53, *p* = 0.025). Finally, total time spent in the ED significantly affected the anxiety levels of the attending parents; the longer they spent in ED, the less anxious they were ( $\beta$  = -0.52, 95% CI -0.75, -0.28, *p* < 0.001).

# 8.3.5 Parents' confidence in using discharge information received from ED staff (Question 65)

Parents' confidence in using discharge information received from ED staff was measured by using used a five-point scale (1=Not at all confident, 2=A little confident, 3=Quite confident, 4=Very confident and 5=Extremely confident) to measure parents' confidence in using the discharge information they had received from the ED staff: "Overall, how confident were you about using the discharge information you received from emergency department staff? Results from GEE modelling for independent predictors of parents' perceptions of confidence in being able to understand and use the information provided are presented in Table 26.

| Covariates                                 | β     | Wald 95% CI  | p   |
|--|-------|--------------|-----|
| Parent's age                               |       |              |     |
| 30 years or younger (reference)            | 0.00  |              |     |
| 31 or older                                | -0.49 | -1.11 - 0.13 | 0.1 |
| Parent's level of education                |       |              |     |
| High school education or lower (reference) | 0.00  |              |     |
| TAFE/Diploma/University degree             | 0.30  | -0.58 - 1.19 | 0.5 |
| Socioeconomic status (defined by SEIFA)    |       |              |     |
| Low SES (reference)                        | 0.00  |              |     |
| Middle SES                                 | -0.13 | -0.58 - 0.33 | 0.6 |

Table 26: Parents' confidence to use the discharge information at home: A GeneralisedEstimating Equation (GEEs) modelling

| High SES  |              | -0.71 - 0.36         | 0.5          |
|---|--------------|----------------------|--------------|
| Years living in Australia                       |              |                      |              |
| All their lives (reference)                     | 0.00         |                      |              |
| Ten years or more                               | 0.09         | -0.44 - 0.61         | 0.8          |
| Less than ten years                             | -0.40        | -1.01 – 0.21         | 0.2          |
| Age of child (continuous)                       | -0.00        | -0.05 - 0.05         | 1.0          |
| Male sex of child                               | -0.02        | -0.38 - 0.34         | 0.9          |
| First visit in a children ED                    | -0.02        | -0.63 – 0.60         | 0.9          |
| Main reason of referral to the ED               |              |                      |              |
| Injury (reference)                              | 0.00         |                      |              |
| Illness   | -0.30        | -0.73 – 0.13         | 0.2          |
| Time from arrival till examined by nurse        |              |                      |              |
| Less than 10 minutes (reference)                | 0.00         |                      |              |
| Ten minutes or more                             | 0.42         | -0.13 - 0.97         | 0.1          |
| Time from arrival till examined by a physician  |              |                      |              |
| Less than 30 minutes (reference)                | 0.00         |                      |              |
| Between 30 to 60 minutes                        | -0.23        | -0.72 - 0.26         | 0.4          |
| More than one hour                              | <u>-0.85</u> | <u>-1.38 – -0.31</u> | <u>0.002</u> |
| Length of time in the ED (continuous)           | 0.04         | -0.08 - 0.16         | 0.5          |
| Anxiety score on arrival to ED (continuous)     | -0.07        | -0.39 – 0.25         | 0.7          |
| Anxiety score on discharge from ED (continuous) | <u>-0.79</u> | <u>-1.28 – -0.30</u> | <u>0.002</u> |

Only two predictors emerged from this model regarding parents' confidence to use discharge information. First, parents who waited longer than one hour to have their child examined by the doctor were significantly less confident than parents who waited less time ( $\beta$  =-0.85, 95% CI -1.38, -0.31, *p* = 0.002). Second, parents with higher anxiety scores on discharge from ED

were more likely to be less confident than parents with lower anxiety scores ( $\beta$  =-0.79, 95% CI -1.28, -0.30, *p* = 0.002).

## 8.3.6 Parents' satisfaction with discharge information (Question 66)

Parents' satisfaction with discharge information was measured by using a five-point scale (1=Not at all satisfied, 2=A little bit satisfied, 3=Quite satisfied, 4=Very Satisfied and 5=Extremely satisfied) the following questions: "Overall, how satisfied were you with the discharge information you received from emergency department staff?". Using GEEs modelling, parents' responses were checked for the influence of demographic variables, emotional states at the time of the ED visit and process features such as the time taken to commence treatment of their child (Table 27).

| Covariates                                 | β            | Wald 95% CI          | р            |
|--|--------------|----------------------|--------------|
| Parents' age                               |              |                      |              |
| 30 years or younger (reference)            | 0.00         |                      |              |
| <u>31 or older</u>                         | <u>-0.57</u> | <u>-1.12 – -0.03</u> | <u>0.038</u> |
| Parents' level of education                |              |                      |              |
| High school education or lower (reference) | 0.00         |                      |              |
| TAFE/Diploma/University degree             | 0.04         | -0.86 - 0.93         | 0.9          |
| Socio-economic status (defined by SEIFA)   |              |                      |              |
| Low SES (reference)                        | 0.00         |                      |              |
| Middle SES                                 | -0.17        | -0.62 - 0.28         | 0.5          |
| High SES                                   | -0.13        | -0.65 – 0.40         | 0.6          |
| Years living in Australia                  |              |                      |              |
| All their lives (reference)                | 0.00         |                      |              |
| Ten years or more                          | -0.17        | -0.75 – 0.42         | 0.6          |
| Less than ten years                        | -0.19        | -0.86 - 0.48         | 0.6          |
| Age of child (continuous)                  | -0.01        | -0.06 - 0.03         | 0.6          |
| Male sex of child                          | -0.05        | -0.45 – 0.35         | 0.8          |

Table 27: Parent's satisfaction with discharge information: A Generalised Estimating Equations (GEEs) model

| First visit in a children ED                    | -0.14        | -0.75 – 0.46         | 0.6               |
|---|--------------|----------------------|-------------------|
| Main reason of referral to the ED               |              |                      |                   |
| Injury (reference)                              | 0.00         |                      |                   |
| Illness   | -0.32        | -0.76 - 0.11         | 0.1               |
| Time from arrival until examined by nurse       |              |                      |                   |
| Less than 10 minutes (reference)                | 0.00         |                      |                   |
| Ten minutes or more                             | 0.39         | -0.31 - 1.10         | 0.3               |
| Time from arrival until examined by a doctor    |              |                      |                   |
| Less than 30 minutes (reference)                | 0.00         |                      |                   |
| Between 30 to 60 minutes                        | -0.22        | -0.73 – 0.30         | 0.4               |
| More than one hour                              | <u>-0.91</u> | <u>-1.46 – -0.36</u> | <u>0.001</u>      |
| Length of time in the ED (continuous)           | 0.11         | -0.01 - 0.37         | 0.07              |
| Anxiety score on arrival to ED (continuous)     | 0.06         | -0.26 - 0.37         | 0.7               |
| Anxiety score on discharge from ED (continuous) | <u>-1.13</u> | <u>-1.55 – -0.71</u> | <u>&lt; 0.001</u> |

Results showed three key independent predictors of the parents' perceptions of satisfaction with the discharge information provided in the ED. Parents aged 31 years or older were less likely to be satisfied with the discharge information received in the ED compared with younger parents ( $\beta$  =-0.57, 95% CI -1.12, -0.03, p = 0.038). Parents who were waiting in the ED more than one hour to have their child examined by the doctor were less satisfied with the discharge information they received than parents who waited less than one hour ( $\beta$  =-0.91, 95% CI -1.46, -0.36, p = 0.001). The final independent predictor of parents perceived satisfaction with discharge information was anxiety. Specifically, parents with higher anxiety scores on discharge from the ED were likely to be less satisfied with the discharge information received than parents ( $\beta$  = -1.13, 95% CI -1.55, -0.71, p < 0.001).

#### 8.3.7 Summary of findings

Most parents reported receiving discharge information about the care of their child at home. Despite relatively good education and English language competencies of the parents responding to the survey, there were factors that influenced parents' anxiety, confidence in using the discharge information provided to them, and satisfaction with the quality of discharge information. Specific factors influencing parents' anxiety were increased waiting time, lower socio-economic backgrounds, higher educational achievement and presenting a child for the first time at an ED. Parents who were more satisfied with ED services for their child were younger than 31 years of age, waited less than one hour in the ED, and reported less anxiety when they left the ED. Similarly, high confidence in using the discharge information among parents was associated with shorter waiting times and lower anxiety at the time of their child's discharge.

## 8.4 Discussion

Stress and anxiety may prevent parents from thinking about the type of information they may need to manage their child, at home, after discharge (Han et al., 2009a). In this study, most parents left the ED with low levels of anxiety. However, higher educated parents, parents from less socially disadvantaged areas, newly arrived parents to Australia, and first time visitors to the Children's ED were more likely than their respective peers to experience higher levels of anxiety. Lower education levels were found to be associated with lower levels of anxiety. Also, a slightly higher level of anxiety was associated with parents presenting with ill children rather than injury-related concerns. Anxiety levels for parents of children with abnormal physical findings were higher than those with normal findings on presentation, which is compatible with previous findings in similar studies (Serinken et al., 2014). Specifically 341 parents of children presenting to an children's ED with an acute blunt head injury provided information on their education levels and their anxiety. Parents with lower education showed greater decreases in anxiety from presentation to discharge (Serinken et al., 2014). This study also reported parents with university qualifications were more difficult to persuade about treatment related issues (Serinken et al., 2014). Also, there is some postulation that social capital rather than income level or perhaps education can more independently predict mental health issues such as anxiety within a community (Steele, Dewa, Lin, & Lee, 2007). Although speculative, it is also possible that more educated parents knew more than less educated parents about what could be wrong with their child and thus had more to be anxious about. Similarly waiting more than 10 minutes for the triage nurse and then waiting more than one hour for treatment was associated with higher levels of parental anxiety. Furthermore, waiting time of more than one hour was associated with increased parental anxiety and

decreased satisfaction. The results from this study were diferent from a previous study (Fitzpatrick et al., 2014) which reported time spent waiting or receiving treatment in the ED did not impact on parental perceptions and overall satisfaction. Therefore, providing information regarding the expected waiting time and visible presence of a nurse in the ED waiting area (maintaining an ED nursing presence within the waiting room to ensure safety within this clinical setting, engaging and communicating with both patients and carers about ED processes, communicating expected waiting times, and providing relevant information on patient-specific health issues) might be influence parents' satisfaction with and understanding of information provided in the ED.

## 8.5 Strengths and limitations of the study

#### 8.5.1 Strengths

Multiple strategies were used to encourage parents to complete the survey. Participants' responses could be obtained remotely via mail, online, or telephone. For mail-delivered surveys, stamped, and addressed envelopes were provided. A broad range of data could be collected to support a stronger understanding of parents' perceptions of the ED discharge process, their satisfaction with the services. Data were obtained using both open and closed question formats in order to comprehensively capture parents' perceptions (Polit & Beck, 2017a). Limiting the time to complete the survey to approximately 10-15 minutes was selected to minimise the barrier of inconvenience to parents.

#### 8.5.2 Limitations

Parents' self-reporting involved more experiences and perceptions than facts; so sometimes responses may not have reflected the reality of the experience in the ED. Also, although parents' perceptions of confidence, anxiety, and satisfaction with ED experiences were included, the questions about these attributes were limited in number. However, it was critical to remain focussed on parents' total perceptions of the ED discharge experience. Giving parents only 36 to 48 hours to return the survey back may have been an inadequate amount of time, given they were providing additional care for a child with health needs. Also, some parents' recall of the discharge information given may have been challenged after 36-48 hours (Bauer et al., 2002). For example, some details of time of presentation and discharge may not always be remembered well. Restricting the survey to only parents able to read and respond

to the English language may have also biased the demographic profile of parents presenting with children to the ED. The statistical analysis strategy was primarily exploratory; a nonhypothesis driven approach was useful in generating some discussion for future research around possible explanations of parents' understanding of discharge information. This limitation arose from unknown expected response rates from parents and non-probability sampling was employed. Results therefore, require cautious interpretation.

Also given the focus on understanding of discharge information, the absence of questions directly asking parents about their health literacy is a limitation of survey. It is acknowledged that questions from an instrument such as the Test of Functional Health Literacy in Adults (TOFHLA) would have been informative. Recently, Morrison, Schapira, Hoffmann, and Brousseau (2014) described health literacy in caregivers of children using the Newest Vital Sign and the shorter version of the TOFHLA (S-TOFHLA) instruments and showed sensitivity in determining health literacy in young adults. The S-TOFHLA has been used successfully in testing the health literacy among 188 parents of paediatric patients, showing approximately 90% had adequate health literacy (Tran, Robinson, Keebler, Walker, & Wadman, 2008). However, the TOFHLA original version takes 20 minutes and the shorter version requires approximately 8 minutes. The pilot results showed the survey took parents 10 to 15 minutes to complete, with 66 questions to answer. Adding more questions was considered carefully by the researcher and her supervisory team; resulting in no additional questions being asked due feedback from participants in the pilot study believing that in its present state, time would not be a barrier to survey completion.

It would have been ideal to report a response rate to the survey and to describe how representative the uptake of the survey was among parents visiting the ED. On the advice of the ED nurse manager, the survey was left in labelled boxes in the ED treatment rooms and also close to the single exist in the ED. Staff in the ED as well as ED volunteers were asked to encourage parents to take a survey to complete at home, but the uptake on any given day was not monitored. The original number of surveys printed for distribution was 100. However, the research assistant also printed more copies, but was unable to quantify the exact number. Also, the number of parents invited to respond to complete the electronic version or the telephone version of the survey was difficult to determine. Therefore, we could not estimate the response rate.

# 8.6 Summary

This chapter explained the research design, methods, and quantitative data analysis and presented key findings of the survey about parents' experience in the ED and perceptions of the discharge information they received in the ED.

The next chapter integrates and discusses the key findings from the four studies; (i) the document analysis (ii) non-participant observation in the ED, (iii) focus group discussion with ED nurses and (iv) the survey of parents who attended the ED with their child.

# **Chapter 9: Integration and Discussion of Thesis Findings**

## 9.1 Introduction

This thesis used mixed method approaches to explore the provision of discharge information for parents to assist in managing their child's care post discharge from the ED, through the conduct of four studies (i) a Document analysis (ii) non-participant observation (iii) focus group discussions with ED nurses and (iv) a survey of parents who attended the ED with their child.

The Donabedian Model of Quality of Care provided the theoretical basis to consider the provision of discharge information in this context within the domains of structure, process, and outcomes. All studies generated findings in these domains that provide new understandings of the provision of discharge information for parents to assist in managing their child post discharge from the ED; providing rich sources of data for further analyses and integration.

The integration of findings identified several potential circumstances under which parents' understanding of discharge information would be either compromised or enhanced. These circumstances are reflected in three main themes (i) the structures that support the provision of discharge information resources for parents; (ii) the impact of waiting times; and (iii) the structures and processes that underpin the model of care in the ED. In the following sections, findings from each study, relating to these key themes are synthesised to further address the research aims and questions.

## 9.2 Integration of findings from the four studies

The mixed methods used in this thesis strongly support data integration for improved depth and breadth of data interpretation. The convergent parallel, mixed methods design planned for data to be collected concurrently and analysed separately or synergistically to support data integration. The synergies between the research questions, the studies in which they were addressed, and the mixed method design used to achieve the research aim are summarised in Table 28.

| Research questions   | Study       | Research-Methods  |
|--|-------------|---|
| 1. What protocols, procedures, guidelines,<br>and resources are used to inform and<br>support the provision of discharge<br>information in the ED? | 1           | <b>Quantitative</b> : Document analysis,<br>SMOG analyses of readability  |
| 2. What are the current practices in the provision of discharge information?   | 2<br>3      | <b>Qualitative</b> : Observations of parents<br>and staff in the ED setting, focus<br>groups with ED nurses                                       |
| 3. What are ED nurses' perceptions of factors that influence the provision of discharge information to parents?                                    | 3           | Qualitative: focus groups with ED nurses  |
| 4. What are parents' perceptions of quality<br>of discharge information received in the<br>ED?   | 2<br>3<br>4 | Qualitative: Observations of parents<br>and staff in the ED setting, focus<br>groups with ED nurses<br>Quantitative: parents' survey<br>responses |

## Table 28: Synergies between research questions, studies, and the mixed method

Integration of the findings from the four studies enable thematic analysis, with three themes emerging Table 29 presents a summary of the thematic analysis.

| Table 29: Summary o | f emerging themes f | from integrated findings |
|---------------------|---------------------|--------------------------|
|---------------------|---------------------|--------------------------|

| Study | Theme 1: The structures<br>that support the<br>provision of discharge<br>information resources<br>for parents | Theme 2: The impact of waiting times | Theme 3: The structures<br>and processes that<br>underpin the model of<br>care in the ED |
|-------|---|--------------------------------------|--|
| 1     | $\checkmark$  |                                      |  |
| 2     | $\checkmark$  | $\checkmark$                         | $\checkmark$   |
| 3     | $\checkmark$  | $\checkmark$                         | $\checkmark$   |
| 4     | $\checkmark$  | $\checkmark$                         | $\checkmark$   |

The first theme concerns the information resources provided to parents to support their child's after discharge from the ED. Findings on the information resources available to support parents in the ED that were generated from the four studies include:

• The printed and online resources available for parents in the children's ED. (Study 1, Questions 1 and 2)

- The printed resources for parents displayed in ED. (Study 2, Questions 1 and 2)
- Observations of parents' responses in the ED when they received resources (Study 2, Question 4)
- How nurses perceived the resources for parents in the ED. (Study 3, Question 3)
- The type of resources provided to parents at their child's discharge from the ED and the parents' perceived usefulness of the resources given to them. (Study 4, Question 4).

The second theme emerging from integration of findings is the impact on provision of discharge information and parents' understanding in the children's ED setting. All four studies provided relevant findings for this theme. Specifically, findings on waiting times were generated through:

- Observations of how long parents waited to see the triage nurses and consulting doctors, as well as total time in ED. (Study 2, Questions 3 and 4)
- Observations of the ED environment. (Study 2, Questions 3 and 4)
- Potential links between waiting times and parents' satisfaction, anxiety, and confidence relating to the quality of discharge information care in the ED setting. (Studies 2 and 4, Question 4)
- ED nurses' views on waiting time pressures, directly in relation to the impact on the process of providing discharge information. (Study 3, Question 3)

The final theme, emerging from the studies related to the model of care in the ED includes:

- Who was providing discharge information for parents. (Studies 2, 3, and 4, Question 2)
- How nurses and medical doctors communicated with parents in the ED setting/ provided discharge information for parents. (Study 2, Question 2)
- How nurses perceived their capacity to improve parents' understanding of discharge information in a children's ED setting. (Study 3, Question 3)

To reiterate, the research questions were answered in three main themes (i) discharge information resources for parents (ii) the impact of waiting times and (iii) the model of care in the ED.

# 9.2.1 Theme 1: The structures that support the provision of discharge information resources for parents

Parent resources to enhance understanding of discharge information can be multi-faceted and may include telehealth, written materials, online resources and parent education opportunities (Parker & Donald, 2010). In the ED, effective communication with parents will ideally assist their child's health and using multiple sources of information may improve parental understanding. In this thesis, all parents received verbal discharge information and individualised patient care advice from a doctor. However, providing additional resources for parents at children's EDs is seen as an opportunity to increase parents' understanding in child health (Al-Harthy et al., 2016; Ismail et al., 2016). Previous studies have reported that the information can be well received. This theme highlights that resources are an important factor to help parents' understanding of discharge information.

The usefulness and satisfaction of available printed resources were confirmed by several sources including parents, in their survey responses and ED nurses, in discussion groups. As such, available resources could be perceived as strongly integrated into the quality of discharge care provided in the ED. Alternatively, printed resources were discussed as being complementary in that after ED staff's verbal discussion with parents, printed resources could be taken home to support the care that parents were expected to provide to their child. Somewhat concerning was the discussion of sources of information that contradicted each other, with examples of inconsistent advice from different ED staff and conflicting advice between printed resources and what nurses described as "inexperienced medical staff".

Almost 50 resources about child-specific conditions were identified and analysed from the online and or, printed resources. These resources were available for staff to distribute to parents leaving the ED. Providing parents with printed information can both confirm and complement parents' understanding of their child's condition; and most importantly how to care for their child after discharge. Printed resources can be accessible for reading immediately and, or later. However, it was observed that parents did not look at the printed resources displayed in the ED, nor were the printed or online resources used to support verbal information provided by ED staff. The printed resources available had inconsistent formatting, difficulties with some English language expectations, and a lack of specific focus on care at home after discharge. Thus, in some circumstances, the strategy of providing additional

printed resources may not be effective in improving parents' understanding of the collective information provided in the ED setting (Taylor & Cameron, 2000).

It is hypothesised that if consistently and carefully designed printed resources were (i) always available and (ii) distributed and explained well to parents, then the quality of care following discharge may improve. Specifically, parents may provide better managed care for their child than currently exists with the piecemeal access and dissemination of existing resources to parents. Although, ED nurses' perceptions suggested a strong belief in the capacity of the existing resources to complement the verbal information provided to parents in caring for their child at home, this may not be the case. Arguably, resources were available online, but accessibility could be compromised in a number of ways. These include: uncertain online access or computer illiteracy for some parents living with significant social disadvantage or, despite having online access, some parents being unwilling to download resources. In this thesis and a previous study (Verma & Byrne, 2010), parents have been observed showing disinterest in resources when ED staff provide them. Thus, the provision of discharge information has not necessarily translated to universal access or improved understanding when parents did not appear to be interested in the resources provided.

The ED Nurses were aware that information that supports parents in caring for their child post discharge needs to avoid complex medical terms because the medical jargon may inadvertently contribute to parents' misunderstanding (Section 7.3.2.2.2 in Chapter 7). The need to think carefully about the language used with parents is supported by recent studies advocating for the use of simple language and visual aids either in written or verbal formats to improve patient understanding (Al-Harthy et al., 2016; Ismail et al., 2016). Indeed, nurse participants took some pride in the availability of the range of printed and online resources of health information for parents. Despite the majority of resources originating from the Royal Children's Hospital in Melbourne, nurses perceived the resources remained very appropriate for parents use in Queensland.

Nurses also discussed that some parents were more willing than others to read resources and ask questions. Nurses explained that even if parents did not immediately read the resources in the ED, the resources could still be useful at a more appropriate time for parents following the discharge of their child from the ED. Previous evidence supports the notion that not all parents immediately read materials provided to them in ED settings (Verma & Byrne, 2010).

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Furthermore, the observation study found that parents who received printed resources from ED staff paid negligible attention to them while they were in the ED. Nonetheless, the tendency for parents to disregard resources while they were in the ED, was unsupported in the parents' survey results; with 33 of the 39 parents (n=79) stating they had used the printed resources received.

In a children's ED setting, parents' language skills can challenge the health literacy required of parents in understanding of discharge information. Difficulties can emerge particularly for parents from non-English speaking backgrounds when there is an absence of bilingual services or staff (Samuels-Kalow et al., 2013). Although ED nurses in the focus groups discussed the value of interpreter services, they also noted that these services designed to support verbal discussion with parents from non-English speaking backgrounds, were not always available. In this ED setting, the printed resources were only available in English and the document analysis showed these resources had English language readability at, or above year 10 standards. With a relatively highly educated group of parents providing responses to the survey, parents reported the printed resources provided to them were easy to understand. However, if the parents had limited education, there could be problems with understanding the information (Tran et al., 2008).

Although resources were only available to staff online and in print, the majority of discussion by nurses, doctors, and parents centred on the printed resources directly available in the ED. Indeed, none of the ED staff was observed referring parents to online resources and only 5% of the 78 parents (n=79) responding to the survey reported receiving information about internet-based resources. This finding may link to a previous investigation into the use of online resources in low-income parents who were unable to distinguish between credible and poorer quality online information and faced additional challenges of understanding the information they accessed (Knapp, Madden, Wang, Sloyer, & Elizabeth Shenkman, 2011). Therefore, limited capacity to understand the appropriateness of online resources could have implications for some parents seeking more understanding about their child's condition and home care.

The ED nurses also discussed concerns that parents who seek their own online resources may risk obtaining inappropriate health information. Thus, parents who lack appropriate discharge

information to care for their child after leaving the ED may inadvertently obtain misleading or unhelpful advice from untrustworthy sources.

Providing multiple forms of discharge information may ensure patient safety at home (Engel et al., 2012; McCarthy et al., 2012; Samuels-Kalow, Stack, & Porter, 2013). Resources range from verbal and handwritten information, pictures, printed pamphlets, CDs, and DVDs to online sources of information (McCarthy et al., 2012). However, printed resources in addition to verbal discussion with ED staff comprised the majority of resources given to parents during the discharge of their child from the ED in this thesis.

Topics of printed and online resources available in the ED appeared appropriate for multiple childhood emergency medicine conditions. Some resources were observed to be placed on display in ED and others were available online; accessible only for staff to distribute to parents.

The resources lacked consistency in format and literacy standards. Only English language resources appeared to be available. Therefore, the resources may have been most useful to parents with strong educational background and a high level of English literacy. Observations of parents in the ED were unable to confirm that staff or parents used the resources, even though some parents put the resources in their handbag. None of the observed parents questioned the resources and none of the staff asked about the parents' understanding of the resources. Despite the lack of observations supporting parents' understanding of the printed resources provided, staff discussed with pride that these resources could help parents care for their child. Nurses also expressed satisfaction with their capacity to use verbal confirmation that parents understood any discussion about their child's care at home following discharge. The findings from the parents' survey confirmed that they found the provided to them resources appropriately helpful in caring for their child. However, links between parents' understanding of verbal and printed resources, and the subsequent care of their child at home remain unclear.

Therefore, information for parents can be useful when they are readable, up to date, and either given directly to parents or made available on display. Consistency of information and formatting of resources are potential areas for improvement within printed and online resources.

#### 9.2.2 Theme 2: The impact of waiting times

Waiting time has the potential to impact parents' understanding of discharge information because increased waiting time was associated with parents' increased anxiety as shown in this thesis. Anxiety may prevent parents from thinking about the type of information they may need to manage their child at home after discharge (Han et al., 2009). In Australia, EDs are working to keep to limits on patients' waiting times. While the times from admission to discharge observed in the ED in this thesis conformed to this policy, nurses reported that the NEAT policy negatively impacted their capacity to engage with parents. With more time, the ED nurses believed they could ask parents questions and better explain the information in the resources than other sometimes less experienced members of staff.

Specifically, the observed median waiting time for triage was 24.5 minutes (range 17 to 76 minutes) and then the time from consultation to discharge was 73.5 minutes (range 21 to 223 minutes); totalling a median waiting time from presentation to discharge in observations from this children's ED of approximately 100 minutes (1 hour, 40 minutes), well within the 4 hours of NEAT policy.

Thus, the interpretation of little time-related stress in a small snapshot of observations (just 10 cases) contrasted with discussions by ED nurses in which they reported that sometimes the pressure of time compromised their quality of care with parents and children. These contrasting findings could be attributed to the selection criteria of observing patients only with triage scores between 3 to 5. Perhaps more time-related stress occurred with more severely injured or ill children, who may have been foremost in the mind of ED nurses during the focus groups.

Also, perhaps because to the inclusion criteria relating to triage scores both the observed waiting time in the ED and for the self reported times from the survey were well within the 4 hours national recommendation from NEAT in emergency medical care and complies with goal that 90% of emergency care patients should leave the ED within 4 hours of their presentation (Sullivan et al., 2016).

However, the parent survey showed that an increased waiting time, longer than one hour, was associated with parents' increased anxiety and decreased satisfaction. Prolonged waiting times were also related to parents' lower confidence in caring for their child following discharge. It is understandable that some parents also have time limits and that even waiting less than four hours can be stressful for parents. No observations recorded the triage nurse explaining to parents how long they might need to wait in the ED, nor were there any observations of other ED staff explaining expected times for consultation. Not knowing how long they were expected to wait may have increased parents' anxiety. As such, leaving the ED with anxiety may also affect parents' understanding and management of their child's care at home (Curran et al., 2017).

Therefore, the impact of time, particularly time pressures on ED nurses may have been limited at critically important times such as when parents were anxious, which in turn, may lead to a lack of confidence in caring for their child. Achieving the NEAT targets can make discharge planning and quality of care difficult, particularly when overcrowding imposes additional time pressures in the ED.

Some anomolies in the data around waiting times are worth noting. Observations of waiting times showed relatively short periods of waiting and limited perceptions of parents anxiety. But observation numbers were low and restricted to less-severely injured or ill children. Nurses believed less time restrictions could provide a higher quality of patient care, yet parents showed associations between longer waiting times and increased anxiety. If parents have to wait longer, then greater care around communicating what is happening at that time, is required to strategically reduce parents' anxiety. Also, the urgency of a child's condition can change while waiting. Ideally, parents with children whose conditions deteriorate following triage assessment should be re-assessed immediately to reduce the waiting time and simultanteously reduce parents' anxiety related to their child's condition in the ED. It is possible that triage nurses could include this type of information to parents at their child's initial assessment.

#### 9.2.3 Theme 3: The structures and processes that underpin the model of care in the ED

The model of care in the ED and roles of the staff can impact on parents' experiences of receiving discharge and information and subsequently their understanding. The model of care at the study site is one in which the medical doctors provided verbal discharge information to all parents. However, nurses did not play a role in providing discharge information to parents. This model seems to limit opportunities for nurses to engage with parents in the ED or at

discharge. However, selected comments from ED nurses in this thesis showed their perceptions of being particularly helpful in assisting parents understand information about their child's condition and treatment.

The quality of care in the ED settings can depend on patients receiving appropriate written and verbal instructions (Gozdzialski et al., 2012). Incomplete health communication can compromise patient care (Samuels-Kalow et al., 2012, 2013) as communication is a key factor in patient understanding (International Federation for Emergency Medicine, 2012). ED nurses can work under challenging conditions. Overcrowding in EDs arises when the staffing capability of the department is surpassed by the number patients either waiting for, or undergoing assessment and treatment or waiting to leave (Curran, 2014). Communication is an important skill of specialist ED nurses (Ak et al., 2011). In this thesis, nurses took pride in their capacity to help parents understand more about their child's condition, provide accurate information, and suggest appropriate care for this child at home.

The observation study confirmed many opportunities for nurses to interact with families and support parents' understanding of their child's progression through the ED; including opportunities to discuss how to manage their child's care at home. The role of the CIN can have the following priorities: maintaining an ED nursing presence within the waiting room to ensure safety within this clinical setting, engaging, and communicating with both patients and carers about ED processes, expected waiting times, and ideally providing relevant information on patient-specific health issues (Emergency Care Institute New South Wales, 2017).

However, findings revealed that few interactions between ED nurses and parents occurred. Parents who were observed waiting for their child's treatment had limited interaction with ED nurses and asked few questions of medical ED staff. Observations showed that provision of discharge information was the responsibility of the doctor rather than the nurse; yet provision of information could have commenced at triage and continued throughout the treatment processes. Previous evidence shows a nurse's role of communication within the waiting room is recommended to decrease waiting times and contributed to risk mitigation. The nurse in this role provides care for patients in the ED waiting room after triage, for example providing analgesia or commencing investigations, detect clinical deterioration and improve communication between patients, parents, and ED staff (Innes, Jackson, Plummer, & Elliott, 2017). Observations also showed that interaction between doctors and nurses with parents was more likely to be about the diagnosis and treatment being provided within the ED, rather than planning for the child's discharge from the ED.

Findings from the parents' survey confirmed that 32 (53%) of 60 parents responding to the question received their verbal discharge information from doctors and only 9 (15%) received information from a nurse. Previous evidence shows that staff communication during discharge processes can amount to less than four minutes of interaction with patients (Vashi & Rhodes, 2011). Further, observations of medical staff have demonstrated that physicians spend approximately 50% of their time in indirect patient care; including talking on the telephone, completing charts, walking in the ED, and communicating with other care providers (Vashi & Rhodes, 2011). Findings from the observation study also confirmed that some ED staff spent their time on completing charts and communicating with other care providers more than providing communication with parents that included discharge information. Yet, nurses from the focus groups perceived one of their professional strengths to lie in helping parents understand key information about managing their child's health.

However, some social desirability from ED nurses' knowledge of professional standards may also have influenced the focus group discussion. In Australia, the Standard 3 of the Guidelines for Professional Practices by registered nurses refers to the need for registered nurses to maintain the 'capability of practice' (Nursing and Midwifery Board of Australia, 2016). More specifically, the guidelines state clearly that registered nurses collectively have responsibilities to provide information and education; enabling people to make decisions and take healthrelated action. Thus, the possibility of knowing what is currently expected in clinical practices of registered nurses may have led to some bias of social desirability in their discussion.

The nurses reported that they valued the opportunity to check parents' understanding of information, but during the observation study, it was the ED doctors rather than nurses asking these types of questions of parents. ED nurses seemed to wait for a need to arise perhaps by parents or by medical staff needing assistance before more directly communicating with parents. Nurses from the focus groups perceived that it was the responsibility of doctors to provide all of the health consultation in the children's ED. Previous research has found that nurses often misunderstand their place in the discharge planning process and they are confused about the process of discharge planning. As such, nurses can perceive they are not in a position to be able to join in discharge planning and they also often focus on immediate

treatment needs and preparation of the patient for discharge, rather than focusing on postdischarge care needs (Han, Barnard, & Chapman, 2009b).

Nurses in the focus group study discussed that they consistently asked parents if they had any questions, yet observations noted that only three of ten parents had questions for the doctor. However, ED nurses were not observed seeking confirmation from parents of their understanding of the information provided by the doctor. Nurses discussed their perceptions of parents' reluctance to ask doctors questions compared with parents' willingness to ask nurses questions. Nurses in the focus groups discussed that their perceived competence came from knowledge and experience in caring for children and families, as well as knowing the resources and current treatment practices for children attending the ED. Approximately 70% of parents (n = 79) responding to the survey acknowledged receiving advice about their child's care at home. However, further analyses from 55 parents showed nurses provided only 24% of this advice. As such, some disconnection within this mostly medical model of care was apparent between nurses' perceptions of strong communication and observations of few interactions occurring among parents, doctors, and nurses in the children's ED.

Moreover, nurses in the focus group study expressed frustration that other staff provided inconsistent or inaccurate information to parents; inconsistencies attributed to a lack of experience in children's ED. Nurses' were concerned that parents were sometimes not afforded the best opportunities to understand their child's condition and appropriately care for their child at home.

In contrast, enablers for good care were noted in the current thesis. Specifically, nurses also discussed the pride of being able to follow up some special patients such as refugee children after their discharge to ensure parents had understood the information provided to them.

Despite the absence of discharge policies or guidelines for nurses to follow, nurses knew the printed resources well and believed they had the sufficient experience to deal with parents' concerns and questions about their child's conditions after discharge. It is possible that within this mostly medical model of care, that the role of nurses within a children's ED setting could extend to further assist parents' understanding of discharge information.

## 9.3 Summary

This chapter discussed whether and how the research questions were answered, and how the emerging themes related to the previous literature. The key themes identified to impact on parents' understanding of discharge information were (i) the structures that support the provision of discharge information resources for parents; (ii) the impact of waiting times; and (iii) the structures and processes that underpin the model of care in the ED.

The final chapter presents the overall conclusions; highlighting strengths and limitations of this thesis and makes recommendations for future research, practice, and staff education.

# **Chapter 10: Conclusions**

### **10.1 Introduction**

This thesis was designed to explore the provision of discharge information for parents to assist in managing their child's care post discharge. This final chapter presents conclusions on the thesis including the contribution of the thesis to the area of research, as well as recommendations for policy, ED nurse practice, and further research. The chapter ends with a review of the strengths and limitations that lead into a final summation of the thesis.

## **10.2** Conclusions

This thesis provides rare insights into parents' understanding of discharge information in a children's ED setting. Perspectives of ED nurses and parents relating to discharge information practice are limited in Australian research and previous studies have reported only single issues and methods (Al-Harthy et al., 2016; Curran et al., 2016; Nibhanipudi et al., 2015). Only one previous study in Australia (Considine & Brennan, 2007) has addressed improving discharge information for parents of children leaving an ED. Specifically, the Australian researchers offered an educational intervention for ED nurses to improve both the amount and quality of discharge advice for parents of febrile children. In the current thesis, for the first time, an exploration of factors impacting parents' understanding of discharge information is presented within the context of the Donabedian Model of Quality of Care. Specifically, the model provided a lens for exploring structure, processes, and outcomes that can influence parents' understanding and consequently the care of their child. Through this model, improvements in the structure of care should lead to enhancements in ED processes that should in turn advance patient/parents' understanding of discharge information to care for their child at home.

Findings from the structural analysis introduced the key aspects of structure impacting on provision and understanding of discharge information. First, a document analysis framework for exploring printed information for parents was developed to improve knowledge about the adequacy of resources for parents' understanding of their child's care at discharge from a children's ED. The resources for parents, obtained from a relatively new children's ED, offered opportunities for parents to learn more about their child's condition from 16 pamphlets openly displayed for parents to take. Indeed, the more comprehensive document analysis revealed the availability of 46 resources relevant to children's emergency conditions that could be used to assist parents' understanding of their child's condition and care during discharge processes and post discharge. However, the most critical omission from the document analysis findings was the absence of a local discharge policy providing guidelines for staff to assist parents in their child's care at home.

There were limitations in the consistency and accuracy of verbal information being provided to parents by all ED staff. The lack of credibility of some online health information readily available to parents was also a source of concern to ED nurses. The document analysis also showed that the high literacy demands of the printed resources may be difficult for some parents to understand and may confuse rather than support, parents' understanding of information provided to them at discharge, for their child's care at home.

Furthermore, processes that were observed in the ED showed parents paying scant regard to the openly displayed resources and staff infrequently providing printed resources to support parents with discharge information. Nonetheless, all parents reported receiving verbal discharge information; mostly from doctors rather than nurses. There is a potential for ED nurses to greatly assist with parents' understanding of discharge information. However, some ED nurses perceived that the demands of NEAT policies around waiting times did not always provide opportunities to engage more comprehensively with parents. In contrast, observations of waiting times and potential sources of stress in ED staff did not support any tension around NEAT guidelines. But, this may be attributed to observations restricting participation to children receiving triage scores of three to five.

The third domain of the Donabedian Model of Quality of Care involves outcomes or consequences of ED services and experiences. Outcomes of parents' satisfaction, anxiety, and confidence following ED experiences with their child were determined from the results of the parents' survey. Findings of the survey showed that waiting times in the ED remained a source of anxiety to some, but not all parents; which was also supported by concerns of nurses in the focus groups. Yet, other findings from the survey were more positive. Most parents reported satisfaction with the quality of care they received in the ED. Satisfaction prevailed despite some contradictory concerns including (i) selected findings from the observation study (such as minimal engagement with parents, poor uptake of resources and little regard to resources provided to parents at discharge), (ii) some ED nurses' discussions on inconsistent

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information, time pressures, and inaccuracy of information provided to parents leaving the ED and (iii) evidence of sub-optimal aspects of printed resources. Moreover, parents expressed confidence in understanding what they needed to do in caring for their child at home. Subsequently, parents perceived the discharge information provided from the ED was easy to understand and useful. Overall, parents' responses in the survey demonstrated positive outcomes. However, the responding group of parents were particularly well educated, and all spoke and read the English language fluently.

#### **10.3 Recommendations**

Several recommendations for (i) policy-makers, (ii) practitioners working in EDs and (iii) future research are supported by the findings of this thesis.

#### 10.3.1 Recommendations for policy makers

First, at policy level, structures for ED staff need to be supported by standardized local and national discharge policies and procedures. Policy and procedures on discharge planning and provision of discharge information including expected standards for health information for parents could inform and guide clinical practice. Policies can include how all ED staff can work collaboratively to ensure parents leave children's ED with the strongest possible understanding of how to care for their child at home. Standardized policies could include how to streamline, update, and ensure discharge information is both consistent and accurate for ED practitioners. Policies can include training new graduate ED staff, time management policies and practices, a strong communication strategy with an emphasis on discharge information, and planning of discharge information for parents in the ED that starts at presentation and ends at discharge. Without these policies, models for quality of care will remain incomplete in this children's ED setting. Also, ongoing review the impact of the implementation NEAT Policy targets and standardised practices should be considered.

Future recommendations include a review of all printed resources for parents so that some parents with low reading capacity (less than level 10 of schooling) will not have difficulty understanding, remembering, and enacting key aspects of the quality of discharge information provided to them in these resources. For consistency, all resources could have the same structure; ensuring that 'care at home' sections are highlighted to parents by ED staff on discharge. Where appropriate, discharge information resources could also more consistently provide links to community resources such as the Asthma Foundation and community providers such as paediatric dietitians for reflux and constipation. The currency of all forms of discharge information requires regular review. Given that information on discharge from ED has been linked to improved parent recall of important advice, some effort into streamlining resources (verbal, written, on-line and other visual aids) appears warranted (Al-Harthy et al., 2016; Ismail et al., 2016). The availability of child ED resources in nationally (or locally) relevant languages other than English, also supports policies seeking inclusive health practices and outcomes.

#### **10.3.2 Recommendations for ED Nursing Practice**

This research found that parents' perceptions of discharge information and self-rated understanding may be more optimistic than direct evaluations of practice from the observed study. More interaction with experienced nurses in the ED may have assisted more than the 70% of parents who reported receiving advice for their child's care at discharge and or, ensured that this advice was particularly easy to understand. ED nursing practices around the provision of discharge information could start at triage, continue during waiting times, encouraging parents to return to the triage station if their child's condition deteriorates, and most importantly include quality control checks for understanding prior to parents leaving the ED with their child (Kourkouta & Papathanasiou, 2014). Therefore, the recommendation is to incorporate the communication skills and expertise of ED nurses in discharge planning to assist in ensuring parents understand the information they receive about their child's care at home. In addition to the recommended roles of the triage nurse, other nurses within the waiting room could continue communication and education for patients in the ED after triage (Innes et al., 2017). There is a possibility of an increased role of the ED nurses in discharging children with higher triage scales (three to five) as these triage categories could open educational opportunities for child's health promotion; without a higher need for the communication to come from an ED doctor.

#### 10.3.3 Recommendations for future research

The recommendation for local collaborative policies around discharge information requires an extensive review of literature, related-policies, and a comprehensive understanding of the strengths and limitations of existing practitioners. Research is also required to inform policy

development on the nature and modality of health information most appropriate for parents. For children's emergency care, practitioners could also be asked questions about related structural, resourcing, and professional collaborations within the ED setting. Outcomes of revised policies could also be followed up by questionnaires completed by parents and all ED staff.

Future research for practitioners is required to understand more about the knowledge, frequency of updates, and consistency of information provided by ED staff. Trials of best practice models could incorporate more frequent engagement of ED nurses with parents around discharge information. This new model of care in the children's ED setting could extend to families with particularly high needs; such as dealing with parents for whom English is not a first language and or parents with high anxiety issues, perhaps related to prolonged waiting times in the ED. Thus, identifying parents at risk of limited understanding of discharge information could improve current practice. Trials of best practice models with more engagement of ED nurses in discharge processes involving the provision of discharge information could be included in future research plans.

Furthermore, future studies could investigate the type of resources available for parents from the ED setting. Specifically, investigations could include greater scrutiny of content, design, and readability of health information. This research could also explore how parents perceive and respond to the information available in these resources. E-health resources for children's emergency settings also require further investigation. Another important aspect of this research would be to test the efficacy of information resources for a diversity of parents in the ED setting.

In summary, it may be helpful to explore strategies that encourage nurses as well as doctors to consistently provide quality discharge information and practices. Overall, nurses may have more time with patients than doctors in the ED setting. Therefore, providing nurses with guidelines and recommendations to assess parents' needs and distribute appropriate resources to parents may also improve the quality of discharge care for parents of children leaving an ED.

## **10.4 Strengths and limitations**

The following section provides the information about the strengths and limitations of this collection of thesis. This type of discourse aims to facilitate critical comments about the credibility of the results and overall conclusions drawn from the thesis.

### 10.4.1 Strengths

Stringent quality measures were consistently applied to establish credibility and trustworthiness of findings as outlined in the methodology chapter (Chapter 4). These included the adherence to the research protocol, the use of a research diary, and transcription of audiotapes that were recorded digitally and transcribed verbatim by the researcher and confirmed by the research team. Also, discussion of findings occurred regularly with supervisors, intensive data integration strategies were applied, and comparisons were consistently made with the Donabedian theoretical framework.

Another important strength of this thesis was the inclusion of both ED nurses and parents' perceptions of discharge information surrounding their experiences in the children's ED. These participants are central to the care of children who present to the ED. Also, the research included observations of the other health professionals interacting with the parents such as medical doctors, physiotherapists, and X-ray radiographers. More specifically, this thesis provided insights from ED nurses who work in the children's ED settings, observations of structures in children's ED settings and how they appeared to support parents, observations of parents' engagement with staff in the ED setting and extensive responses from parents about their perceptions of the quality of discharge information care.

A further strength of the thesis lies in the multiple approaches employed to capture this insight into discharge information for parents needing to care for their child at home following a visit to a children's ED. Approaches included the use of a documents analysis, observations, focus group discussion, and a survey. These approaches enabled an in-depth analysis of each separate data collection as well as enriching an understanding of how interactions occurred among and within the structure, processes, and outcomes relating to staff and parents in an ED setting. Qualitative data from the observation and focus group studies provided comprehensive profiles of how parents were engaged throughout their experiences in the ED setting and how nurses perceived their support for parents in the ED. Qualitative data also provided the rich basis on which concepts around barriers and enablers to parents' understanding were described. Patterns and trends in parents' perceptions of their experience in the children's ED emerged from the quantitative survey. Results from the 79 parents who responded to the survey were also useful in providing insight into relationships from inferential statistical analyses; specifically using generalized estimating equations (GEEs) that explored correlations between parents' demographic profiles and their perceived experiences in the ED setting. Therefore, the final collective strength in this thesis is the mixed methods of qualitative and quantitative analyses that supported a depth and breadth of findings.

#### 10.4.2 Limitations

This thesis is not without limitations. The single-centred setting may not apply more broadly in Australia or elsewhere in the world. Within the observation study, parents' anxiety and satisfaction were reported via the researcher's perceptions, which may involve some bias. Observations were limited and perhaps biased by the times made available to the researcher to observe. The richness of focus group data may have been compromised by small attendance numbers in each group. However, fitting focus groups in around busy schedules and the voluntary nature of the research precluded larger participation rates. Other staff in the ED were minimally included through observations of their engagement with parents in the ED, but only nurses were more directly engaged in verbally providing insights into their perceptions of parents' understanding of discharge information. Parent recruitment was limited to those with strong English language speaking backgrounds, which again may have introduced some sampling bias. Without additional resources for interpreters and translation, it was difficult to extend the inclusion criteria to parents of non-English speaking backgrounds. Also, parents' surveys were offered to parents intermittently over a 12-month period, yet only 79 responses were available for analyses and it was not possible to determine response rates. Therefore, there may be some selection bias among parents and staff that should be acknowledged in the findings of this thesis. However, non-response bias of parents, other staff and nurses who did not participate in the research is particularly difficult to quantify.
### **10.5 Conclusion**

This thesis has comprehensively investigated the structures, processes and outcomes relating to parents' understanding of discharge information in an ED setting. Strategies and future research to improve the provision of discharge information were outlined. Ultimately, the findings in this research and future endeavours can be used to help parents experience a high quality of care for their child following discharge from the ED.

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# Appendices

## Appendix 1 Summary of key papers used in the literature review

#### Summary of key papers for paediatric patients used in the literature review

| Title         | Author | Objective      | Result                          | Methods  | Setting             | Sample               |
|---------------|--------|----------------|---------------------------------|--|---------------------|----------------------|
|               | /Date  | /Aim           |                                 |  |                     |                      |
| 1. Do         | Waism  | To determine   | Full understanding was found in | Parents were requested at discharge to           | At the ED of an     | 195 parents of       |
| parents       | an et  | parents'       | 72% and 78% of the parents at   | complete a 13 items questionnaire distributed    | urban tertiary care | children who were    |
| understand    | al.,   | understanding  | the respective centers for the  | by the principal investigator at different times | paediatric facility | discharged home      |
| emergency     | 2003   | of ED          | diagnosis, and in 82% and87%    | of the day.                                      | and a suburban      | after ED.            |
| department    |        | discharge      | for the treatment instructions. |  | level II general    |                      |
| discharge     |        | instructions   | The most contributory factor to | The diagnosis criteria included understanding    | hospital in Israel. |                      |
| instructions? |        | and factors    | lack of understanding was staff | of the nature of the medical problem (e.g.       |                     |                      |
| A Survey      |        | that may       | use of medical terminology.     | infection, allergic reaction, or trauma), its    |                     |                      |
| Analysis      |        | affect it      |                                 | etiology (viral or bacterial for infection, or   |                     |                      |
|               |        |                |                                 | mechanism of injury for trauma), and or          |                     |                      |
|               |        |                |                                 | affected; the treatment instructions criteria    |                     |                      |
|               |        |                |                                 | included understanding of the nature of the      |                     |                      |
|               |        |                |                                 | treatment recommended (antibiotics,              |                     |                      |
|               |        |                |                                 | symptomatic, or bronchodilator).                 |                     |                      |
|               |        |                |                                 |  |                     |                      |
|               |        |                |                                 | Full understanding for each category was         |                     |                      |
|               |        |                |                                 | defined as a score of 3 (out of 3), partial      |                     |                      |
|               |        |                |                                 | understanding as a score of 2, and poor          |                     |                      |
|               |        |                |                                 | understanding as 1.                              |                     |                      |
| 2. Role of    | Waism  | To investigate | Full understanding of the       | At discharge by the physician, all were given a  | An urban tertiary   | A convenience        |
| diagnosis-    | an et  | the            | diagnosis was noted in 73% of   | disease-specific information sheet to            | care paediatric     | sample of 95 parents |
| specific      | al.,   | contribution   | the parents who received the    | accompany the physician's discharge              | facility in Israel  | of children          |
| information   | 2005   | of diagnosis-  | information sheet and 72% of    | instructions. Thereafter, the parents were       |                     | discharged home      |
| sheets in     |        | specific       | the parents in our previous     | asked to complete the same 13-item               |                     | from the emergency   |
| parents'      |        | information    | study who did not.              | questionnaire used in our previous study,        |                     | department           |
| understandin  |        | sheets at      | Corresponding rates of          | covering demographics, level of anxiety, and     |                     |                      |
| g of          |        | discharge      | understanding of the treatment  | quality of physician's explanation, in addition  |                     |                      |

| omorgonau     |         | from the         | instructions were 0.2% and 0.2%          | to a description in their own words, of their     |                      |                      |
|---------------|---------|------------------|--|---|----------------------|----------------------|
| entergency    |         |                  | An statistical analysis the              | to a description, in their own words, or their    |                      |                      |
| department    |         | emergency        | On statistical analysis, the             | child s diagnosis and treatment instruction       |                      |                      |
| discharge     |         | department       | distribution of the diagnosis-           | and an indication of their preferred auxiliary    |                      |                      |
| instructions  |         | on parental      | specific information sheet               | method of delivery of information                 |                      |                      |
|               |         | understanding    | significantly improved parental          |   |                      |                      |
|               |         | of the           | understanding of the treatment           |   |                      |                      |
|               |         | discharge        | instructions ( <i>P</i> =0.025), but not |   |                      |                      |
|               |         | instructions     | of the diagnosis ( <i>P</i> =0.54).      |   |                      |                      |
| 3. Drug       | Kaestli | To determine     | Parents and patients expressed           | 7 week prospective design – gathering             | The PED of a         | 53 parents and 9     |
| information   | et.al., | parents' and     | the need to see more                     | expectations in a two-section standardised        | tertiary             | patients over 12     |
| at paediatric | 2014    | patients'        | information on prescribed                | questionnaire including 24 questions using a      | centre (Geneva       | completed a          |
| emergency     |         | expectations     | drugs relating to: delays                | categorical rating (Likert scale from 1 to 6: 1 = | University Hospital) | questionnaire on     |
| department    |         | regarding        | between subsequent doses if              | useless, to $6 = very$ useful) developed by a     |                      | expectations of drug |
| discharge:    |         | drug             | not effective: regular or "on            | multidisciplinary staff team (2 ED doctors and    |                      | information          |
| what are      |         | information.     | demand" dosage.                          | 2 hospital pharmacists).                          |                      |                      |
| parents'/pati |         |                  | discontinuation of treatment             |   |                      |                      |
| ents'         |         |                  | relating to the child's response.        |   |                      |                      |
| expectations  |         |                  | acute symptoms that require              |   |                      |                      |
| 2             |         |                  | emergency care meal-related              |   |                      |                      |
| ·             |         |                  | timing of administration side            |   |                      |                      |
|               |         |                  | offorts of drugs                         |   |                      |                      |
| 4. Davia      | Kaaatii | To commons       | A total of 125 potients were             | Decision estimate (0, 10 years) with Franch       | The ED of the        | 125 modiatria        |
| 4. Drug       | Kaestii | To compare       | A total of 125 patients were             | Paediatric patients (U=16 years) with French-     | The ED of the        | 125 pediatric        |
| Information   | et.al., | parentai         | recruited (phase A: 56; phase B:         | speaking parents discharged from ED of the        | pediatric            | patients aged 0–16   |
| leaflets      | 2016    | correct          | 69). Drug information leaflets           | paediatric department before (phase A) and        | department (125      | years with French-   |
| improve       |         | knowledge of     | were given to 63/69 ED patients          | after (phase B) intervention.                     | beds) of Geneva      | speaking             |
| parental      |         | treatment        | (91%), covering 96/138                   |   | University Hospitals | parents admitted to  |
| knowledge     |         | with and         | prescribed                               | Intervention Supply and brief comment of          | in Switzerland       | the ED and           |
| of their      |         | without          | drugs (70%). Parental                    | drug information leaflets focusing on specific    |                      | discharged with at   |
| child's       |         | supply of        | knowledge was significantly              | information not available in official drugs       |                      | least one prescribed |
| treatment at  |         | customized       | improved in phase B (dose:               | information documents.                            |                      | medication during    |
| paediatric    |         | drug             | 62.3% to 89.1%; frequency:               |   |                      | the pharmacist's     |
| emergency     |         | information      | 57.9% to 85.5%; duration:                | Follow-up Semi-structured phone interview         |                      | working hours        |
| department    |         | leaflets for the | 34.2% to 66.7%; indication:              | within 72 hr after discharge to evaluate the      |                      | (08:00–17:00,        |
| discharge     |         | 10 most          | 70.2% to 94.9%; p<0.0001).               | percentage of parents with correct                |                      | weekdays, during the |
|               |         | commonly         | Phase B and collection of drugs          | knowledge of dose, frequency, duration and        |                      | data collection      |
|               |         |                  |  | indication of drugs. Multivariate analysis to     |                      |                      |

|  |                           | prescribed<br>drugs.  | at usual pharmacy were<br>significant<br>factors associated with correct<br>knowledge.   | identify factors associated with correct<br>knowledge (phases A/B, drugs collection at<br>usual pharmacy, drugs categories).  |  | periods) were<br>enrolled.   |
|--|---------------------------|---|--|---|--|--|
| 5. Essential<br>Content for<br>Discharge<br>Instructions<br>in Pediatric<br>Emergency<br>Care<br>A Delphi<br>Study | Curran<br>et.al.,<br>2016 | To identify the<br>5 most<br>essential<br>discharge<br>instruction<br>content<br>elements that<br>should be<br>communicate<br>d to all<br>caregivers of<br>children who<br>present to the<br>emergency<br>department<br>(ED) with<br>asthma,<br>vomiting/diarr<br>hea,<br>abdominal<br>pain, fever,<br>minor head<br>injury, or<br>bronchiolitis. | A total of 37 emergency<br>clinicians completed all 4<br>rounds of the Delphi.<br>Consensus for the final 30<br>content items ranged from<br>51.4% to 100%. Items<br>pertaining to<br>diarrhoea/vomiting, abdominal<br>pain, fever, and bronchiolitis<br>obtained relatively high levels<br>of consensus for all top 5 items.<br>The majority of items (n = 19<br>[63.3%]) that reached<br>consensus across the illness<br>presentations were associated<br>with instructions intended to<br>educate caregivers on instances<br>when they should return to the<br>ED department. | Using a modified Delphi technique, 6 lists<br>were distributed to a panel of experts from<br>EDs across Canada using a secure online<br>survey tool with the goal of achieving the 5<br>most essential discharge instruction<br>elements.         | Pediatric<br>emergency<br>clinicians from 15<br>EDs<br>across Canada.    | 37 medical and<br>nursing leaders at<br>each ED site with a<br>goal of recruiting a<br>total of 20 to 25<br>physicians and 20 to<br>25 registered nurses<br>from across the 15<br>sites. Panel experts<br>were required to<br>have at least 8 years<br>of experience<br>working in an ED with<br>pediatric patients. |
| 6.<br>Emergency<br>department<br>visits for<br>children with<br>acute<br>asthma:                                   | Camp<br>et.al,20<br>14    | The extent to<br>which parents<br>of children<br>with asthma<br>implement<br>recommendat<br>ions provided   | Thirty-two percent of 148<br>children were not on inhaled<br>corticosteroids prior to their ED<br>visit. Eighty percent of parents<br>identified upper respiratory<br>tract infections (URTIs) as the  | A prospective study. Parents were asked<br>questions on asthma triggers, ED care<br>(including education and discharge<br>recommendations), and asthma management<br>strategies used at home shortly after the ED<br>visit and again at 6 months. | The ED of tertiary<br>care pediatric<br>hospital in British<br>Columbia. | 148 children with a<br>previous diagnosis of<br>asthma who visited<br>the ED for an asthma<br>exacerbation<br>and were 0.5 to 15<br>years of age.  |

| discharge     | by the ED | primary trigger for their child's |  |  |
|---------------|-----------|-----------------------------------|--|--|
| instructions. | staff.    | asthma.                           |  |  |
| parental      |           | -No parent received or            |  |  |
| plans, and    |           | implemented any specific          |  |  |
| follow-       |           | asthma strategies to reduce the   |  |  |
| through of    |           | impact of URTIs: 82% of parents   |  |  |
| care—a        |           | did not receive any printed       |  |  |
| prospective   |           | asthma education materials.       |  |  |
| study         |           | - Most (66%) parents received     |  |  |
| ,             |           | verbal instructions on how to     |  |  |
|               |           | manage their child's future       |  |  |
|               |           | asthma exacerbations.             |  |  |
|               |           | - Of those, one-third of families |  |  |
|               |           | were told to return to the ED.    |  |  |
|               |           | - Parents were rarely advised to  |  |  |
|               |           | bring their child to their family |  |  |
|               |           | doctor in the event of a future   |  |  |
|               |           | exacerbation.                     |  |  |
|               |           | -At 6 months, parents             |  |  |
|               |           | continued to use the ED           |  |  |
|               |           | services for asthma               |  |  |
|               |           | exacerbations in their children,  |  |  |
|               |           | despite reporting feeling         |  |  |
|               |           | confident in managing their       |  |  |
|               |           | child's asthma.                   |  |  |
|               |           |                                   |  |  |

| 7. A Study To | Nibhani | to determine    | The survey results show that      | The instructions were explained to the 500    | A Pediatric        | 500 parents        |
|---------------|---------|-----------------|-----------------------------------|---|--------------------|--------------------|
| Determine     | pudi    | post discharge  | the majority favour disease       | parents both verbally as well as in a written | Emergency Room at  | volunteered to     |
| The Post-     | et.al., | instructions,   | specific discharge                | format in their language of preference with   | the Metropolitan   | participate in the |
| Discharge     | 2015    | follow up by    | instructions DSD (410/500) over   | the understanding that they will follow       | Hospital Center in | study              |
| Instructions  |         | Spanish         | generic discharge GD              | instructions. The parents scored the survey   | the United states  |                    |
| Follow-Up By  |         | speaking        | instructions (44/500).            | for both generic as well as disease specific  |                    |                    |
| Spanish       |         | parents with    | However, the results of the post  | discharge instructions as per their choice,   |                    |                    |
| Speaking      |         | regards to      | telephone call observation        | using the scoring system. All the parents,    |                    |                    |
| Parents In    |         | discharge       | were different. After 2 to 5      | 44/500 in the generic group and 410/500 in    |                    |                    |
| Paediatric    |         | instructions    | days, parents (38/44 of GD and    | the disease specific group, were contacted by |                    |                    |
| Emergency     |         | for a disease   | 350/410 of DSD) were able to      | telephone 2 to 5 days after discharge from    |                    |                    |
| Room          |         | specific versus | be contacted by phone, and        | the ER to evaluate 5 categories namely        |                    |                    |
|               |         | generic         | had the following positive        | diagnosis, clinical information, medication   |                    |                    |
|               |         | discharge       | responses in all 5 categories.    | dosages, return to ER, and finally to keep up |                    |                    |
|               |         | from the        | However, the results of post      | the follow up appointment                     |                    |                    |
|               |         | pediatric       | telephone call observation        |   |                    |                    |
|               |         | emergency       | were different.                   |   |                    |                    |
|               |         | room.           | 1. Diagnosis (condition of the    |   |                    |                    |
|               |         |                 | child) and how the child's        |   |                    |                    |
|               |         |                 | condition is improving: GD-       |   |                    |                    |
|               |         |                 | 36/38 and DSD 340/350             |   |                    |                    |
|               |         |                 | 2. Clinical information: GD30/38  |   |                    |                    |
|               |         |                 | and DSD 287/350.                  |   |                    |                    |
|               |         |                 | 3. Medications prescribed,        |   |                    |                    |
|               |         |                 | frequency & dosages: GD35/38      |   |                    |                    |
|               |         |                 | & DSD 340/350                     |   |                    |                    |
|               |         |                 | 4. Return to the ER when          |   |                    |                    |
|               |         |                 | condition worsen: GD 35/38 &      |   |                    |                    |
|               |         |                 | DSD 340/350                       |   |                    |                    |
|               |         |                 | 5. Follow up of appointment:      |   |                    |                    |
|               |         |                 | GD 20/38 & DSD 182/350 Both       |   |                    |                    |
|               |         |                 | the positive and negative         |   |                    |                    |
|               |         |                 | responses in all 5 categories     |   |                    |                    |
|               |         |                 | were compared and the             |   |                    |                    |
|               |         |                 | unpaired t-test result showed     |   |                    |                    |
|               |         |                 | statistically significant         |   |                    |                    |
|               |         |                 | differences with a two- tailed p- |   |                    |                    |

|  |                                   |  | value of 0.0032 Spanish<br>speaking - parents have the<br>same preference both for<br>specific disease discharge<br>instructions as well as generic<br>discharge instructions and most<br>of the instructions were<br>followed well.   |  |   |   |
|--|-----------------------------------|--|--|--|---|---|
| 8. Efficacy of<br>patient<br>discharge<br>instructions:<br>A pointer<br>toward<br>caregiver<br>friendly<br>communicati<br>on methods<br>from<br>paediatric<br>emergency<br>personnel | Al-<br>Harthy,<br>et.al.,<br>2015 | To evaluate<br>the efficacy of<br>discharge<br>instructions<br>for post-<br>pediatrics<br>emergency<br>visit | -Verbal only, written only, or<br>both verbal and written<br>discharge instructions were<br>providedWritten and verbal<br>instructions, when provided<br>together, were the most<br>effective modes of<br>communication with caregivers.<br>- The majority of the<br>respondents were<br>unaware of the follow-up plan<br>(64.16%), unable to identify<br>problems that would<br>necessitate a follow-up<br>(58.96%),<br>and unable to identify the signs<br>and symptoms that would<br>require a revisit (62.43%)<br>irrespective of the mode of<br>instruction. However, more<br>attention is necessary because<br>of the 34.68% of the subjects<br>who left the hospital without<br>discharge instructions. – | This observational cross-sectional survey<br>conducted in the Department of Pediatric<br>Emergency, included 173 literate adult<br>caregivers who had given their consent.<br>Those who had been on admission earlier<br>and been discharged from the emergency<br>department were excluded.<br>- Demographic data and variables like<br>knowledge of medicine and treatment<br>follow-up were collected using a structured<br>questionnaire and analyzed using SPSS<br>version 16 | The department of<br>Pediatric<br>Emergency at King<br>Abdul Aziz Medical<br>City, Riyadh,<br>Kingdom of Saudi<br>Arabia. | 173 parents/<br>caregivers of patients<br>discharged from<br>pediatric emergency. |

|   |                        |  | <ul> <li>-Instructions given both verbally<br/>and in writing were observed to<br/>be more effective than verbal<br/>only or written only.</li> <li>-The effectiveness of discharge<br/>instructions was highly<br/>influenced by the level of<br/>education of the caregivers.</li> <li>- Improved caregiver friendly<br/>methods of communication<br/>from the paediatric emergency<br/>health-care team are necessary<br/>for the delivery of discharge<br/>instructions.</li> </ul>   |  |  |  |
|---|------------------------|--|---|--|--|--|
| 9. Effect ofLinTelephone vsetVideo20Interpretationn on ParentComprehensionCommunication andUtilization inthe PediatricEmergencyDepartment:ARandomizedClinical Trial | ion<br>:t.al.,<br>:015 | To test the<br>effect of<br>telephone vs<br>video<br>interpretation<br>on<br>communicatio<br>n during<br>pediatric<br>emergency<br>care. | Among 208 parents who<br>completed the survey, those in<br>the video arm were more likely<br>to name the child's diagnosis<br>correctly than those in the<br>telephone arm (85 of 114<br>[74.6%] vs 52 of 87 [59.8%]; P =<br>.03) and less likely to report<br>frequent lapses in interpreter<br>use (2 of 117 [1.7%] vs 7 of 91<br>[7.7%]; P = .04). No differences<br>were found between the video<br>and telephone arms in parent-<br>reported quality of<br>communication (101 of 116<br>[87.1%] vs 74 of 89 [83.1%]; P =<br>.43) or interpretation (58 of 116<br>[50.0%] vs 42 of 89 [47.2%]; P =<br>.69). Video<br>Interpretation was more costly | Randomized trial of telephone vs video<br>interpretation at<br>a free-standing, university-affiliated pediatric<br>emergency department (ED). A convenience<br>sample of 290 Spanish-speaking parents of<br>pediatric ED patients with limited English<br>proficiency were approached from February<br>24 through August 16, 2014, ofwhom249<br>(85.9%) enrolled; of these, 208 (83.5%)<br>completed the follow-up survey (91 parents<br>in the telephone arm and 117 in the video<br>arm). Groups did not differ significantly by<br>consent or survey completion rate, ED factors<br>(e.g., ED crowding), child factors (e.g., triage<br>level, medical complexity), or parent factors<br>(e.g., birth country, income). Investigators<br>were blinded to the interpretation modality<br>during outcome ascertainment. Intention-to-<br>treat data were analyzed August 25 to<br>October 20, 2014. | Seattle Children's<br>Hospital emergency<br>department (ED) in<br>the United States. | 208 parents of<br>children who<br>presented to an ED<br>were recruited from<br>February to August<br>2014, 5 to 6 days per<br>week (including 1<br>weekend day each<br>week) from 2 to 10<br>PM. |

|                 |         |               | \$61 [\$36] vs \$31 [\$20] <sup>.</sup> P <   |   |                 |                        |
|-----------------|---------|---------------|---|---|-----------------|------------------------|
|                 |         |               | 001)  |   |                 |                        |
|                 |         |               | Parent-reported adherence to                  |   |                 |                        |
|                 |         |               | the assigned modality was                     |   |                 |                        |
|                 |         |               | higher for the video arm (106 of              |   |                 |                        |
|                 |         |               | 114 [93 0%] vs 68 of 86 [79 1%]               |   |                 |                        |
|                 |         |               | P = 0.04                                      |   |                 |                        |
|                 |         |               | -Families with limited English                |   |                 |                        |
|                 |         |               | proficiency who received video                |   |                 |                        |
|                 |         |               | Interpretation were more likely               |   |                 |                        |
|                 |         |               | to correctly name the child's                 |   |                 |                        |
|                 |         |               | diagnosis and had fewer lapses                |   |                 |                        |
|                 |         |               | in interpreter use. Use of video              |   |                 |                        |
|                 |         |               | interpretation shows promise                  |   |                 |                        |
|                 |         |               | for improving communication                   |   |                 |                        |
|                 |         |               | and patient care in this                      |   |                 |                        |
|                 |         |               | population.                                   |   |                 |                        |
| 10.             | Bucaro  | To improve    | This outreach program                         | This research developed a nurse-facilitated | ED children's   | During                 |
| Facilitating a  | & Black | parental      | promotes safety for patients by               | post-discharge callback program, the ED     | hospital In the | a year-long period,    |
| safe            | et.al., | understanding | • enabling us to contact many                 | Outreach Nurse Program, to promote family   | United states   | the outreach nurses    |
| transition      | 2014    | of discharge  | families after discharge                      | understanding and relieve parental anxiety. |                 | reinforced             |
| from the        |         | instructions  | to clarify discharge instructions,            | Our ED Outreach Nurse Program is managed    |                 | discharge              |
| pediatric       |         |               | assist with follow-up care, and               | by experienced pediatric emergency nurses,  |                 | instructions for 2,122 |
| emergency       |         |               | promote success in caring for                 | and it operates                             |                 | patients, and 630 of   |
| department      |         |               | patients                                      | daily.                                      |                 | them                   |
| to home         |         |               | at home.                                      |   |                 | participated in the    |
| with a post-    |         |               | <ul> <li>supplying families with a</li> </ul> | To determine whether our goal for improving |                 | survey.                |
| discharge       |         |               | consistent, knowledgeable                     | parental understanding of discharge         |                 |                        |
| phone call: a   |         |               | nurse to discuss concerns and                 | instructions was met, we                    |                 |                        |
| quality-        |         |               | answer questions                              | conducted a survey of a random sample of    |                 |                        |
| improvemen      |         |               | about their child's care.                     | parents to                                  |                 |                        |
| t initiative to |         |               | <ul> <li>giving staff a consistent</li> </ul> | determine whether the outreach nurse's      |                 |                        |
| improve         |         |               | method for follow-up with                     | phone call was                              |                 |                        |
| patient         |         |               | high-risk patients.                           | perceived as being beneficial               |                 |                        |
| safety.         |         |               | <ul> <li>creating a standardized</li> </ul>   |   |                 |                        |
|                 |         |               | process for follow-up when                    |   |                 |                        |

|  |  | findings result after<br>discharge.<br>• formulating new child health<br>information sheets for<br>specific patient populations.<br>• developing<br>educational/resource<br>information for our<br>adolescent patients.<br>• identifying deterioration or<br>social concerns and<br>making appropriate referrals.   |   |   |  |
|--|--|---|---|---|--|
| 11. UsingBlochTVideoet. al,ifDischarge2013dInstructionsinas anaAdjunct tocStandarduWrittencInstructionseImproveddCaregivers'(fUnderstandipng of TheirfChild'sEmergencyDepartmentVisit,Plan, andFollow-Up.ARandomized | To determine<br>if adding video<br>discharge<br>instructions<br>affects<br>caregivers'<br>understanding<br>of their child's<br>emergency<br>department<br>(ED) visit,<br>plan, and<br>follow-up. | Of 436 caregivers enrolled, 220<br>received written and 216<br>received video discharge<br>instructions. The follow-up<br>questionnaire was completed<br>by 341 caregivers. The group<br>receiving video discharge<br>instructions scored significantly<br>higher in the ED (12.2 vs 8.9)<br>and 2 to 5 days after discharge<br>(11.1 vs 7.8). At follow-up, 29%<br>of the written<br>and 42% of the video groups<br>rated their discharge<br>instructions as being<br>extremely helpful.<br>Questionnaire for Fever:<br>1. What temperature is<br>considered a fever?<br>2. What are signs of fever that<br>you could see in your child? | A randomized controlled trial. Caregivers of<br>patients, aged 29 days to 18 years, with a<br>diagnosis of fever, vomiting or diarrhoea, and<br>wheezing or asthma were randomised into<br>written or video discharge instruction groups.<br>In the ED, caregivers read standard written<br>discharge instructions or watched a<br>3-minute video based on their child's<br>diagnosis. They were then asked questions<br>regarding information covered in these<br>instructions. After completing the 20-point<br>questionnaire, standard discharge procedure<br>was followed.<br>Caregivers were contacted by phone 2 to 5<br>days after discharge for a follow-up<br>questionnaire. Usefulness of the discharge<br>instructions was<br>also assessed. | An academic<br>paediatric ED in the<br>United States. | 436 Caregivers of<br>pediatric patients<br>aged 29 days to 18<br>years diagnosed with<br>wheezing or asthma<br>exacerbation, fever,<br>or vomiting and/or<br>diarrhea. |

| 12 Effect of  | Considi                | to overning  | <ul> <li>4. How long should you expect<br/>your child to have a fever?</li> <li>5. When should your child<br/>return to the ED or to their<br/>doctor?</li> </ul>   | A pro/post tost docign was used. The   | A major community     | 40 families (22 pro   |
|---|------------------------|--|---|--|-----------------------|---|
| an evidence-<br>based<br>education<br>program on<br>ED discharge<br>advice for<br>febrile<br>children | ne et.<br>al.,<br>2007 | the effect of<br>an<br>educational<br>intervention<br>on discharge<br>advice given<br>to parents<br>leaving the<br>emergency<br>department<br>with a febrile<br>child. | intervention, the number of<br>parents leaving the emergency<br>department with no advice<br>decreased by 48% (p = 0.002).<br>Reports of written advice<br>increased by 69.7% (p < 0.001)<br>and there was a 38.4% increase<br>in reports of verbal advice<br>(p = 0.014). Parents leaving the<br>emergency department with<br>both written and verbal advice<br>increased from 0 to 55.6% (p <<br>0.001). Reports of advice by<br>nursing staff<br>increased by 52% (p < 0.001)<br>and there were significant<br>increases in specific instructions<br>related to oral fluid<br>administration (22.7 vs. 77.8, p<br>% 0.001) and use of antipyretic<br>medications (27.2 vs. 77.8, p $\%$<br>0.001). | outcome measure was parental advice<br>regarding pediatric fever management and<br>the intervention for the study was an<br>educational intervention for emergency<br>department nursing staff that consisted of<br>two tutorials. Data were collected using<br>structured telephone interviews.<br>The researchers telephoned families within<br>48 hours of ED presentation and asked if<br>fever management advice had been given<br>prior to leaving the ED. If no advice was given,<br>parents were thanked for their time and the<br>interview was completed.<br>If parents reported that advice was given,<br>they were asked<br>about the type of discharge advice (written<br>and/or verbal<br>advice), who provided the advice (medical<br>and/or nursing<br>staff), and specific instructions regarding<br>temperature monitoring, oral fluid<br>administration, administration of medications<br>traditionally used for antipyretic (paracetamol<br>and ibuprofen) and when to return to the ED<br>or family doctor. | hospital in Australia | intervention and 18<br>post intervention)<br>with children who<br>had fever as a<br>component of their<br>illness were recruited<br>into<br>the study. The<br>inclusion criteria<br>were as follows: (i)<br>Fever was a<br>component of the<br>child's ED<br>presentation; (ii)<br>Children<br>were discharged<br>from the ED; (iii)<br>Parents spoke<br>enough English to<br>provide informed<br>consent and<br>complete a<br>telephone interview. |

| 13. Impact   | Ismail  | To determine   | Sixty-three caregivers            | Caregivers who presented to the PED with a      | An urban academic | 63 caregivers ≥18      |
|--------------|---------|----------------|-----------------------------------|---|-------------------|------------------------|
| of Video     | et.al., | if video       | participated in the study.        | child's chief complaint of fever or closed head | PED in the United | years of age who       |
| Discharge    | 2016    | discharge      | Eleven participants had less      | injury (CHI) were included and randomized       | States            | presented to the PED   |
| Instructions |         | instructions   | than a high school (HS)           | into a control or intervention group. Each      |                   | between September      |
| for          |         | when added     | education and 52 had more         | group received standard discharge               |                   | and November 2012      |
| Paediatric   |         | to standard of | than a HS education. Thirty-one   | instructions, and the intervention group        |                   | with a child whose     |
| Fever and    |         | care written   | children presented with fever     | additionally, viewed a video. Participants      |                   | discharge diagnosis    |
| Closed Head  |         | and verbal     | and 32 with CHI. The              | completed a post-test on knowledge and          |                   | included fever or CHI. |
| Injury from  |         | instruction    | intervention group had            | were followed 2 weeks post-visit to             |                   |                        |
| the          |         | improved       | significantly higher percentage   | determine follow-up care.                       |                   |                        |
| Emergency    |         | caregivers'    | of correct answers on             |   |                   |                        |
| Department   |         | comprehensio   | postintervention tests (median    |   |                   |                        |
|              |         | n of their     | [Mdn] = 88.89) than the control   |   |                   |                        |
|              |         | child's        | (Mdn = 75.73; < 0.0001).          |   |                   |                        |
|              |         | diagnosis,     | Participants in the intervention  |   |                   |                        |
|              |         | disease        | group with less than a HS         |   |                   |                        |
|              |         | process, and   | education (Mdn = 89.47) and       |   |                   |                        |
|              |         | discharge      | more than HS education (Mdn =     |   |                   |                        |
|              |         | instructions.  | 88.89) had similar test scores (p |   |                   |                        |
|              |         |                | = 0.13), whereas those in the     |   |                   |                        |
|              |         |                | control group with less than a    |   |                   |                        |
|              |         |                | HS education (Mdn = 66.67)        |   |                   |                        |
|              |         |                | had significantly lower test      |   |                   |                        |
|              |         |                | scores than those with more       |   |                   |                        |
|              |         |                | than a HS education (Mdn =        |   |                   |                        |
|              |         |                | 77.78; p = 0.03). Conclusion: For |   |                   |                        |
|              |         |                | caregivers with children who      |   |                   |                        |
|              |         |                | presented to the PED with fever   |   |                   |                        |
|              |         |                | and CHI, video discharge          |   |                   |                        |
|              |         |                | instructions improved caregiver   |   |                   |                        |
|              |         |                | comprehension of the child's      |   |                   |                        |
|              |         |                | diagnosis and disease process     |   |                   |                        |
|              |         |                | when added to verbal and          |   |                   |                        |
|              |         |                | written instructions.             |   |                   |                        |

| Title            | Author/      | Objective/Aim   | Result                                  | Methods                            | Setting                       | Sample              |
|------------------|--------------|-----------------|---|------------------------------------|-------------------------------|---------------------|
|                  | Date         |                 |   |                                    |                               |                     |
| 1. Comprehension | Spandorfer   | To assess       | Overall comprehension                   | All patients who were discharged   | The Temple University         | 247 patients who    |
| of Discharge     | et.al., 1995 | patients'       | rates were judged to be                 | from the ED were interviewed.      | Hospital ED. The hospital is  | were discharged     |
| Instructions     |              | comprehension   | good,                                   | The patients were asked three      | located in an area of         | from the ED during  |
| by Patients      |              | of their        | although 23% of patients                | questions regarding                | Philadelphia with a high      | 12 separates        |
| in an Urban      |              | emergency       | exhibited no                            | comprehension of instructions.     | poverty rate.                 | time slots.         |
| Emergency        |              | department      | understanding                           | 1.What did the doctor tell you     |                               |                     |
| Department       |              | discharge       | of at least one component               | was wrong with you?                |                               |                     |
|                  |              | instructions.   | of                                      | 2. Did the doctor tell you to take |                               |                     |
|                  |              | To determine if | their discharge                         | any medications? How did he or     |                               |                     |
|                  |              | inner-city      | instructions.                           | she tell you to use each of them?  |                               |                     |
|                  |              | patients'       | Mean reading ability of                 | 3.Were you told to return to the   |                               |                     |
|                  |              | literacy levels | the                                     | emergency department or to see     |                               |                     |
|                  |              | are adequate to | patients were at the sixth-             | another doctor?                    |                               |                     |
|                  |              | comprehend      | grade                                   | Patients were encouraged to        |                               |                     |
|                  |              | written         | level. The ED's printed                 | read from their discharge          |                               |                     |
|                  |              | discharge       | discharge instructions                  | instruction sheet. If the          |                               |                     |
|                  |              | instructions.   | were written at                         | subjects' answers were             |                               |                     |
|                  |              | comprehension   | an11 <sup>th</sup> grade reading level. | incomplete, the interviewer        |                               |                     |
|                  |              | of their        | Patients with low literacy              | prompted, once for further         |                               |                     |
|                  |              | emergency       | scores were more likely to              | information                        |                               |                     |
|                  |              | department      | have                                    | Patients' literacy was assessed    |                               |                     |
|                  |              | discharge       | poor comprehension of                   | using the Wide Range               |                               |                     |
|                  |              |                 | instructions.                           | Achievement                        |                               |                     |
|                  |              |                 |   | Test (WRAT). WRAT is a widely      |                               |                     |
|                  |              |                 |   | used, reliable, and easily. less   |                               |                     |
|                  |              |                 |   | than 5 minutes.                    |                               |                     |
|                  |              |                 |   |                                    |                               |                     |
| 2. Patient       | Logan et     | To determine    | Of the patients completing              | Discharged patients are given a    | An urban teaching hospital ED | Of the 199 patients |
| understanding of | al., 1996    | whether         | the interview, 72% could                | discharge sheet with written       | with an annual census of      | who were            |
| emergency        |              | patients could  | read the discharge                      | documentation of their discharge   | approximately 45,000          | discharged during   |
| department       |              | read their ED   | instructions. The illiteracy            | diagnosis and instructions.        | patients.                     | the interview       |
| discharge        |              | discharge       | rate was higher for                     | Several common instructions are    |                               | periods, 173 (87%)  |
| instructions.    |              | instruction     | patients with less than 9               | printed, with boxes for the        |                               | were asked to       |

### Summary of additional key papers for adult patients or caretakers used in the literature review

| sheets and     | years of education and for  | physician to check when            | participate; 160 |
|----------------|-----------------------------|------------------------------------|------------------|
| recall their   | patients aged 50 to 59      | applicable; there is also blank    | agreed, and 153  |
| discharge      | years. There was no         | space for additional handwritten   | patients (79%)   |
| diagnosis,     | association between         | instructions. The instructions are | completed the    |
| treatment, and | patient race, sex, or       | written at a seventh-grade         | interview.       |
| follow-up plan | literacy. The correct       | reading. All ambulatory patients   |                  |
| when           | diagnosis was given by      | discharged home from the ED        |                  |
| interviewed    | 79% of patients, correct    | Patients were interviewed          |                  |
| immediately on | treatment information by    | immediately after discharge        |                  |
| discharge from | 49%, and correct follow-    | outside the emergency              |                  |
| the ED.        | up information by 82%.      | department to determine            |                  |
|                | Overall, 37% of patients    | whether they could read their      |                  |
|                | answered all questions      | discharge instructions and recall  |                  |
|                | correctly and 8%            | their diagnosis and treatment      |                  |
|                | answered all questions      | plan. The following questions      |                  |
|                | incorrectly. No association | were then asked:                   |                  |
|                | was found between           |                                    |                  |
|                | frequency of correct        | 1. Can you please read me your     |                  |
|                | responses and variables     | instruction sheet?                 |                  |
|                | examined.                   | 2. What did the doctor think was   |                  |
|                | Miscommunication of         | wrong with you?                    |                  |
|                | discharge information       | 3. What did the doctor want you    |                  |
|                | occurs frequently;          | to do at home?                     |                  |
|                | illiteracy does not         | 4.When did the doctor want you     |                  |
|                | completely account for      | to follow up?                      |                  |
|                | the observed low rates of   | Interviews were conducted          |                  |
|                | recall.                     | during 19 days in September        |                  |
|                |                             | 1992, over a total of              |                  |
|                |                             | approximately 60 hours. All shifts |                  |
|                |                             | and all days of the week were      |                  |
|                |                             | represented.                       |                  |
|                |                             | 5 -10 minutes                      |                  |
| Comprehension of<br>Emergency<br>Department Care<br>and<br>nd<br>Hal, 2009discharge,<br>patients'<br>comprehension<br>of their ED care<br>and instructions<br>and their<br>When They Do<br>Not<br>Understand?discharge,<br>patients aware of<br>Notunderstand their ED care<br>instructions. Moreover,<br>mostnot possible to conduct a face-to-<br>face interview with the<br>participant, the research assistant<br>attempted to schedule a<br>telephone interview. All<br>telephone interviews were<br>comprehension<br>deficiencies in<br>theirMichigan, USA academic<br>teaching hospital ED cares for<br>approximately 51,000 adult<br>patients appear to be<br>understanding and report<br>in appropriate confidence<br>in their comprehension.Michigan, USA academic<br>telephone interview with the<br>participant, the research assistant<br>attempted to schedule a<br>telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionsMichigan, USA academic<br>teaching hospital.<br>ED cares for<br>approximately 63,000 adult<br>patients per year;<br>and and recall.Speaking patients<br>or their primary<br>caretakers<br>after ED discharge.<br>(Please note that<br>this is the only<br>study that referred<br>to caretakers within<br>adult populations) |
|---|
| Emergency<br>Department Care<br>and<br>Instructions: Are<br>Patients Aware of<br>When They Do<br>Not<br>Understand?patients'<br>comprehension<br>of their ED care<br>and instructions<br>and their<br>awareness of<br>their<br>comprehension.or their discharge<br>instructions. Moreover,<br>most<br>patients appear to be<br>unaware of their lack of<br>understanding and report<br>in their comprehension.face interview with the<br>participant, the research assistant<br>attempted to schedule a<br>telephone interview. All<br>telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionsteaching hospital ED cares for<br>approximately 51,000 adult<br>patients per year; and a<br>community teaching hospital.<br>ED provides care for<br>approximately 63,000 adult<br>patients per yearor their primary<br>caretakers<br>after ED discharge.<br>(Please note that<br>this is the only<br>study that referred<br>to caretakers within<br>adult populations)   |
| Department Care<br>and<br>Instructions: Are<br>Patients Aware of<br>When They Do<br>Not<br>Understand?comprehension<br>of their ED care<br>and instructions<br>and their<br>awareness of<br>deficiencies in<br>their<br>comprehension.instructions. Moreover,<br>most<br>patients appear to be<br>unaware of their lack of<br>understanding and report<br>in appropriate confidence<br>in their comprehension.participant, the research assistant<br>attempted to schedule a<br>telephone interview. All<br>telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionsapproximately 51,000 adult<br>patients per year; and a<br>community teaching hospital.<br>ED provides care for<br>approximately 63,000 adult<br>patients per yearcaretakers<br>after ED discharge.<br>(Please note that<br>this is the only<br>study that referred<br>to caretakers within<br>adult populations)  |
| and<br>Instructions: Are<br>Patients Aware of<br>When They Do<br>Not<br>Understand?of their ED care<br>and instructions<br>and their<br>awareness of<br>their<br>in their comprehension.most<br>patients appear to be<br>unaware of their lack of<br>understanding and report<br>in their comprehension.attempted to schedule a<br>telephone interview. All<br>telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionspatients per year; and a<br>telephone interview. All<br>their sis the only<br>study that referred<br>to caretakers within<br>adult populations)  |
| Instructions: Are<br>Patients Aware of<br>When They Do<br>Not<br>Understand?and instructions<br>and their<br>awareness of<br>deficiencies in<br>their<br>comprehension.patients appear to be<br>unaware of their lack of<br>understanding and report<br>in their comprehension<br>and recall.telephone interview. All<br>telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionscommunity teaching hospital.<br>ED provides care for<br>approximately 63,000 adult<br>patients per year(Please note that<br>this is the only<br>study that referred<br>to caretakers within<br>adult populations)  |
| Patients Aware of<br>When They Do<br>Not<br>Understand?and their<br>awareness of<br>deficiencies in<br>their<br>comprehension.unaware of their lack of<br>understanding and report<br>in appropriate confidence<br>in their comprehension<br>and recall.telephone interviews were<br>completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionsED provides care for<br>approximately 63,000 adult<br>patients per yearthis is the only<br>study that referred<br>to caretakers within<br>adult populations)  |
| When They Do<br>Not<br>Understand?awareness of<br>deficiencies in<br>their<br>comprehension.understanding and report<br>in appropriate confidence<br>in their comprehension<br>and recall.completed within 24 hours of<br>discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionsapproximately 63,000 adult<br>patients per yearstudy that referred<br>to caretakers within<br>adult populations)   |
| Not<br>Understand?deficiencies in<br>their<br>comprehension.inappropriate confidence<br>in their comprehension<br>and recall.discharge to minimize recall bias.<br>-Participants rated their<br>subjective understanding of 4<br>domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructionspatients per yearto caretakers within<br>adult populations)   |
| Understand?       their comprehension.       in their comprehension and recall.       -Participants rated their subjective understanding of 4 domains:       adult populations)         (1) diagnosis and cause; (2) ED care; (3) post-ED care, and (4) return instructions       care; (3) post-ED care, and (4)       return instructions   |
| comprehension.       and recall.       subjective understanding of 4         domains:       (1) diagnosis and cause; (2) ED         care; (3) post-ED care, and (4)       return instructions         Fundmental       Fundmental   |
| domains:<br>(1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructions   |
| (1) diagnosis and cause; (2) ED<br>care; (3) post-ED care, and (4)<br>return instructions   |
| care; (3) post-ED care, and (4)<br>return instructions  |
| return instructions   |
| Execute 1   |
| Example   |
| DIAGNOSIS   |
| This first series of questions is   |
| about your diagnosis; in other  |
| words,  |
| what the medical team thought   |
| was wrong with you today (or  |
| <u>vesterday</u> ).   |
| Using the poor to excellent scale   |
| How would you rate your   |
| understanding of underlined   |
| above?  |
| Poor (1) Fair(2) Good(3) Very   |
| Good(4) Excellent(5)  |
| -Using the second scale from not  |
| at all to extremely, now difficult  |
| wds it for you to   |
|   |
| NUL dL dll (L) A ll (Le $(2)$<br>Mederately (2) Quite a bit (A)   |
| Woder alery (5) Quite a bit (4)   |
|   |

| EMERGENCY DEPARTMENT CARE  |  |
|--|--|
| The next series of questions is  |  |
| about <u>what was done for your</u>  |  |
| medical problem in the   |  |
| emergency department.  |  |
| Using the poor to excellent scale -  |  |
| How would you rate your  |  |
| understanding of underlined  |  |
| above?   |  |
| Poor (1) Fair(2) Good(3)   |  |
| Very Good(4) Excellent(5)  |  |
|  |  |
| - Using the second scale, how  |  |
| difficult was it for you to  |  |
| understand underlined above?   |  |
| Not at all (1) A little (2)  |  |
| Moderately (3) Quite a bit (4)   |  |
| HOME CARE  |  |
| The next series of questions is  |  |
| about <u>what you have to do to</u>  |  |
| take care of your medical  |  |
| problem at home.   |  |
| -Using the poor to excellent scale,  |  |
| how would you rate your  |  |
| understanding ofunderlined   |  |
| above?   |  |
| Poor (1) Fair (2) Good (3)   |  |
| Very Good (4) Excellent (5).   |  |
| Using the second scale, how  |  |
| difficult was it for you to  |  |
|  |  |
| understandunderlined above?  |  |
| Not at all (1) A little (2)  |  |
| understandunderlined above?       Not at all (1)       A little (2)       Moderately (3) Quite a bit (4)   |  |
| understandunderlined above?         Not at all (1)       A little (2)         Moderately (3) Quite a bit (4)         RETURN INSTRUCTIONS   |  |
| understandunderlined above?         Not at all (1)       A little (2)         Moderately (3) Quite a bit (4)         RETURN INSTRUCTIONS         The next series of questions is |  |

|   |                       |  |   | changes should cause you to<br>return to the emergency<br>department.<br>-Using the poor to excellent scale,<br>how would you<br>rate your understanding<br>ofunderlined above?<br>Poor (1) Fair (2) Good (3)<br>Very Good (4) Excellent (5)<br>. Using the second scale, how<br>difficult was it for you to<br>understandunderlined above?<br>Not at all (1) A little (2)<br>Moderately (3) Quite a bit (4)  |  |   |
|---|-----------------------|--|---|---|--|---|
| 4. Patient<br>Understanding of<br>Emergency<br>Department<br>Discharge<br>Instructions:<br>Where Are<br>Knowledge<br>Deficits Greatest? | Engel et<br>al., 2012 | To further<br>characterize<br>knowledge<br>deficits and<br>identify gaps in<br>knowledge that<br>may place the<br>patient at risk<br>for<br>complications<br>or poor<br>outcomes | <ul> <li>Patients frequently leave<br/>the ED with incomplete<br/>understanding of their<br/>discharge instructions.</li> <li>Patients' failure to read<br/>written instructions<br/>appears to contribute to<br/>the identified deficit.</li> <li>Knowledge deficits are<br/>most frequent in the<br/>domains of home care<br/>(i.e., self-care other than<br/>medications) and return to<br/>ED instructions (which<br/>symptoms or changes<br/>should cause patients to<br/>come back to the ED).</li> </ul> | Phone interviews of adult<br>English-speaking patients within<br>24 to 36 hours after ED discharge.<br>The patient was then asked about<br>the<br>information and instructions, he<br>or she received during the visit.<br>Questions targeted five domains:<br>1) diagnosis ("what were you told<br>was wrong with you")<br>2) medications ("what<br>medications, if any, were you told<br>to take")<br>3) home care ("were you told to<br>do other things to take care of<br>this problem besides taking<br>medication")<br>4) follow-up ("are you supposed<br>to follow-up with any doctors<br>about this problem") | An academic urban teaching<br>hospital in Chicago with a<br>census of approximately<br>85,000 patients per year. | 159 patients<br>discharged from<br>the ED with one of<br>five common<br>diagnoses were<br>eligible for<br>enrolment: ankle<br>sprain, back pain<br>(muscle strain),<br>head injury, kidney<br>stone, or laceration<br>(closed with staples<br>or stitches). The<br>highest frequency<br>discharge diagnoses<br>in ED setting. |

|                |           |                 |                             | 5) return to ED instructions<br>("which symptoms or changes |                            |                   |
|----------------|-----------|-----------------|-----------------------------|---|----------------------------|-------------------|
|                |           |                 |                             | should cause you to come back to                            |                            |                   |
|                |           |                 |                             | the ED").   |                            |                   |
|                |           |                 |                             | - Scores of understanding (partial,                         |                            |                   |
|                |           |                 |                             | minimal, or no understanding)                               |                            |                   |
|                |           |                 |                             | All questions were open-ended                               |                            |                   |
|                |           |                 |                             | with follow-up prompts to ensure                            |                            |                   |
|                |           |                 |                             | that patients had the opportunity                           |                            |                   |
|                |           |                 |                             | to provide as much information                              |                            |                   |
|                |           |                 |                             | as possible. An additional                                  |                            |                   |
|                |           |                 |                             | question was asked about                                    |                            |                   |
|                |           |                 |                             | whether or not the patient had                              |                            |                   |
|                |           |                 |                             | read the discharge instructions.                            |                            |                   |
| 5. Compliance  | Gignon et | To assess       | Nearly half of the patients | A semi-structured interview.                                | A French teaching hospital | 36 patients older |
| with emergency | al., 2014 | patient         | reported difficulties       | Using a standardized instrument                             | emergency department.      | than 18 years     |
| department     |           | understanding   | understanding their drug    | that addressed 4 components:                                | Approximately 50,000       | discharged from   |
| discharge      |           | of ED discharge | prescription (the dose or   | demographic data,   | patients attend this       | the emergency     |
| instructions   |           | instructions    | purpose of the treatment).  | understanding, compliance, and                              | emergency department each  | department.       |
|                |           |                 | Most patients said that     | satisfaction. The interview                                 | year.                      |                   |
|                |           |                 | their poor understanding    | featured both open-ended                                    |                            |                   |
|                |           |                 | primarily was related to    | questions and Likert scale                                  |                            |                   |
|                |           |                 | lack of clarity of the      | questions. One-on-one interview.                            |                            |                   |
|                |           |                 | written prescription.       | The patient's understanding and                             |                            |                   |
|                |           |                 |                             | satisfaction with the information                           |                            |                   |
|                |           |                 |                             | provided about the diagnosis,                               |                            |                   |
|                |           |                 |                             | treatment, and follow-up were                               |                            |                   |
|                |           |                 |                             | then addressed. When a problem                              |                            |                   |
|                |           |                 |                             | with understanding was                                      |                            |                   |
|                |           |                 |                             | identified, the patient was                                 |                            |                   |
|                |           |                 |                             | advised to seethe ED physician                              |                            |                   |
|                |           |                 |                             | for further explanation. If the                             |                            |                   |
|                |           |                 |                             | patient did not wish to see the                             |                            |                   |
|                |           |                 |                             | physician, the patient was asked                            |                            |                   |
|                |           |                 |                             | to say from who he/she expected                             |                            |                   |
|                |           |                 |                             | to obtain more information (e.g.,                           |                            |                   |
| 1              | 1         | 1               |                             |   |                            |                   |

|                    |              |                 |                            | a pharmacist, family physician, or |                          |                       |
|--------------------|--------------|-----------------|----------------------------|------------------------------------|--------------------------|-----------------------|
|                    |              |                 |                            | another person)                    |                          |                       |
|                    |              |                 |                            |                                    |                          |                       |
|                    |              |                 |                            |                                    |                          |                       |
| 6. Older Patients' | Hastings     | To describe     | A substantial number of    | Understanding of discharge         | An academic              | 92 Patients who       |
| Understanding of   | et al., 2011 | older patients' | older adults discharged    | information was assessed by        | medical center ED in the | were 65 years and     |
| Emergency          |              | understanding   | from the                   | telephone survey performed         | United states.           | older were eligible   |
| Department         |              | of emergency    | ED may be at risk for      | within 72 hours of ED discharge.   |                          | for inclusion if they |
| Discharge          |              | department      | adverse events because of  | Patients or proxies were asked     |                          | were discharged       |
| Information and    |              | (ED) discharge  | poor under-                | about their understanding of 4     |                          | home from the ED      |
| Its Relationship   |              | information and | standing of discharge      | areas of discharge information     |                          | on a study            |
| With Adverse       |              | to explore the  | information. (Overall,     | including the following:           |                          | enrolment             |
| Outcomes           |              | relationship    | 20.7% of patients (or      | (1) diagnosis/cause of problem),   |                          | dav                   |
|                    |              | between         | proxies) reported not      | (2) self-care instructions.        |                          | ,                     |
|                    |              | understanding   | understanding their        | (3) expected time of symptoms or   |                          |                       |
|                    |              | of FD discharge | diagnosis 16 3% did not    | illness                            |                          |                       |
|                    |              | information and | understand self-care       | (4) return precautions (i e        |                          |                       |
|                    |              | adverse out     | instructions and 63% did   | symptoms that might be danger      |                          |                       |
|                    |              | come            | not understand how long    | signals that they were getting     |                          |                       |
|                    |              | come            | their symptoms /or illness | worse) Each question was           |                          |                       |
|                    |              |                 | were expected to last      | nbrased as follows:                |                          |                       |
|                    |              |                 | (Table 2) The majority of  | Pased on what you were told by     |                          |                       |
|                    |              |                 | (Table 2). The majority of | the dester and (or purses in the   |                          |                       |
|                    |              |                 | patients (55.7%) also ulu  | The doctor and of your visit did   |                          |                       |
|                    |              |                 | not understand what        | ED, at the end of your visit, did  |                          |                       |
|                    |              |                 | symptoms might be          | you have a clear understanding     |                          |                       |
|                    |              |                 | danger signals that they   | of xxx? Patients also were asked   |                          |                       |
|                    |              |                 | were getting worse (return | about discharge medications and    |                          |                       |
|                    |              |                 | precautions). Of the 56    | follow-up information. Survey      |                          |                       |
|                    |              |                 | patients (60.9%) who       | items pertaining to discharge      |                          |                       |
|                    |              |                 | reported being prescribed  | information were written for this  |                          |                       |
|                    |              |                 | a new medication to take   | study based on clinic experience   |                          |                       |
|                    |              |                 | after going home from the  | and after review of pertinent      |                          |                       |
|                    |              |                 | ED, most reported          | literature                         |                          |                       |
|                    |              |                 | understanding the          |                                    |                          |                       |
|                    |              |                 | medication's schedule      |                                    |                          |                       |
|                    |              |                 | (96.4%) and planned        |                                    |                          |                       |
|                    |              |                 | duration (89.3%);          |                                    |                          |                       |

| 7. Do patients<br>understand<br>discharge<br>instructions?   | Zavala &<br>Schaffer<br>2011 | to identify and<br>describe areas<br>of patient<br>confusion<br>about ED<br>discharge<br>instructions   | however, only 58.9%<br>reported understanding<br>potential side effects of<br>the medication)<br>Fifteen subjects (31%)<br>requested information<br>about<br>their aftercare instructions<br>that required further<br>clarification by the<br>investigator, and 15<br>subjects (31%) described a<br>diagnosis- related concern<br>that revealed poor<br>comprehension of<br>instructions   | Follow-up telephone calls placed<br>to patients 1 day after ED<br>discharge in order to assess their<br>understanding of aftercare<br>instructions. patients' responses<br>to the following open-ended<br>queries: (1) "Tell me how you are<br>doing today" and (2) "Do you<br>have any questions about your<br>treatment or discharge<br>instructions?"  | ED of Reston Hospital Centre,<br>located in Reston, Virginia.                            | 50 adult patients,<br>aged 18 years or<br>older discharged<br>from ED  |
|--|------------------------------|---|--|---|--|--|
| 8. "Sign right here<br>and you're good to<br>go": a content<br>analysis of<br>audiotaped<br>emergency<br>department<br>discharge<br>instructions | Vashi et.al.,<br>2011        | to quantitatively<br>and qualitatively<br>assess the quality<br>and content of<br>verbal discharge<br>instructions at 2<br>emergency<br>departments<br>(EDs). | 55% of patient tapes<br>contained audible discharge<br>instructions. The<br>majority of discharges were<br>conducted by the primary<br>provider (emergency<br>physician or nurse<br>practitioner).<br>Ninety-one percent of<br>discharges included some<br>opportunity to ask questions,<br>although most of these were<br>minimal. Only 22% of<br>providers confirmed patients'<br>understanding of<br>instructions.<br>-Verbal ED discharge<br>instructions are often<br>incomplete, and most<br>patients are given only<br>minimal opportunities to ask | This was a secondary data analysis of<br>844 ED audiotapes collected during a<br>study of<br>patient-emergency provider<br>communication at 1 urban and 1<br>suburban ED. ED visits of<br>nonemergency adult<br>female patients were recorded with a<br>digital audiotape. Of 844 recorded ED<br>visits, 477 (57%) audiotapes<br>captured audible discharge<br>instructions suitable for analysis.<br>Audiotapes were double coded for<br>the following<br>discharge content: (1) explanation of<br>illness, (2) expected course, (3) self-<br>care, (4) medication instructions, (5)<br>symptoms prompting return to the<br>ED, (6) time-specified for follow-up<br>visit, (7) follow-up care instructions,<br>(8) | an urban academic tertiary<br>medical center ED and a<br>suburban community hospital ED. | 844 English-speaking<br>female patients aged<br>18 to 65 years and<br>presenting to the ED<br>during data collection<br>periods were eligible<br>for the study. Patients<br>triaged as medically<br>nonemergency were<br>recruited sequentially<br>from the ED waiting<br>rooms. |

|   |                       |   | questions or confirm<br>understanding.   | opportunities for questions, and (9)<br>patient confirmation of<br>understanding.   |   |   |
|---|-----------------------|---|--|---|---|---|
| 9. Emergency<br>department<br>discharge<br>instructions<br>comprehension<br>and compliance<br>study | Clark et al.,<br>2005 | To assess patient<br>comprehension of<br>emergency<br>department<br>discharge<br>instructions and<br>to describe other<br>predictors of<br>patient<br>compliance with<br>discharge<br>instructions. | The inter-rater reliability of<br>physician rating scores was<br>high (kappa = 0.66).<br>Approximately 60% of<br>subjects demonstrated<br>reading ability at or below a<br>Grade 7 level.<br>Comprehension was<br>positively associated with<br>reading ability ( $r = 0.29$ , $p =$<br>0.01) and English as first<br>language ( $r = 0.27$ , $p = 0.01$ ).<br>Reading ability was positively<br>associated with years of<br>education ( $r = 0.43$ , $p <$<br>0.0001) and first language ( $r = 0.24$ , $p = 0.03$ ), and<br>inversely associated with age<br>( $r = -0.21$ , $p = 0.05$ ). Non-<br>English first language and<br>need for translator were<br>associated with poorer<br>comprehension of discharge<br>instructions but not related<br>to compliance. Compliance<br>with discharge instructions<br>was correlated with<br>comprehension ( $r = 0.31$ , $p =$<br>0.01) but not associated with<br>age, language, education,<br>years in anglophone country,<br>reading ability, format of<br>discharge instructions,<br>follow-up modality or<br>association with a family<br>physician | Patients departing from the<br>emergency department of an inner-<br>city teaching hospital were invited to<br>undergo a structured interview and<br>reading test, and to participate in a<br>follow-up telephone interview 2<br>weeks later. Two physicians, blinded<br>to the other's data, scored patient<br>comprehension of discharge<br>information and compliance with<br>discharge instructions. Inter-rater<br>reliability was assessed using a<br>kappa-weighted statistic, and<br>correlations were assessed using<br>Spearman's rank correlation<br>coefficient and Fisher's exact test. | The emergency department of<br>Toronto hospital in Canada | Of 106 patients<br>approached, 88 (83%)<br>were enrolled. Thus,<br>this study involved 88<br>patients who<br>attended the ED and<br>were not admitted to<br>the hospital. |

| -Emergency department         |  |  |
|-------------------------------|--|--|
| patients demonstrated poor    |  |  |
| reading skills. Comprehension |  |  |
| was the only factor           |  |  |
| significantly related to      |  |  |
| compliance; therefore, future |  |  |
| interventions to improve      |  |  |
| compliance with emergency     |  |  |
| department instructions will  |  |  |
| be most effective if they     |  |  |
| focus on improving            |  |  |
| comprehension.                |  |  |

## **Appendix 2 Ethics approval**

## **Research Ethics Committee of the Australian Catholic University**

## 2015-124R Registration of External Ethics Approval

KP

Kylie Pashley <Kylie.Pashley@acu.edu.au> on behalf of Res Ethics <Res.Ethics@acu.edu.au>

## Reply all

Tue 26/05/2015, 9:29 AM Karen Flowers <Karen.Flowers@acu.edu.au>; Kodchanipa Phonpruk; Res Ethics <Res.Ethics@acu.edu.au> Inbox

Dear Karen,

Principal Investigator: Prof Karen Flowers Student Researcher: Kodchanipa Phonpruk (HDR student) Ethics Register Number: 2015-124R Project Title: An investigation of the provision of discharge information to parents to care for their child post-discharge from the emergency department: A mixed method study. Risk Level: Multi Site Date Approved: 26/05/2015 Ethics Clearance End Date: 30/06/2016

The Australian Catholic University Human Research Ethics Committee has considered your application for registration of an externally approved ethics protocol and notes that this application has received ethics approval from Metro North Hospital and Health Service, The Prince Charles Hospital HREC [Reference: HREC/15/QPCH/70].

The ACU HREC accepts the ethics approval with no additional requirements, save that ACU HREC is informed of any modifications of the research proposal and that copies of all progress reports and any other documents be forwarded to it. Any complaints involving ACU staff must also be notified to ACU HREC (National Statement 5.3.3)

We wish you well in this research project.

Regards,

Kylie Pashley on behalf of ACU HREC Chair, Dr Nadia Crittenden Ethics Officer | Research Services Office of the Deputy Vice Chancellor (Research) res.ethics@acu.edu.au

#### **Research Ethics Committee of the hospital**

Enquiries to: Office Ph: Our Ref: <u>R&ETPCH@health.qld.gov.au</u> (07) 3139 4198 (07) 3139 4500 Low Risk Final Approval

6 May 2015

Queensland Government

Human Research Ethics Committee Metro North Hospital and Health Service The Prince Charles Hospital Building 14 Rode Road, Chermside QLD 4032

Professor Karen Flowers C/- Professor Paul Fulbrook Nursing Research and Practice Development The Prince Charles Hospital Dear Professor Flowers

RE: HREC/15/QPCH/70: An investigation of the provision of discharge information to parents to care for their child post-discharge from the emergency department: A mixed method study.

Thank you for submitting your Low Risk project for ethical and scientific review. I am pleased to advise that The Prince Charles Hospital Human Research Ethics Committee reviewed your submission and upon recommendation, the Chair has granted final approval for your low risk project.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the Human Research Ethics Committee has granted approval of this research project. The documents reviewed and approved on 6 May 2015 include:

| Document   | Version | Date          |
|--|---------|---------------|
| Application (AU/10/FCCD15)   |         |               |
| Protocol   | 1       | 25 March 2015 |
| Participant Information Sheet and Consent Form:<br>Parents/Guardians         | 2       | 27 March 2015 |
| Participant Information Sheet and Consent Form: ED Staff                     | 2       | 27 March 2015 |
| Participant Information Sheet and Consent Form:<br>Parents/Guardian's Survey | 1       | 31 March 2015 |
| Document Audit Tool  | 1       | 31 March 2015 |
| Trigger Questions for Focus Group and Prompts                                | 1       | 31 March 2015 |
| Parent's Survey  | 1       | 31 March 2015 |
| Observation Checklist  | 1       | 31 March 2015 |

This information will be tabled at the next HREC meeting held 28 May 2015 for noting.

Please note the following conditions of approval:

| Office                               | Postal                      | Phone          |
|--------------------------------------|-----------------------------|----------------|
| Research, Ethics & Governance Office | Building 14                 | (07) 3139 4500 |
| The Prince Charles Hospital          | Rode Road, Chermside Q 4032 | (07) 3139 4198 |

- 1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including any unforeseen events that might affect continued ethical acceptability of the project.
- Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in revised documents. Further advice on submitting amendments is available from <u>http://www.health.gld.gov.au/ohmr/documents/researcher\_userguide.pdf</u>
- Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office/r (by-passing the HREC).
- 4. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly the HREC for review and, once HREC approval has been granted, then submit to the RGO.
- 5. The HREC is notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- The Principal Investigator will provide research status reports, annually and on completion of the research, to the HREC. <u>http://www.health.qld.gov.au/tpch/documents/tools\_progrep.dot</u>
- The Human Research Ethics Committee or Hospital and Health Service Administration may inquire into the conduct of any research it approves for a specific site; or which the Committee has approved when conducted outside at multiple Hospital & Health Service sites.

HREC approval is valid until 30 June 2016.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer on 3139 4500. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from <a href="http://www.health.qld.gov.au/ohmr/html/regu/regu">http://www.health.qld.gov.au/ohmr/html/regu/regu</a> home.asp.

*You are reminded that this letter constitutes ethical approval only.* You must not commence this research project at a site until separate authorisation from the Hospital and Health Service CEO or Delegate of that site has been obtained.

A copy of this approval must be submitted to the relevant Hospital & Health Services Research Governance Officer/s or Delegated Personnel with a completed Site Specific Assessment (SSA) Form for authorisation from the CEO or Delegate to conduct this research at the site/s listed below.

The HREC wishes you every success in your research.

Yours faithfully

RCD

Dr Russell Denman Chair

HUMAN RESEARCH ETHICS COMMITTEE METRO NORTH HOSPITAL AND HEALTH SERVICE Enquiries to: Office Ph: Amendment Ref: R&ETPCH@health.qld.gov.au (07) 3139 4198 (07) 3139 4500 Amendment 02



2 March 2016

Human Research Ethics Committee Metro North Hospital and Health Service The Prince Charles Hospital Building 14 Rode Road, Chermside QLD 4032

Professor Karen Flowers C/- Kodchanipa Phonpruk Nursing Research and Practice Devolvement Centre The Prince Charles Hospital

Dear Professor Flowers

Re: HREC/15/QPCH/70: An investigation of the provision of discharge information to parents to care for their child post-discharge from the emergency department: A mixed method study.

I am pleased to advise that The Prince Charles Hospital Human Research Ethics Committee reviewed the amendments submitted and upon recommendation, the Chair has granted approval for the following:

- Protocol Version 2 dated 10 February 2016
- Participant Information Sheet and Consent Form: Telephone Survey Version 1 dated 2 February 2016
- Parent's Survey Version 1 dated 2 February 2016

This information will be tabled at the HREC meeting on 24 March 2016 for noting.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

Please be advised that in the instance of an investigator being a member of the HREC, they are absented from the decision making process relating to that study.

On behalf of the Human Research Ethics Committee, I would like to wish you every success with your research endeavour.

| Office                               | Postal                      | Phone          |
|--------------------------------------|-----------------------------|----------------|
| Research, Ethics & Governance Office | Building 14                 | (07) 3139 4500 |
| The Prince Charles Hospital          | Rode Road, Chermside Q 4032 | (07) 3139 4198 |
|                                      |                             |                |

Yours truly,

allant signed by Dig ann DN cDe th.gld.gov.au

Anne Carle Executive Officer Research, Ethics and Governance Unit The Prince Charles Hospital

## Appendix 3 Document Audit Tool

## Audit Tool for Hospital Protocols, Procedures, and guidelines on discharge information in the Emergency Department (ED)

| Question  | Yes /No | Comments                        |
|---|---------|---------------------------------|
| Question  1. Does the hospital have any protocols, procedures and guidelines on discharge planning and in particular providing discharge information in the ED? | Yes /No | Comments         What are they? |
|   |         |                                 |

|  | 105/110   | comments   |
|--|---|--|
|  |   | Other<br>How staff able to access?<br>On what are the documents based? (National, International, state, hospital<br>sources, literature) |
| 2. Do the documents include recommendations on categories of discharge information to be provided in the ED?       Ye         If Yes, do they include:       Patient diagnosis and treatment       Ye         • Patient diagnosis and treatment       Ye         • individualised patient self-care information and instructions       Ye         • information about community resources       Ye         • follow- up instructions & return to ED instructions       Ye         • referrals to community health providers       Ye | 'es       No         'es       No | What is recommended for information on diagnosis and other categories of information?  |

| Question   | Yes/No   | Comments                                |
|--|--|---|
| <ul> <li>3. Do the documents include recommendations<br/>on staff training for providing discharge<br/>information? If Yes, do they include: <ul> <li>Quality of discharge information</li> <li>Communicating with parents</li> <li>Communicating with non-English<br/>speaking populations</li> <li>Communicating with patients/parents<br/>under stress</li> </ul> </li> </ul>   | Yes No Vo Ves No Vo Ves No Ves No Vo Ves No Vo Ves No Vo Ves No Ves Ves No Ves  | If yes, what are these recommendations? |
| <ul> <li>4. Do the documents provide include<br/>recommendations on which ED staff should<br/>provide discharge information in the ED?<br/>If yes, who give the discharge information <ul> <li>Medical</li> <li>Nurse</li> <li>Allied health</li> <li>Administration</li> <li>Someone else</li> </ul> </li> </ul>  | Yes No Ye | If yes, what are these recommendations? |
| <ul> <li>5. Do the documents include recommendations<br/>on how to give the discharge information for<br/>patients/parents?</li> <li>If yes, Do they discuss the following: <ul> <li>How to deliver discharge information?</li> <li>How to ensure parents' understanding?</li> <li>Use Interpreter/translator</li> <li>Asking if there are any more questions?</li> <li>Use of information resources such as<br/>leaflets, text messages?</li> </ul> </li> </ul> | Yes No   | If yes, what are these recommendations? |

## Appendix 4 Observation Checklists

## **Observations: Structure**

| Feature                             | Observed                     | Comment |
|-------------------------------------|------------------------------|---------|
| 1. Usual staffing pattern in the ED | Medical                      |         |
|                                     | Nursing                      |         |
|                                     | Allied health                |         |
|                                     | Administration               |         |
|                                     | Other                        |         |
| 2. Number of                        | Consultants                  |         |
| In the ED                           | Registrars                   |         |
|                                     | Residents                    |         |
| 3. Number of                        | RNs                          |         |
| nurses                              | ENs Students                 |         |
|                                     | Unit manager                 |         |
| 4.Number of                         | Types of consultation spaces |         |
| consultation<br>spaces              |                              |         |
|                                     |                              |         |
| 5. Types of resources visible       | Poster on the wall           |         |
|                                     | Pamphlet printed             |         |
|                                     | CDs/DVDs                     |         |
|                                     | Other                        |         |
|                                     |                              |         |
|                                     |                              |         |
|                                     |                              |         |

| Feature  | Observed   | Comment |
|--|--|---------|
| 6. Types of<br>information<br>available for<br>parents   | <ul> <li>Verbal</li> <li>CDs/DVDs</li> <li>Hand writing</li> <li>Website/E-mail</li> <li>Pamphlet printed</li> <li>Picture</li> <li>Other</li> </ul> |         |
| 7. Parents and<br>children able to<br>stay together  | yesNo  |         |
| 10.Written<br>information<br>10.1Easy to read –<br>format and layout<br>clear<br>10.2Concise – clear<br>and to the point<br>10.3 Various<br>Language | yesNo<br>yesNo<br>yesNo<br>How many languages?   |         |
| 11. Interpreters<br>are available  | yesNo<br>How many interpreters   |         |
| 12. Visible<br>information for<br>parents that<br>interpreters are<br>available  |  |         |

### Data types for each case

| Child Code: Do               | ayDate Time   | AM/PM.  |
|------------------------------|---|---------|
| Feature                      | Observed  | Comment |
| 1.Type of presentation       | Illness      Injury   |         |
| 2. Triage Score              | □ 3   |         |
|                              | □ 4<br>□ 5  |         |
| 3.Accompanying the child     | Parents   |         |
|                              | □ Other   |         |
| 4. Age of the child          | YearsMonths   |         |
| 5.Child's pain               | No     Moderate     Worst       Pain     Pain     Pain $1$ $1$ $1$ $0$ $1$ $2$ $3$ $4$ $5$ $6$ $7$ $8$ $9$ $10$ |         |
|                              |   |         |
| 6.Admission time             | AM/PM   |         |
| 7. Waiting time              | HoursMinutes  |         |
| 8.Consultation time          | AM/PM   |         |
| 9.Discharge information time | AM/PM   |         |

### Process

## Staff

| Feature   | Observation  | Comment |
|---|--|---------|
| 1. Number of staff<br>interacting with the<br>child and parents and<br>for what purpose | Types of staff interacting Who provides discharge information?   |         |
|   |  |         |
| 2. Resources given to parents   | <ul> <li>Verbal</li> <li>CDs/DVDs</li> <li>Hand writing</li> <li>Website/E-mail</li> <li>Pamphlet printed</li> <li>Picture</li> <li>Other</li> </ul>   |         |
| 3. Information provided to parents  | <ul> <li>Patient status and treatment</li> <li>Individualised patient self-care</li> <li>information and instructions</li> <li>Information about community resources</li> <li>Follow- up instructions &amp; return to ED</li> <li>instructions</li> <li>Referrals to community health providers</li> </ul> |         |
| 4. Opportunity for parent to ask questions  | YesNo  |         |
| 5. Staff answers easy to understand?  | YesNo  |         |

### Parent

| Observation   |                       | Ass        | essment        |                        | Comment |
|---|-----------------------|------------|----------------|------------------------|---------|
| 1. Parents' anxiety   | Calm Back             | in control | Slipping out   | t of control Panic!    |         |
|   |                       |            |                |                        |         |
|   | 0 1 2                 | 2 3 4      | 5 6 7 8        | 8910                   |         |
| 2. Parents seem to<br>have been to the ED<br>before   | □ Yes                 |            |                |                        |         |
| 3. Parent appears<br>to understand<br>discharge<br>information<br>provided by staff   | □ Yes                 |            |                |                        |         |
| <ul> <li>4. Number of<br/>questions asked by<br/>parents before<br/>leaving the ED</li> <li>4.1 Types of<br/>questions asked</li> </ul> |                       |            |                |                        |         |
| 4.2 Answers easy to understand  | Very E<br>Easy<br>5 4 | Easy Fair  | difficult<br>2 | Very<br>difficult<br>1 |         |
| 5. Parent observed<br>reading written<br>information<br>provided by staff   | □ Yes                 |            |                |                        |         |
| 5. Parent appears satisfied   |                       | 99         |                |                        |         |

## Appendix 5 The Trigger questions for Focus group and prompts

## Script for moderator /research assistant

Good morning/afternoon and welcome. Thanks for taking the time to join our discussion about your experiences in providing discharge information to parents. My name is ....., and I will serve as the moderator for today's focus group discussion. Assisting me is..... The purpose of today's discussion is to hear about your experiences of providing discharge information to parents. You were invited because you work with parents who present with their children in ED. There are no right or wrong. We expect that you will have differing points of view. Please feel free to share your point of view even if it differs from what others have said. If you want to follow up on something that someone has said, you want to agree, disagree, or give an example, feel free to do that. Don't feel like you have to respond to me all the time. Feel free to have a conversation with one another about this topic. The moderator's role here is to ask some trigger questions, listening, and make sure everyone has a chance to share. We're interested in hearing from each of you. So, if you're talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you. We just want to make sure we hear from all of you. Feel free to get up and get more refreshments if you would like. (.....Name......), and I will both be taking notes to help us remember what is said and we don't want to miss any of your discussions. We will be on a first name basis today, and we won't use any names in any reports. You may be assured of complete confidentiality. Well, let's begin by having each person in the room tell us your name also check that all have signed the consent form.

## **Focus Group Trigger Question**

| Focus Group Trigger Question     | Prompts, if required                     |
|----------------------------------|--|
| 1. Please tell us about how      | Use of Policies procedures, guidelines   |
| discharge information is         | Types of information provided            |
| provided to parents or guardians |  |
| in your ED?                      | How the information is given and by whom |
|                                  | Resources provided for parents           |
|                                  |  |

| Fact Sheets (Information in each Fact                  |
|--|
| Sheetgeneral or specific , How the information in      |
| each Fact Sheet is given to care their child at home ) |
| Ensuring parents understand                            |
| Evidence based practice                                |
| How they respond when parents don't seem to            |
| understand   |
| NESB parents (Interpreting services)                   |
| Other Challenges?                                      |
| What works well?                                       |
| Other queries arising from your observations           |
| Anything else you would like to share?                 |

## **Appendix 6 Parents' survey**

#### **Parents' Survey**

Dear parent or guardian,

You recently attended The Prince Charles Hospital Emergency Department with your child. You may recall that you agreed to participate in a survey about the experiences of parents or guardians of children treated and discharged from this department.

We thank you for agreeing to participate in this study.

Your participation is very important, as your answers will help to inform future directions and developments within the children's emergency department.

Permission for you to participate in this study has been given by the Emergency Department Director and ethical approval has been granted by The Prince Charles Hospital Human Research Ethics Committee (HREC/10/FCCD/15).

Your participation in this study is voluntary, and your consent to participate in the study will be implied by your completion and submission of the survey.

All data will be collected ANONYMOUSLY. The research team will not know who has provided answers.

Thank you for participating.

Please tick ( $\vee$ ) the box appropriate relevant to your circumstance or complete the answer. There is no right or wrong answer. Please choose the answer which represents your opinion. If you prefer not to answer a question, please leave it blank.

#### SECTION 1: ABOUT YOU

This section contains 9 questions about you.

#### 1. What is your relationship to the child who attended the Emergency Department?

| Mother                  |
|-------------------------|
| Father                  |
| Legal Guardian (male)   |
| Legal Guardian (female) |
| Other, please specify   |

#### 2. How old are you?

| Less than 20 years |
|--------------------|
| 20-30 years        |
| 31-40 years        |
| 40+ years          |

3. If you are a Queensland resident, what is your home postcode OR if you are not a Queensland resident, what is the postcode of the address you were staying at on the date of your child's attendance at the emergency department? \_\_\_\_\_\_

#### 4. What is your highest level of education?

| Did not finish high school  |
|-----------------------------|
| Completed year12            |
| TAFE certificate or diploma |
| Bachelor's degree           |
| Post graduate qualification |
| Other, please specify       |

#### 5. Were you born in Australia?

| Yes                                      |
|--|
| No, please specify your country of birth |

#### 6. How many years have you lived in Australia?

| I have always lived in Australia |  |
|----------------------------------|--|
| Less than 5 years                |  |
| 6-10 years                       |  |
| 10+ years                        |  |
| I live overseas                  |  |

#### 7. What is the main language spoken at home?

| English  |
|--|
| Other, please specify the main language spoken at home |

## 8. Do you identify yourself as Indigenous Australian, or Torres Strait Islander, or of Pacific/South Sea Islander descent?

| No                         |  |
|----------------------------|--|
| Indigenous Australian      |  |
| Torres Strait Islander     |  |
| Pacific/South Sea Islander |  |

# 9. Have you been to this or any other children's emergency department before this recent presentation?

| No, this is my first time to a children' emergency department |
|---|
| Yes, I have been one other time                               |
| Yes, 2 times before   |
| Yes, 3 or more times  |

#### SECTION 2: ABOUT YOUR CHILD IN THE CHILDREN'S EMERGENCY DEPARTMENT

This section contains 2 questions about your child.

#### 10. What is your child's gender?

| Male   |
|--------|
| Female |

#### 11. On the day you recently attended the emergency department, how old was your child?

\_\_\_\_\_Years\_\_\_\_\_ months

#### SECTION3: DETAILS ABOUT YOUR VISIT TO THE CHILDREN'S EMERGENCY DEPARTMENT

This section contains 10 questions about your recent visit to the Children's Emergency Department with your child.

12. What was the date and approximate time of your child's arrival at the emergency department?

Date\_\_\_\_\_Time\_\_\_\_AM/PM

13. Approximately what time did you and your child leave the emergency department?

Date\_\_\_\_\_Time \_\_\_\_\_AM/PM

14. Why did you take your child to the emergency department?

| My child was sick      |
|------------------------|
| My child was injured   |
| Other (please specify) |

15. In your own words, please describe your child's condition and what prompted you to take him/her to the emergency department.

#### 16. How busy was the emergency department when you first arrived?

| Extremely Busy | Very busy | Quite busy | A little bit busy | Not Busy at all |
|----------------|-----------|------------|-------------------|-----------------|
| 5              | 4         | 3          | 2                 | 1               |

#### **17.** How noisy was the Emergency Department during your stay?

| Extremely noisy | Very noisy | Quite noisy | A little bit noisy | Not noisy at all |
|-----------------|------------|-------------|--------------------|------------------|
| 5               | 4          | 3           | 2                  | 1                |

#### 18. Approximately how long did you wait before you were first seen by a nurse?

| Less than 10 minutes     |
|--------------------------|
| Between 10 to 30 minutes |
| More than 30 minutes     |

#### 19. Approximately how long did you wait before you were first seen by a doctor?

| Less than 30 minutes     |
|--------------------------|
| Between 30 to 60 minutes |
| More than 1 hour         |

#### 20. What were you told was wrong with your child? (What diagnosis were you given?)

21. Please describe what was done for your child (the treatment your child) received while you were in the emergency department.

#### SECTION 4: AFTER VISITING THE EMERGENCY DEPARTMENT

This section is about the information you were given, whilst in the Children's Emergency Department, about what to do for your child when you returned home. This section contains 37 questions.

## 22. Regarding this visit to the emergency department, were you advised to give your child any medicines when you returned home?



→ Please go to question 26 →Please go to question 23,24 and 25

#### 23. Which medicines were you advised to give?

24. What was the medicine for?

25. Who gave you the advice?

26. Regarding this visit to the emergency department, were you advised to do any other things to look after your child when you returned home (other than giving medicine)?

| No  |
|-----|
| Yes |

→ Please go to question 29 →Please go to question27 and 28

#### 27. What were you advised to do?

#### 28. Who gave you the advice?

29. Before you left the emergency department, did anyone advise you to visit your family doctor or any other medical service with your child?



→ Please go to question 33 →Please go to question 30, 31 and 32

30. Who/what were you advised to visit?

31. Why were you advised to visit them?

#### 32. Who gave you the advice?

33. When you were in the emergency department, were you advised to return to the emergency department should your child's signs or symptoms return?

| No  |
|-----|
| Yes |

→ Please go to question 36
 → Please go to question 34 and 35

34. What were you told?

#### 35. Who gave you the advice?

THE FOLLOWING QUESTIONS ARE ABOUT THE DIFFERENT WAYS THAT YOU MAY HAVE BEEN GIVEN DISCHARGE INFORMATION WHILE YOU WERE IN THE EMERGENCY DEPARTMENT.

#### 36. Were you given any verbal (spoken) discharge information?



→ Please go to question 40 →Please go to question 37, 38 and 39

#### 37. Who provided the verbal (spoken) discharge information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

#### 38. How easy was the verbal (spoken) information to understand?

| Very difficult | Quite difficult | Quite easy | Very easy | Extremely easy |
|----------------|-----------------|------------|-----------|----------------|
| 1              | 2               | 3          | 4         | 5              |

# **39.** How useful was the verbal (spoken) information to help you care for your child when you returned home?

| Not at all useful | A bit useful | Quite useful | Very Useful | Extremely useful |
|-------------------|--------------|--------------|-------------|------------------|
| 1                 | 2            | 3            | 4           | 5                |

#### 40. Did you receive any handwritten discharge information?



 $\rightarrow$  Please go to question 44

 $\rightarrow$  Please go to question 41, 42 and 43

#### 41. Who provided the handwritten information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

#### 42. How easy was the handwritten information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

## 43. How useful was the handwritten information to help you care for your child when you returned

home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

#### 44. Were you given any printed discharge information e.g. a pamphlet or typed instructions?

| No  |  |
|-----|--|
| Yes |  |

→ Please go to question 48 →Please go to question 45, 46 and 47

## 45. Who provided the printed information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

#### 46. How easy was the printed information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

#### 47. How useful was the printed information to help you care for your child when you returned

home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

#### 48. Were you provided with any Internet-based (website) discharge information?

**No**  $\rightarrow$  Please go to question 52

**Yes**  $\rightarrow$  Please go to question 49, 50 and 51

#### 49. Who provided the Internet-based information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

#### 50. How easy was the Internet-based information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

#### 51. How useful was the Internet-based information to help you care for your child when you

#### returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

#### 52. Were you given any discharge information in the form of pictures or diagrams?

| No  | $\rightarrow$ |
|-----|---------------|
| Yes | $\rightarrow$ |

 $\rightarrow$  Please go to question 56

 $\rightarrow$  Please go to question53, 54 and 55

#### 53. Who provided the picture/diagram information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

#### 54. How easy was the picture or diagram information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

# 55. How useful was the picture or diagram information to help you care for your child when you returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### 56. Were you provided with any discharge information in the form of a CD or DVD?

**No**  $\rightarrow$  Please go to question 60



#### 57. Who provided the CD/DVD information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

#### 58. How easy was the CD/DVD information to understand?

| Very difficult | Quite difficult | Quite | Very | Extremely | I did not look at it |
|----------------|-----------------|-------|------|-----------|----------------------|
|                |                 | easy  | easy | easy      |                      |
| 1              | 2               | 3     | 4    | 5         | 0                    |

59. How useful was the CD/DVD information to help you care for your child when you returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

#### SECTION 5: THE FIRST WEEK AFTER YOU RETURNED HOME

This section contains 3 questions about you and your child in the first week after you returned home from the Children's Emergency Department.

#### 60. Following this visit to the emergency department, what care did you provide for your child when you returned home?

61. When you returned home, did you have any difficulties managing your child's illness or injury?



If Yes, please describe your difficulties and how you handled them

62. After you returned home, in the first week, did you need to return to the children's emergency department again for the same problem?

| No  |
|-----|
| Yes |

If <u>Yes</u>, please describe what happened

#### SECTION 6: YOUR OVERALL EXPERIENCE OF THE EMERGENCY DEPARTMENT

This section contains 4 questions about your experience during and after your recent visit to the Children's Emergency Department.

Please feel free to answer each question in the way that best represents your personal view.

#### 63. How anxious were you when you arrived with your child at the emergency department?

| Extremely<br>anxious | Very anxious | Quite anxious | A little anxious | Not at all<br>anxious |
|----------------------|--------------|---------------|------------------|-----------------------|
| 5                    | 4            | 3             | 2                | 1                     |

64. When you left the emergency department, how anxious did you feel about being able to care for your child when you got home?

| Extremely<br>anxious | Very anxious | Quite anxious | A little anxious | Not at all<br>anxious |
|----------------------|--------------|---------------|------------------|-----------------------|
| 5                    | 4            | 3             | 2                | 1                     |

65. Overall, how confident were you about using the discharge information you received from emergency department staff?

| Not at all confident | A little confident | Quite confident | Very confident | Extremely<br>confident |
|----------------------|--------------------|-----------------|----------------|------------------------|
| 1                    | 2                  | 3               | 4              | 5                      |

66. Overall, how satisfied were you with the discharge information you received from the Emergency Department staff?

| Not at all satisfied | A little bit<br>satisfied | Quite satisfied | Very Satisfied | Extremely<br>satisfied |
|----------------------|---------------------------|-----------------|----------------|------------------------|
| 1                    | 2                         | 3               | 4              | 5                      |

Thank you for taking the time to complete our survey.

## **Appendix 7 Parents' telephone survey**

## Parents' telephone survey

## To be completed in the ED as part of recruitment

#### SECTION 1: ABOUT YOU and YOUR CHILD

#### 1. What is your relationship to the child who attended the Emergency Department?

| Mother                  |
|-------------------------|
| Father                  |
| Legal Guardian (male)   |
| Legal Guardian (female) |
| Other, please specify   |

#### 2. How old are you?

| Less than 20 years |  |
|--------------------|--|
| 20-30 years        |  |
| 31-40 years        |  |
| 40+ years          |  |

3. If you are a Queensland resident, what is your home postcode OR if you are not a Queensland resident, what is the postcode of the address you were staying at on the date of your child's attendance at the emergency department? \_\_\_\_\_\_

#### 4. What is your highest level of education?

| Did not finish high school  |
|-----------------------------|
| Completed year12            |
| TAFE certificate or diploma |
| Bachelor's degree           |
| Post graduate qualification |
| Other, please specify       |

#### 5. Were you born in Australia?

| Yes                                      |
|--|
| No, please specify your country of birth |

#### 6. How many years have you lived in Australia?

| I have always lived in Australia |  |
|----------------------------------|--|
| Less than 5 years                |  |
| 6-10 years                       |  |
| 10+ years                        |  |
| I live overseas                  |  |

#### 7. What is the main language spoken at home?

| English               |  |
|-----------------------|--|
| Other, please specify |  |

## 8. Do you identify yourself as Indigenous Australian, or Torres Strait Islander, or of Pacific/South Sea Islander descent?

| No                         |
|----------------------------|
| Indigenous Australian      |
| Torres Strait Islander     |
| Pacific/South Sea Islander |

#### 9. Have you been to this or any other children's emergency department?

| No, this is our first time to a children' emergency department |
|--|
| Yes, we have been one other time                               |
| Yes, 2 times before  |
| Yes, 3 or more times   |

#### 10. What is your child's gender?

| Male   |  |
|--------|--|
| Female |  |

#### 11.How old is your child?

\_\_\_\_Years\_\_\_\_\_ months

#### 12. Why did you bring your child to the emergency department?

| My child was sick      |
|------------------------|
| My child was injured   |
| Other (please specify) |

#### 13. What prompted you to take him/her to the emergency department today?

## 14. How anxious are you feeling about your visit to the Emergency Department?

| Extremely<br>anxious | Very anxious | Quite anxious | A little anxious | Not at all<br>anxious |
|----------------------|--------------|---------------|------------------|-----------------------|
| 5                    | 4            | 3             | 2                | 1                     |

## Approximate time of child's arrival at the emergency department.

| Date | Time | AM/PM |
|------|------|-------|
|      |      |       |
### **Telephone Survey**

### SECTION 2: DETAILS ABOUT YOUR VISIT TO THE CHILDREN'S EMERGENCY DEPARTMENT

This section contains questions about your recent visit to the Children's Emergency Department with your child.

### 15. Approximately what time did you and your child leave the emergency department?

Date\_\_\_\_\_Time \_\_\_\_\_AM/PM

### 16. How busy was the emergency department when you first arrived?

| Extremely Busy | Very busy | Quite busy | A little bit busy | Not Busy at all |
|----------------|-----------|------------|-------------------|-----------------|
| 5              | 4         | 3          | 2                 | 1               |

### 17. How noisy was the Emergency Department during your stay?

| Extremely noisy | Very noisy | Quite noisy | A little bit noisy | Not noisy at all |
|-----------------|------------|-------------|--------------------|------------------|
| 5               | 4          | 3           | 2                  | 1                |

### 18. Approximately how long did you wait before you were first seen by a nurse?

| Less than 10 minutes     |
|--------------------------|
| Between 10 to 30 minutes |
| More than 30 minutes     |

### 19. Approximately how long did you wait before you were first seen by a doctor?

| Less than 30 minutes     |
|--------------------------|
| Between 30 to 60 minutes |
| More than 1 hour         |

### 20. What were you told was wrong with your child? (What diagnosis were you

given?)\_\_\_\_\_

21. Please describe what was done for your child (the treatment your child) received while you were in the emergency department.

| <br> | <br> |  |
|------|------|--|
| <br> | <br> |  |
|      | <br> |  |
|      | <br> |  |

### **SECTION 3: AFTER VISITING THE EMERGENCY DEPARTMENT**

This section is about the information you were given, whilst in the Children's Emergency Department, about what to do for your child when you returned home.

Depending upon your responses, it contains up to 37 questions.

## 22. Regarding this visit to the emergency department, were you advised to give your child any medicines when you returned home?



→ Please go to question 26 →Please go to question 23,24 and 25

### 23. Which medicines you were advised to give?

24. What the medicine was for?

### 25. Who gave you the advice?

26. Regarding this visit to the emergency department, were you advised to do any other things to look after your child when you returned home (other than giving medicine)?

| No  |
|-----|
| Yes |

→ Please go to question 29 →Please go to question27 and 28

### 27. What you were advised to do?

### 28. Who gave you the

advice?\_\_\_\_\_

29. Before you left the emergency department, did anyone advise you to visit your family doctor or any other medical service with your child?

| No  |
|-----|
| Yes |

→ Please go to question 33 →Please go to question 30, 31 and 32

30. Who/what were you advised to visit?

### 31. Why you were advised to visit them?

### 32. Who gave you the advice?

**33.** When you were in the emergency department, were you advised to return to the emergency department should your child's signs or symptoms return?

| No  |
|-----|
| Yes |

→ Please go to question 36
→ Please go to question 34 and 35

### 34. What you were told?

| 35. | Who | gave | you | the | advice? |
|-----|-----|------|-----|-----|---------|
|-----|-----|------|-----|-----|---------|

| THE FOLLOWING QUESTIONS ARE ABOUT THE DIFFERENT WAYS THAT YOU MAY HAVE BEEN | I GIVEN |
|---|---------|
| DISCHARGE INFORMATION WHILE YOU WERE IN THE EMERGENCY DEPARTMENT.           |         |

### 36. Were you given any verbal (spoken) discharge information?

| No  |
|-----|
| Yes |

→ Please go to question 40 → Please go to question 37, 38 and 39

### 37. Who provided the verbal(spoken) information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

### 38. How easy was the verbal (spoken) information to understand?

| Very difficult | Quite difficult | Quite easy | Very easy | Extremely easy |
|----------------|-----------------|------------|-----------|----------------|
| 1              | 2               | 3          | 4         | 5              |

## **39.** How useful was the verbal (spoken) information to help you care for your child when you returned home?

| Not at all useful | A bit useful | Quite useful | Very Useful | Extremely useful |
|-------------------|--------------|--------------|-------------|------------------|
| 1                 | 2            | 3            | 4           | 5                |

### 40. Did you receive any handwritten discharge information?

No Yes  $\rightarrow$  Please go to question 44

 $\rightarrow$  Please go to question 41, 42 and 43

### 41. Who provided the handwritten information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

### 42. How easy was the handwritten information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

### 43. How useful was the handwritten information to help you care for your child when you returned

home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### 44. Were you given any printed discharge information e.g. a pamphlet or typed instructions?

| No  | _ |
|-----|---|
| Yes | _ |

→ Please go to question 48→Please go to question 45, 46 and 47

### 45. Who provided the printed information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If <u>Other</u>, please state who gave you the information.

### 46. How easy was the printed information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

### 47. How useful was the printed information to help you care for your child when you returned

home?

| Not at all | A bit  | Quite  | Very   | Extremely | I did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### 48. Were you provided with any Internet-based (website) discharge information?

| No  |
|-----|
| Yes |

→ Please go to question 52 → Please go to question 49, 50 and 51

### 49. Who provided the Internet-based information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

### 50. How easy was the Internet-based information to understand?

| Very difficult | Quite difficult | Quite | Very | Extremely | I did not look at it |
|----------------|-----------------|-------|------|-----------|----------------------|
|                |                 | easy  | easy | easy      |                      |
| 1              | 2               | 3     | 4    | 5         | 0                    |

### 51. How useful was the Internet-based information to help you care for your child when you

### returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### 52. Were you given any discharge information in the form of pictures or diagrams?

**No**  $\rightarrow$  Please go to question 56

**Yes**  $\rightarrow$  Please go to question 53, 54 and 55

### 53. Who provided the picture/diagram information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

### 54. How easy was the picture or diagram information to understand?

| Very difficult | Quite difficult | Quite | Very | Extremely | I did not look at it |
|----------------|-----------------|-------|------|-----------|----------------------|
|                |                 | easy  | easy | easy      |                      |
| 1              | 2               | 3     | 4    | 5         | 0                    |

### 55. How useful was the picture or diagram information to help you care for your child when you returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### 56. Were you provided with any discharge information in the form of a CD or DVD?

| No  |
|-----|
| Yes |

 $\rightarrow$  Please go to question 60 **Yes**  $\rightarrow$  Please go to question 57, 58 and 59

### 57. Who provided the CD/DVD information?

| Nurse                 |
|-----------------------|
| Doctor                |
| Both nurse and doctor |
| Other                 |

If Other, please state who gave you the information

### 58. How easy was the CD/DVD information to understand?

| Very difficult | Quite difficult | Quite<br>easy | Very<br>easy | Extremely<br>easy | I did not look at it |
|----------------|-----------------|---------------|--------------|-------------------|----------------------|
| 1              | 2               | 3             | 4            | 5                 | 0                    |

59. How useful was the CD/DVD information to help you care for your child when you returned home?

| Not at all | A bit  | Quite  | Very   | Extremely | l did not use it |
|------------|--------|--------|--------|-----------|------------------|
| Useful     | useful | useful | useful | useful    |                  |
| 1          | 2      | 3      | 4      | 5         | 0                |

### **SECTION 4: AFTER YOU RETURNED HOME**

This section contains 3 questions about you and your child after you returned home from the Children's Emergency Department.

60. Following this visit to the emergency department, what care did you provide for this child when you returned home?

61. When you returned home, did you have any difficulties managing your child's illness or injury?



If <u>Yes</u>, please describe your difficulties and how you handled them

62. After you returned home, in the first week, did you need to return to the children's emergency department again for the same problem?

| No  |
|-----|
| Yes |

If Yes, please describe what happened

### SECTION 5: YOUR OVERALL EXPERIENCE OF THE EMERGENCY DEPARTMENT

This section contains 4 questions about your experience during and after your recent visit to the Children's Emergency Department.

Please feel free to answer each question in the way that best represents your personal view.

### 63. How anxious were you when you arrived with your child at the emergency department?

| Extremely<br>anxious | Very anxious | Quite anxious | A little anxious | Not at all<br>anxious |
|----------------------|--------------|---------------|------------------|-----------------------|
| 5                    | 4            | 3             | 2                | 1                     |

64. When you left the emergency department, how anxious did you feel about being able to care for your child when you got home?

| Extremely<br>anxious | Very anxious | Quite anxious | A little anxious | Not at all<br>anxious |
|----------------------|--------------|---------------|------------------|-----------------------|
| 5                    | 4            | 3             | 2                | 1                     |

65. Overall, how confident were you about using the discharge information you received from emergency department staff?

| Not at all confident | A little confident | Quite confident | Very confident | Extremely<br>confident |
|----------------------|--------------------|-----------------|----------------|------------------------|
| 1                    | 2                  | 3               | 4              | 5                      |

66. Overall, how satisfied were you with the discharge information you received from the Emergency Department staff?

| Not at all satisfied | A little bit<br>satisfied | Quite satisfied | Very Satisfied | Extremely<br>satisfied |
|----------------------|---------------------------|-----------------|----------------|------------------------|
| 1                    | 2                         | 3               | 4              | 5                      |

### **Telephone Survey Script**

Script 1 – Recruited

May I please speak to \_\_\_\_\_?

Hello, my name is \_\_\_\_\_\_ from TPCH. Thank you for agreeing to take part in a phone survey about your recent experiences in the emergency department. Is this a convenient time to do the survey now?

If yes

Do you have any questions regarding to the information from the survey?

If yes respond to questions

If No begin the survey

If No, ask if a more convenient time can be arranged.

If Yes schedule appointment \_\_\_\_\_\_am/pm. Date\_\_\_\_\_

If they wish to withdraw, explain their rights again and thank them.

Script 2 – End

Thank you very much for your time and participation. Is there anything else you want to say about the discharge information in relation to your experience in the Emergency Department?

Have a good (day/evening).

## Participant Information Sheet: Parent/Guardian's Survey

|                  | -   |
|------------------|---|
| HREC No:         | HREC/15/QPCH/70   |
| Project Title:   | An investigation of the provision of discharge information to parents |
|                  | to care for their child post-discharge from the emergency department: |
|                  | A mixed method study  |
| Name of          | Professor Karen Flowers, Professor Paul Fulbrook, Professor           |
| Researchers:     | Geraldine Naughton, Dr. George Mnatzaganian, Dr Frances Kinnear,      |
|                  | Kodchanipa Phonpruk   |
| Sponsor Details: | Non-Applicable  |
|                  |   |

### **Research Lay Title**

Discharge information for parents in the Children's Emergency Department

### Invitation

You are invited to participate in this study because you have brought your child to the ED today and your child has been discharged home. You are invited to complete an anonymous survey about your experience. Your participation is entirely voluntary and should you choose not to take part, it will not affect in any way the quality of your child's current or future treatment at the hospital.

### Purpose of the study

The purpose of the study is to better understand parents' experiences of receiving and using discharge information from the ED.

### What will happen if you decide not to participate?

You are free to decline the invitation to take part in this study. If you choose not to participate, your child will continue to receive all usual care and treatment. Your decision not to participate in the study will not affect in any way the quality of treatment provided to your child at The Prince Charles Hospital.

### What will happen if you decide to participate?

If you agree to participate in this study, please complete the attached survey 24 to 36 hrs after you return home from the hospital. The survey will ask you to provide some information about yourself and your child, particularly focussing on the discharge information you received in the ED. The survey should take no longer than 10 - 15 minutes to complete. Your responses to the survey will be anonymous, so please don't write your name on the survey.

You have the choice of completing the survey on paper or online if you have access to the internet.

If you choose to complete the paper survey, please use the attached survey and return it in the reply-paid envelope provided. There are further instructions on the survey.

If you choose to complete the survey online, please use this web link to access the survey https://www.surveymonkey.com/r/ED Parent Survey

If you have any difficulties with the web link, please email https://www.EDparentsurvey@gmail.com

Your email address will not be retained.

### Benefits

There are no immediate benefits to you for completing the survey. However, you will be contributing to a better understanding of parents' experiences receiving discharge information and how this can be improved.

### **Risks and Side Effects**

It is not expected that you will have any extra risks or side effects from taking part in this study.

### **Reimbursement/Compensation**

There is no payment for taking part in this study.

### Disclosure

This study is unfunded

### **Further Information**

If you would like further information or have other questions you can contact the Principal Researcher.

### **Contact Details:**

Professor Paul Fulbrook

Nursing Director Research & Practice Development

The Prince Charles Hospital

Rode Road, Chermside QLD 4032

Phone: 07 3139 4087

E-mail : Paul.Fulbrook@health.qld.gov.au

### Independent Contact

If you have any other questions or concerns and wish to discuss your involvement with someone not connected with the study then you may contact Ms Anne Carle, Executive Officer, Research Ethics and Governance Unit, The Prince Charles Hospital on 07 3139 4500 who will forward your concerns to the Chair of the Human Research Ethics Committee.

# Appendix 9: Information sheet, consent form and revocation form for Parents/Guardian's telephone survey

## Participant Information Sheet: Parent/Guardian's telephone survey

| HREC No:         | HREC/15/QPCH/70  |
|------------------|--|
| Project Title:   | Parents' experience in the Children's Emergency department                             |
| Name of          | Professor Karen Flowers, Professor Paul Fulbrook, Professor                            |
| Researchers:     | Geraldine Naughton, Dr George Mnatzaganian, Dr Frances Kinnear,<br>Kodchanipa Phonpruk |
| Sponsor Details: | Non-Applicable   |

### **Research Lay Title**

Parents' experience in the Children's Emergency department

### Invitation

You are invited to participate in this study because you have brought your child to the ED today. You are invited to complete a survey about your experience by telephone interview. Your participation is entirely voluntary and should you choose not to take part, it will not affect in any way the quality of your child's current or future treatment at the hospital.

### Purpose of the study

The purpose of the study is to better understand parents' experiences in the Children's Emergency Department.

### What will happen if you decide not to participate?

You are free to decline the invitation to take part in this study. If you choose not to participate, your child will continue to receive all usual care and treatment. Your decision not to participate in the study will not affect in any way the quality of treatment provided to your child at The Prince Charles Hospital.

### What will happen if you decide to participate?

If you agree to participate in this study, you will be asked some questions about yourself while you are waiting in the Emergency Department with your child and then contacted by telephone 36 to 48 hrs later. The survey questions should take no longer than 10-15 minutes to complete and the phone survey will also be audiotaped. Your responses to the survey questions will be confidential.

### Benefits

There are no immediate benefits to you for completing the survey. However, you will be contributing to a better understanding of parents' experiences in the Emergency Department.

### **Risks and Side Effects**

It is not expected that you will have any extra risks or side effects from taking part in this study.

### **Reimbursement/Compensation**

There is no payment for taking part in this study.

### **Confidentiality and Privacy**

All of your information will be kept confidential. All the study forms will only include a number for identification, so your name and contact details will be kept separate from your study data. Transcriptions of audiotaped survey will not identify you. All paper copies of data will be kept in secure storage when not in use and electronic data will be password protected.

### Disclosure

This study is unfunded

### **Further Information**

If you would like further information or have other questions you can contact the Principal Researcher.

### **Contact Details:**

Professor Paul Fulbrook

Nursing Director Research & Practice Development

The Prince Charles Hospital

Rode Road, Chermside QLD 4032

Phone: 07 3139 4087

E-mail: Paul.Fulbrook@health.qld.gov.au

### Independent Contact

If you have any other questions or concerns and wish to discuss your involvement with someone not connected with the study then you may contact Ms Anne Carle, Executive Officer, Research Ethics and Governance Unit, The Prince Charles Hospital on 07 3139 4500 who will forward your concerns to the Chair of the Human Research Ethics Committee.

## **Consent Form: Parents/Guardian's telephone survey**

| HREC No:             | HREC/15/QPCH/70   |
|----------------------|---|
| Project Title:       | Parents' experience in the Children's Emergency department  |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook, Professor<br>Geraldine Naughton, Dr George Mnatzaganian, Dr Frances<br>Kinnear, Kodchanipa Phonpruk |
| Sponsor Details:     | Non-Applicable  |

I agree to participate in the above-named project and in so doing acknowledge that:

- I have read and understood the information provided in the Information Letter about the study, requesting my permission to be contacted by telephone 36 to 48 hrs after Emergency Department with my child. I have been informed that the phone survey will be audiotaped.
- I am aware that, although the project is directed to the development of knowledge of Emergency Department care, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to my child.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment provided for my child.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I understand that, in respect of any information gathered during the course of the project; confidentiality will be maintained. In the event of any results of the project being published, I will not be identified in anyway.

| Participant's telephone number: _ |            |       |       |
|-----------------------------------|------------|-------|-------|
| A convenient time to call:        |            |       | AM/PM |
| Participant's name:               | Signature: | Date: | //    |
| Name of Investigator:             | Signature: | Date: | / /   |

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## **Revocation of Consent Form: Parents/Guardian's telephone survey**

| HREC No:             | HREC/15/QPCH/70  |  |
|----------------------|--|--|
| Project Title:       | Parents' experience in the Children's Emergency department   |  |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook,<br>Professor Geraldine Naughton, Dr George<br>Mnatzaganian, Dr Frances Kinnear, Kodchanipa<br>Phonpruk |  |
| Sponsor Details:     | Non-Applicable   |  |

• I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with The Prince Charles Hospital Metro North Health Service District.

Participant's name (please print): .....

| (Signature) |  |  |
|-------------|--|--|
|-------------|--|--|

This Revocation of Consent should be forwarded to:

Professor Paul Fulbrook,

Nursing Director

Research & Practice Development

The Prince Charles Hospital

Metro North Hospital and Health Service

Rode Road, Chermside, Qld, 4032

Appendix 10: Information sheet, consent form and revocation form for Staff observation and focus group

| HREC No:         | HREC/15/QPCH/70  |
|------------------|--|
| Project Title:   | An investigation of the provision of discharge information to<br>parents to care for their child post-discharge from the<br>emergency department: A mixed method study |
| Name of          | Professor Karen Flowers, Professor Paul Fulbrook, Professor  |
| Researchers:     | Geraldine Naughton, Dr George Mnatzaganian, Dr Frances<br>Kinnear, Kodchanipa Phonpruk   |
| Sponsor Details: | Non-Applicable   |

## **Participant Information Sheet: Observation (ED staff)**

### **Research Lay Title**

Discharge information for parents in the Children's Emergency Department

### Invitation

As you work in the Children's Emergency Department, you are invited to participate in observation of a sample of parents as they progress through the ED with their child. You would be observed interacting with consenting parents in the Emergency Department, though the focus of the research is on the parents' experience.

The results of the study will contribute to the evidence base for discharge practices, protocols, procedures, guidelines, and resources that may increase parents' understanding of discharge information.

Your participation is entirely voluntary, and should you choose not to take part, it will not affect in any way your employment at the hospital.

### Purpose of the study

The purpose of the study is to investigate parents' experiences of receiving and using discharge information from the Children's ED to care for their child at home.

### What will happen if you decide not to participate?

You are free to decline the invitation to take part in this study. You can change your mind and withdraw from the study at any time over the project period without consequences to your employment at the Prince Charles Hospital.

### What will happen if you decide to participate?

If you agree to participate in this study, you will be asked to sign a consent form. Please ensure that questions about the study have been satisfactorily answered before you sign the consent form.

If you choose to participate in the observation activity, you will be consenting to be observed by the student researcher during your interactions with the parents being observed in the ED.

The student researcher will not be involved in any aspects of care, nor will she ask any questions. She will be sitting quietly in the background. The notes taken during observation will be used for the study which may be published or may be provided to other researchers in a form that does not identify you in any way.

### Benefits

There are no immediate benefits to you for sharing your experience or your process of care or in being observed. However, you will be contributing to the knowledge base about discharge processes.

### **Risks and Side Effects**

It is not expected that you will experience any risks or side effects from taking part in this study.

### **Reimbursement/Compensation**

This study will be undertaken in the Children's Emergency Department within The Prince Charles Hospital. There is no payment for taking part in this study.

### **Confidentiality and Privacy**

All of your information will be kept confidential. All the study forms will only include a number for identification, so your name and contact details will be kept separate from your study data. Transcriptions of audio taped focus group discussions will not identify you. All paper copies of data will be kept in secure storage when not in use and electronic data will be password protected.

### Disclosure

This study is unfunded, and there are no restrictions on dissemination of the study results.

### **Further Information**

If you would like further information or have other questions you can contact the Researcher.

### **Contact Details:**

Professor Paul Fulbrook

Nursing Director Research & Practice Development

The Prince Charles Hospital

Rode Road, Chermside QLD 4032

Phone: 07 3139 4087

E-mail: Paul.Fulbrook@health.qld.gov.au

### **Independent Contact**

If you have any other questions or concerns and wish to discuss your involvement with someone not connected with the study then you may contact Ms Anne Carle, Executive Officer, Research Ethics and Governance Unit, The Prince Charles Hospital on 07 3139 4500 who will forward your concerns to the Chair of the Human Research Ethics Committee.

### **Observation Participant Consent Form: Emergency Department Staff**

| HREC No:             | HREC/15/QPCH/70  |
|----------------------|--|
| Project Title:       | An investigation of the provision of discharge information to<br>parents to care for their child post-discharge from the<br>emergency department: A mixed method study |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook, Professor<br>Geraldine Naughton, Dr George Mnatzaganian, Dr Frances<br>Kinnear, Kodchanipa Phonpruk                  |
| Sponsor Details:     | Non-Applicable   |

I agree to participate in the above-named project and in so doing acknowledge that:

- I have been informed as to the nature and extent of any risk to me. I have read and understood the information provided in the observation Information sheet, with the understanding that I may be observed during interactions with parents of children in the ED.
- I am aware that, although the project is directed to the expansion of emergency care knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect my employment in the Prince Charles Hospital.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect my employment in the Prince Charles Hospital.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that the research assistant may be informed that I am taking part in the project.
- I understand that, in respect of any information gathered during the course of the project; confidentiality will be maintained. In the event of any results of the project being published, I will not be identified in any way.
- I agree to be observed in the ED, while parents are being followed through the ED with their child.

Participant's name: ..... Date: \_ / \_ / \_ / \_\_

| Name of Investigator: | Signature: | Date: / | ' / | / |
|-----------------------|------------|---------|-----|---|
|                       | -0         | ····/   | '   |   |

## **Observation Participant Revocation of Consent Form**

| HREC No:             | HREC/15/QPCH/70  |
|----------------------|--|
| Project Title:       | An investigation of the provision of discharge<br>information to parents to care for their child post-<br>discharge from the emergency department: A mixed<br>method study |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook,<br>Professor Geraldine Naughton, Dr. George<br>Mnatzaganian, Dr Frances Kinnear, Kodchanipa<br>Phonpruk                  |
| Sponsor Details:     | Non-Applicable   |

• I hereby wish to WITHDRAW my consent to participate in research project as described above and understand that such withdrawal WILL NOT jeopardise my employment at The Prince Charles Hospital Metro North Health Service District.

| Participant's name | (please print): |
|--------------------|-----------------|
|--------------------|-----------------|

(Signature).....

| Date: | // | / |
|-------|----|---|
|-------|----|---|

This Revocation of Consent should be forwarded to:

Professor Paul Fulbrook,

**Nursing Director** 

**Research & Practice Development** 

The Prince Charles Hospital

Metro North Hospital and Health Service

Rode Road, Chermside, Qld, 4032

Appendix 11: Information sheet, consent form and revocation form for Parents/guardians observation

# Participant Information Sheet: Observation in the ED (Parents/Guardians)

| HREC No:         | HREC/15/QPCH/70  |
|------------------|--|
| Project Title:   | Parents' experience in the Children's Emergency Department                             |
| Name of          | Professor Karen Flowers, Professor Paul Fulbrook, Professor                            |
| Researchers:     | Geraldine Naughton, Dr George Mnatzaganian, Dr Frances Kinnear,<br>Kodchanipa Phonpruk |
| Sponsor Details: | Non-Applicable   |

### **Research Lay Title**

Parents' experience in the Children's Emergency Department

### Invitation

You are invited to participate in this study because you have brought your child to the ED today. I am a paediatric nurse from Thailand undertaking a PhD and I am interested in Children's Emergency Departments in Australia. I would like to observe your journey through the ED with your child from admission through to discharge.

### Purpose of the study

The purpose of this study is to learn about the experience of parents in the children's ED to inform improvements in emergency department care.

### What will happen if you decide not to participate?

You are free to decline the invitation to take part in this study. If you choose not to participate, your child will continue to receive all usual care and treatment. Your decision not to participate in the study will not affect in any way the quality of treatment provided to your child at The Prince Charles Hospital.

### What will happen if you decide to participate?

If you agree to participate in this study, you will be asked to sign a consent form to give permission for your journey through the ED with your child to be observed. I will not be involved in any aspects of care, nor will I ask any questions. I will be sitting quietly in the background. The notes taken during observation of your experience in the ED will be used for the study which may be published or may be provided to other researchers in a form that does not identify you or this child in any way.

### Benefits

There are no immediate benefits from supporting the study. However, you will contribute to a better understanding of parents' experiences in the emergency department and potential improvements in emergency department care.

### **Risks and Side Effects**

There are no foreseen risks in participating in an observation of your experiences today.

### **Reimbursement/Compensation**

This study will be undertaken while you are in the Emergency Department within The Prince Charles Hospital. There is no payment for taking part in this study.

### **Confidentiality and Privacy**

All of your information will be kept confidential and private. All the study forms will only include a number for identification, so your name and contact details will be kept separate from your study data. All paper copies will be kept in secure storage when not in use and electronic data will be password protected.

### Disclosure

This study is unfunded.

Further Information

If you would like further information or have other questions you can contact the Researcher.

### **Contact Details:**

Professor Paul Fulbrook

Nursing Director Research & Practice Development

The Prince Charles Hospital

Rode Road, Chermside QLD 4032

Phone: 07 3139 4087

E-mail : Paul.Fulbrook@health.qld.gov.au

### **Independent Contact**

If you have any other questions or concerns and wish to discuss your involvement with someone not connected with the study then you may contact Ms Anne Carle, Executive Officer, Research Ethics and Governance Unit, The Prince Charles Hospital on 07 3139 4500 who will forward your concerns to the Chair of the Human Research Ethics Committee.

## **Observation Consent Form: Parents/Guardians**

| HREC No:             | HREC/15/QPCH/70  |  |  |
|----------------------|--|--|--|
| Project Title:       | Parents' experience in the Children's Emergency department   |  |  |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook,<br>Professor Geraldine Naughton, Dr. George Mnatzaganian,<br>Dr Frances Kinnear, Kodchanipa Phonpruk |  |  |
| Sponsor Details:     | Non-Applicable   |  |  |

I agree to participate in the above-named project and in so doing acknowledge that:

- I have read and understood the information provided in the Information Letter about the study, requesting my permission to be observed with my child during the time I am in the Emergency Department.
- I am aware that, although the project is directed to the expansion of Emergency Department care knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to my child.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment provided for my child.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that the research assistant may be informed that I am taking part in the project.
- I understand that, in respect of any information gathered during the course of the project; confidentiality will be maintained. In the event of any results of the project being published, I will not be identified in any way.

| Participant's name: | .Signature: | Date: | / / | 1 |
|---------------------|-------------|-------|-----|---|
|                     |             | /     | '   |   |
|                     |             |       |     |   |

| Name of Investigator: | Signature:    | Date:  | / | / |
|-----------------------|---------------|--------|---|---|
|                       | e.B. aca el m | Date:/ | / |   |

| HREC No:             | HREC/15/QPCH/70   |  |
|----------------------|---|--|
| Project Title:       | Parents' experience in the Children's Emergency department  |  |
| Name of Researchers: | Professor Karen Flowers, Professor Paul Fulbrook,<br>Professor Geraldine Naughton, Dr. George<br>Mnatzaganian, Dr Frances Kinnear, Kodchanipa<br>Phonpruk |  |
| Sponsor Details:     | Non- Applicable   |  |

## **Observation Revocation of Consent Form: Parents/Guardians**

• I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with The Prince Charles Hospital Metro North Health Service District.

Participant's name (please print): .....

| ignature) |
|-----------|
|-----------|

| Date:// | _ |
|---------|---|
|---------|---|

This Revocation of Consent should be forwarded to:

Professor Paul Fulbrook, Nursing Director Research & Practice Development The Prince Charles Hospital

Metro North Hospital and Health Service

Rode Road, Chermside, Qld, 4032