

# Examining the patient experience in a paediatric oncology outpatient clinic

Kalissa Jeanette Brooke-Cowden

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Department of Health Systems and Populations,  
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and  
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## Summary

Evidence regarding patient experiences within the paediatric oncology outpatient context is limited. This study examined the patient/carer experience focussing on patient wait times, patient-clinician interactions and progression through outpatient visits. A mixed-methods design using a time and motion study and semi-structured interviews was employed. Quantitative data collection from 20 patients/family units generated timing evidence of the outpatient visit, while qualitative data obtained from 24 interviews of patients and carers provided vital information from the patient/carer perspective. The results showed that, during an outpatient visit of over 4 hours' duration, patients spend almost 3.5 hours of 'waiting' (including over one hour of waiting before a doctor consultation, and over 2 hours receiving treatment), and participate in an average doctor-patient consultation of approximately 12 minutes. Key factors influencing the outpatient experience included the unpredictable duration of wait intervals, patient-clinician relationships, communication and provision of information, lack of autonomy and oncology-derived complexities. Patients and carers most valued ongoing relationships with their care providers, and the quality of service provided by the clinic. Obtaining patient-centric evidence of a health service is essential in monitoring service quality, understanding service impacts and for future service improvements. Investigation of the patient perspective provides a more comprehensive understanding of the service and ensures that the patient voice is considered.

## Statement of Originality

*This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.*

(Signed) \_\_\_\_\_ Date: 17/10/2019

Candidate's name



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## Abbreviations

A&E – Accident and Emergency

Av. - Average

CMO – Career Medical Officer

CPOE – Computerised Provider Order Entry

CVL – Central Venous Line

DES – Discrete Event Simulation

EHR – Electronic Health Record

eMR – Electronic Medical Records

eMM - Electronic Medical Management

ERI – Emotional Reaction Instrument

IS – Information Software

IV - Intravenous

No. – Number

PACU – Paediatric Ambulatory Care Unit

PDA - Personal Digital Assistant

Port – Port-a-cath

TMS - Time and Motion Study

TV - Television

WOMBAT – Work Observation Method By Activity Timing

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# CHAPTER ONE: INTRODUCTION

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# 1. Introduction

This introductory chapter establishes the scope of the research presented in this thesis by giving an overview of paediatric oncology in the outpatient setting and highlighting the importance of examining the patient experience. A statement of the research aim concludes this brief synopsis.

## 1.1 The Merit in Examining Outpatient Paediatric Oncology: A Public Health Aspect

The medical specialty of oncology involves the “investigation, diagnosis and treatment of people with cancer or suspected cancer” (1). This is further specialised into paediatric oncology, which explicitly refers to the management and treatment of children with cancer, from newborn until the age of 18 years. As a cancer diagnosis is non-discriminatory and ubiquitous, the examination of, and improvements in paediatric cancer services has a comprehensive community-wide application. This thesis will consider the nature of outpatient paediatric oncology visits from the patient (and carer) perspective.

The public demand for cancer treatment services has risen over recent decades following an increased global incidence of cancer diagnoses and the expanding utility of chemotherapy treatments (2-5). Whilst the incidence of childhood cancer remained relative stable in Australia over the decade 1996 – 2005, childhood cancer incidence has actually risen by 34% from 1983 – 2015, with predictions of a further increase to 38% over the next two decades (to 2035) (6). Similar increases have been reported in Asia and North America (6). This has service planning implications including workforce requirements, hospital bed capacities and service delivery to the increasing number of childhood cancer patients (6). Owing to hospital capacity constraints, a notable trend in the reliance and preference for the delivery of cancer care in an ambulatory (or outpatient) setting has been observed in both adult and paediatric patients (2, 3, 7-9). Technological advancements, in parallel with increasing sophistication and evolution of procedures and treatment regimens, have enabled the safe operation of paediatric chemotherapy administration in the outpatient setting (10, 11). Accordingly, administration of chemotherapy has undergone a transformative process in which

governance has largely changed from an inpatient to an outpatient practice (7, 9, 11-13). Delivery of paediatric oncology services in the outpatient setting has become a normative practice, representing certain cost and staff efficiencies for the healthcare provider, and convenience for patients and their families (13). However, service limitations such as fixed operational hours and finite resourcing, have resulted in lengthy wait times (12, 13). This has given rise to considerable stress and frustration for patients and their carers, whilst negatively impacting staff morale (13). Confronted with the burden of increasing demand and an exacerbation of negative sequelae, it is imperative that any forward planning of services be evidence-based. Development of “public strategy, planning and investment” for our future population needs must be underpinned by patient experience data, to facilitate the provision of optimal standards of care and favourable clinical outcomes (p.120)(3).

Chemotherapy administration (the use of medications to treat cancer) in children presents unique challenges in its delivery and safety. The provision of oncology treatments in paediatric patients is acknowledged as procedurally complex, with inherent risks in ordering, administration and monitoring which serve to differentiate oncology from other medical specialties (14, 15). Patient dosing requirements are individualised according to diagnosis, patient physiology and fluctuating clinical status, and chemotherapy regimens must be precisely calculated due to their high toxicity and narrow therapeutic windows (7, 11, 16, 17). Challenges specific to the delivery of paediatric chemotherapy include unanticipated and frequent adjustments of chemotherapy orders, fragmentation of care, communication issues, and the intense monitoring which is required (7). Systems and processes which promote safety in paediatric chemotherapy are necessary, especially in the outpatient context (16). Implementation of health information technologies, such as electronic medication management systems (eMM) and electronic medical records (eMR) with clinical decision support, have been shown to reduce most serious medication errors and subsequent patient harms, in addition to decreasing clinical workflow inefficiencies (18-20). Immediacy of staff access to a comprehensive patient record promotes the flow of information between clinicians and patients, ultimately improving care coordination (12).

The potential benefits of health information technologies also include the prospect of improving the patient experience by minimising treatment delays, thereby ameliorating significant

stress and enhancing the quality of patient-clinician encounters. Wait periods experienced by recipients of outpatient oncology services are invariably problematic, thus service improvements often focus on this aspect of care.

## **1.2 Research Aim**

This project sought to examine the experience of paediatric oncology outpatients, with respect to waiting times, progression through the outpatient visit and the patient-clinician interaction.

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# CHAPTER TWO: LITERATURE

## REVIEW

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## **2. Literature Review**

As outlined in the preceding chapter, a burgeoning demand for paediatric oncology services in recent times has necessitated the expansion and evolution of outpatient chemotherapy services to cater for an increased public need. Service must be guided by evidence that is patient-centric to ensure relevance to the recipients of the service. Research efforts to date have largely examined general (adult) oncology services. It is prudent, therefore, to seek understanding and insight into the conditions faced by paediatric patients and their families, in order to evaluate contentious issues and challenges found within this context.

Through a review of the literature, this chapter will examine established evidence of patient experiences in outpatient clinics of paediatric oncology services. It also seeks to identify the approaches used to examine patient experiences.

### **2.1 Database Search**

A search of the literature involved consultation of three databases: MEDLINE, SCOPUS and Google Scholar. Final key terms and filtering of the journal articles retrieved in the literature search are presented in Table 1. Filtering of the literature resulted in the retrieval of 25 articles from Medline, 14 articles from Scopus, and 35 from Google Scholar. A paucity of research was identified in the area of outpatient paediatric oncology. Accordingly, comparative studies in general oncology services, adult oncology services, and other paediatric sub-specialty clinics were included for the purpose of examining studies of patient experiences in this setting.

**Table 1. Database Search**

Database	Search Terms	Exclusions
<b>Medline</b>	Drug therapy Oncology service, hospital Outpatients clinic, hospital Waiting times	Language (non-English) Complementary or alternative medicine Clinical/pharmacological studies Cost-efficiency studies
<b>Scopus</b>	Child* OR p*ediatric (abstract) Chemotherapy OR “Chemotherapy administration” OR oncology OR cancer (abstract) Wait* OR “patient journey” OR “patient satisfaction” OR “patient experience” Outpatient* OR “day unit” OR clinic OR “day therapy” (abstract)	Non-oncological Non-patient focused studies Nursing – general Appointment scheduling Clinical non-attendance Medical scheduling Palliative care Patient discharge focus Primary or secondary care Primary care referrals In-patient service Strategy/quality assurance/performance management/policy reports Surgical Education focus Waiting list investigations
<b>Google Scholar</b>	Searched to provide definitions: oncology, chemotherapy administration, work sampling and time and motion studies  Cross-referencing of articles accessed from Medline and Scopus	

## 2.2 Defining Patient Experience

In the published literature, patient experiences or journeys are ambiguously defined according to the idiosyncrasies of each study, thus often incorporate different criteria. The difficulty, according to Bate and Robert (2006), is that experience cannot be “accessed or observed directly” (p.308)(21). In reviewing the literature, the magnitude of the challenge involved in examining and

quantifying patient experiences was evident. The construct of 'patient experience' represents a unique, indeterminate and encompassing dimension which influences patient perception (22). Coulter et al. (2014) conclude that an optimal means for gathering patient experience data is lacking (23). LeVela and Gallan (2014) highlight the difficulties in deciding upon which concepts to focus, for example: quality, patient-centredness or satisfaction (amongst other concepts) (22). A review of the literature illustrated disparity between usage of the terms 'patient journey' and 'patient experience.' These two terms whilst sometimes used interchangeably, are often poorly defined. 'Patient journey' is commonly affiliated with process mapping techniques, whereas 'patient experience' more closely correlates with a determination of patient satisfaction and perceived quality of care.

McKinnon et al. (1998) examined outpatient experiences across several medical specialties to obtain a broad patient perspective about their visits and to establish the role effective patient-clinician communication has on patient experience, satisfaction and engagement (24). Yates (2004) refers to the cancer patient journey, describing its passage over an extensive time frame from the point of diagnosis, onward. Within this article, the patient journey was likened to a 'complex maze,' comprising numerous treatments conducted across a variety of health care settings, with a multitude of health providers (25). Trebble et al. (2010) also use patient journey terminology, characterising encounters at a more basic level and defining the process of care as "a series of consecutive events or steps" (p.394)(26). This perspective aligns more closely with the scope of the current study, in which patient experiences in outpatient paediatric oncology encompasses patient encounters with the health system as patients navigate through their outpatient visit. Consideration of the patient experience in this paediatric oncology setting is defined from patient arrival at clinic reception, to the completion of chemotherapy treatment during an observed outpatient visit. At a more granular level, and in the context of this study, the outpatient visit may be composed of a series of patient-clinician encounters interspersed by wait times; whereby patient-clinician encounters refer to interactions between the patient and doctors or nursing staff.

## **2.3 Examining Patient Experience**

Examination of patient experiences or journeys is primarily used to improve health outcomes and service delivery, and to measure the quality of care received (27). Meyer (2019) states that “patient experience is integral to patient-centred care” and has positive affiliations with both clinical safety and medical outcomes (p.103)(28). However, the justification for choosing a research methodology, as reported in the published literature, differs according to the outcome measures desired and availability of resources. LeVela and Gallan (2014) note an increasing desire for evaluation and measurement of patient experience and suggest that whilst broader healthcare goals encompass the provision of cost-effective population level health services, input from the recipients of these services will ensure a patient-centric focus (22). The controversy in standardising an approach for gauging patient experiences remains (22, 27). Consequently, considerable variation exists in the processes used for analysing patient experiences, as individual healthcare providers are unrestricted in determining the nature of measurement or surveillance of their service. Baron (2009) refers to the patient journey as a process, arguing that establishing patients’ expectations and learning about their experiences is fundamental when redesigning and improving the delivery of patient-centred care (29).

Investigations of patient experiences or journeys in the existing literature frequently involved the aspects of wait times, provider communication and patient/family interaction with clinicians. Several studies evaluated patient experience within a psychosocial context. The principal focal points for investigating patient experience included:

- patient satisfaction with respect to wait times;
- patient satisfaction with respect to service quality; and
- psychosocial factors influencing patient experiences.

### **2.3.1. Patient Satisfaction Measures Relating to Wait Times**

Patient satisfaction was consistently evaluated in the context of patient experiences and patient journeys. Satisfaction, frequently expressed in terms of wait times and waiting room

experiences, was the focus of the majority of studies in outpatient oncology when evaluating service quality and service delivery (3, 4, 13, 16, 30-41). Wait times were invariably considered the worst aspect of care delivery in the outpatient setting. Complaints often centred around experiencing unacceptable delays, leading to service dissatisfaction (13, 34, 39). Unsurprisingly, improving or enhancing patient wait times were fundamental goals for many such studies, and a variety of approaches for accomplishing this aim were described in the literature.

Hendershot et al. (2005) identified various factors contributing to the lengthy waits patients experience in outpatient oncology, including: lengthy registration processes, lag times associated with accessing results from lab tests, necessary time spent performing patient assessments and preparation of treatments, and capacity and resource constraints (13). In their study, improvements in waiting times were achieved by creating an express pathway for a cohort of clinically-well acute lymphoblastic leukaemia patients (13). The patient population serviced by the clinic were segmented according to their treatment pathways, and nursing resources were optimised to improve patient flow within the existing clinic operating hours. The cohort of patients with shorter treatment times were effectively expedited, providing additional capacity for the remainder of the patient population, and shortening the wait periods overall (13).

Process mapping was used in several studies to address the issue of reducing patient wait times, and to subsequently inform new practice processes (3, 20, 33). Specific reductions in patient wait times were reported by some researchers. In their general oncology clinic study, Kallen et al. (2012) note an overall reduction in patient wait time of 19.4 minutes (representing a 26.8% reduction) (35). This was accomplished through process mapping and the institution of appointment scheduling and management software. Pirnejad et al. (2013) conducted a pre—post study to measure the difference in wait times and reported an overall reduction in turnaround time of 18.9 minutes for their paediatric oncology patients, for a common chemotherapy protocol (20). A Canadian study by Suss et al. (2017) conducted in an adult outpatient oncology unit, used process mapping and simulation modelling to achieve a 44% reduction in patient wait times (39). An earlier study in Iran by Asefzadeh (1997), was unique in documenting wait times and timing of patient-clinician encounters in a paediatric outpatient setting, using a manual sampling method (41). The

study described the methodology as a non-computerised data collection technique, whereby a paper-based checklist issued to each patient, was presented to staff at each treatment service station attended by patients during their visit. Staff members manually recorded entry and exit times to services within the clinic, for each patient over a 24-hour period. Analysis of the data was used to determine the length of waiting times and clinician consultations. On average, paediatric patients were found to wait 77 minutes, for a 3.4-minute appointment with a doctor (41). Despite a preoccupation with improving wait times in oncology clinics, Thomas et al. (1997) advise that this matter is secondary to the importance of care quality, suggesting that “an over-reliance on reducing waiting times to enhance patient satisfaction may be misplaced” (p.54)(4).

Wait times have been found to exert some influence over patients’ perceived quality of care. Becker and Douglass (2008), for example, report a discrepancy between actual wait times and perceived wait times, suggesting that an association exists between the attractiveness of the outpatient environment and overall satisfaction and quality of care (31). Several other researchers were found to endorse this idea (42, 43). Additionally, Rondeau (1998) suggests that satisfaction in the general patient population may be determined by the quality of the wait experience, highlighting the factors from Maister’s earlier propositions (1995), including concepts such as waiting seems longer if unoccupied or when the duration is unknown, and when patients are anxious. See Table 2 (Copyright Permission Licence Number 4680590741629 – See Appendix B for document) (44).

Note: In the context of this thesis, “wait time” and “waiting time” are used interchangeably and may be defined as a period of time during which a patient is not interacting with or receiving care from clinic staff.

**Table 2. "Psychological Factors Moderating the Perception of the Clinic Waiting Experience" (Maister, 1985)(44).**

<b>Psychological Factors Moderating the Perception of the Clinic Wait Experience<sup>21</sup></b>	
<p><b>Unoccupied Time Feels Longer than Occupied Time</b></p> <p>When customers are unoccupied, they will be more likely to experience boredom and will witness the passage of time more slowly. <i>Implication:</i> fill wait times by engaging, entertaining, or educating patients. <i>Example:</i> provide interesting and engaging reading materials for adults or fun play toys for children.</p>	<p>inform patients how long they will be required to wait before receiving the service. <i>Example:</i> clinic appointment times are strictly enforced, and if unable, patients are constantly updated of their place in the queue.</p>
<p><b>Pre-process Waits Seem Longer than In-process Waits</b></p> <p>When wait times are occupied with activities that relate to the upcoming service, customers are more likely to believe that the service has already begun. <i>Implication:</i> differentiate stages of waiting by providing patients with various pre-process activities. <i>Example:</i> require patients to fill out health information, receive pre-treatment or counseling, or watch a customized health video presentation before receiving the primary service.</p>	<p><b>Unexplained Waits Feel Longer than Explained Waits</b></p> <p>When customers understand the causes for the service delay, they will be more patient and less anxious. <i>Implication:</i> communicate extensively with patients concerning the wait experience. <i>Example:</i> provide updates to patients every 15 minutes informing them of queue progress and how long they will have to wait.</p>
<p><b>Anxiety Makes Waits Feel Longer</b></p> <p>When customers are unsure about the treatment and its outcomes, they are more likely to feel apprehensive and anxious. <i>Implication:</i> reduce anxiety associated with the wait process. <i>Example:</i> entertain children with a puppet show or magic tricks or provide beverages, snacks, or condiments to those waiting.</p>	<p><b>Unfair Waits Seem Longer than Equitable Waits</b></p> <p>When customers are unsure of the selection rules governing the wait process, believe them to be unfair, or believe they are being applied in an inconsistent way, they will be less likely to be tolerant of a lengthy wait. <i>Implication:</i> codetermine with patients the decision rules governing how the wait queue will be serviced. <i>Example:</i> a service queue that works on a "first-come, first-served" basis can be used as a way of combating perceived unfairness.</p>
<p><b>Uncertain Waits Seem Longer than Known, Finite Waits</b></p> <p>When customers know how long they will have to wait, they will tend to experience the passage of time more quickly. <i>Implication:</i> use an appointment system or</p>	<p><b>Solo Waits Feel Longer than Group Waits</b></p> <p>When customers are required to wait in isolation with others, they are less likely to be tolerant of a long wait. <i>Implication:</i> increase the communal sense of the wait process by encouraging social bonding among those waiting. <i>Example:</i> pre-seat those in the clinic according to age, socioeconomic status, personality attributes, interests, medical condition, etc.</p>

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### **2.3.2. Patient Satisfaction Measures and Quality of Care**

In the interpretation of patient experience, the perception of quality of care by patients was another consistent theme. Care quality, found to strongly correlate with patient satisfaction, encompasses the comfort of patients (and families or carers) with the level of care received from clinic staff. Whilst many factors contributed to patient assessments of outpatient oncology service quality, communication of information by clinicians appeared to be paramount (4, 9, 10, 31, 34, 36, 37, 42, 45-47). Provider communication of information (exchange of information between clinicians and patients), appeared to be closely linked with perceived quality of care, such that patients who felt better informed about their condition reported higher satisfaction levels (36, 47). Research by Fossa et al. (1996), in the examination of an adult oncology outpatient service, linked patient satisfaction with feelings of being well-informed, having meaningful patient-clinician interactions and experiencing minimal wait times during the treatment cycle (36). Meaningful patient-clinician interactions can be achieved through the development of trusting relationships, which promotes effective communication between patients and their treating doctor (48). With the advent of medical technologies such as the electronic medical record (eMR), speculation has emerged over potential ramifications for the patient-clinician interaction. Investigations into impacts on this relationship have largely focussed on the clinician's viewpoint, however, a cross-sectional survey conducted by Sharaani et al. (2017) explored the patient perspective. This study assessed the impact of computer use on interpersonal and communication skills of doctors in family medical clinics. The findings indicated that most patients (62%) did not consider computer use detrimental, however 14% of patients did report a negative effect on interactions (49). The study reported that the strongest predictor of good communication between patients and their treating doctors, was having an ongoing relationship. Additionally, use of the eMR to share information with patients, was found to enhance communication (49). A recent qualitative research study conducted in Lebanon reported similar findings; patients predominantly agreed that eMR use within patient-clinician consultations was beneficial, enhancing the encounter with regards to information retrieval, and sharing of information (50). However, computer use was perceived to negatively impact discussion of personal or intimate issues, and some patients were reluctant to interrupt clinicians whilst using the computer (50).



A patient's perception of care quality was also influenced by the caring attitudes of doctors, familiarity with the treating nurses, teamwork exhibited by clinic staff, and patients seeing their own doctor (reflecting continuity of care) (4, 9, 10, 13, 34, 36, 37, 42, 47). Satisfaction and comfort levels of patients were reportedly higher under these circumstances. Patients rated the standard of care as being higher when emotional support was forthcoming, i.e. with doctors exhibiting concern over patient wellbeing; questions or concerns were adequately addressed by clinicians; and when doctors demonstrated familiarity or personal knowledge of a patient's history (9, 34, 36, 42, 45, 47). Interestingly, Brown et al. (2006) noted that higher overall ratings of perceived quality of care were likely in patients whose health status was better (34).

### **2.3.3. Patient Experiences and Psychosocial Impacts**

Psychosocial support in the clinic waiting area has long been recognised as a significant source of concern for oncology patients, their families and carers. In a paediatric oncology study, Corsano et al. (2010) described the waiting room experience as a condition of stress and anxiety for parents, admixed with an underlying boredom encountered by all those waiting (51). Survey data revealed that children considered the outpatient experience as routine, although low levels of anxiety, fear, sadness and discomfort were also noted. To resolve and improve the patient/carer experience, it was suggested that social and spatial distractions be provided for patients, in addition to the facilitation of social interaction amongst parents (51). This resonates with earlier recommendations from a study conducted by Hoffman and Futterman (1971), in which "institutionalised social structures" involving therapeutic use of the waiting period, were suggested to facilitate resilience and active coping mechanisms of patients and their family members (p.79)(52). In an adult oncology study, Hjorleifsdottir et al. (2010) examined patient satisfaction regarding their care and service, asserting that cancer treatments impact patients psychosocially by prolonging both dependency on healthcare providers and distress as a result of their condition, negatively influencing patient satisfaction (10).

## 2.4 Methodological Approaches for Evaluating Patient Experience

The measurement tools and techniques employed in examining or enhancing patient experiences included a combination of surveys or questionnaires, simulations, process mapping, interviews and observational techniques. Due to the age constraints of paediatric patients, family members (usually parents) and treating staff were often included as study participants.

Surveys or questionnaires were found to be the most widely used research tools for collecting patient experience data in oncology (2-4, 10, 13, 31, 35-37, 42, 45, 51, 53-57). These quantitative methodologies are advantageous in their relative simplicity, and in allowing large sample sizes as well as greater capacity for comparisons and associations (49). Examples include research by Fossa et al. (1996), in which several questionnaires were conducted over a 2-year interval; and the development and distribution of a comprehensive quality of life (QOL) questionnaire by Hjörleifsdóttir et al. (2010), specifically tailored to the outpatient oncology population (10, 36). It must be noted that these examples were targeted towards the general oncology population, rather than the paediatric sub-population. Capturing data on patient experiences was commonly conducted using Likert-type survey instruments, which were usually distributed to the parents, caregivers or family members of the patient. Survey or questionnaire data was used in some studies to draw comparisons over different timeframes, or otherwise data were simply collated pre- and post-implementation (20, 35, 45, 58).

Data derived from qualitative methods such as interviews, focus groups or ethnographic studies, are suggested as being more representative of the patient experience (22, 59, 60). Further detail, contextual evidence and deeper understanding of patient experiences can be elicited from collecting qualitative data compared with using quantitative data alone (23, 60). However, qualitative measures do not yield comparison data, and require greater time investment (49). In searching the literature for experiences in outpatient paediatric oncology, use of the following modalities have been illustrated: observational techniques; process mapping; simulations; interventions and/or pilot programs, mixed-method and multi-method approaches. Examples of

different methodologies for assessing patient experience as reported in the literature, are presented in Appendix B (**Table 13. Methodologies for Examining Patient Experiences**).

Mixed- and multi-method approaches included the use of direct or indirect patient and staff observations, often in conjunction with interviews, surveys and other techniques (3, 8, 13, 31, 35, 43, 57, 60). In several studies, observational evidence assisted in constructing flowcharts of the patient treatment cycle, and further aided the interpretation and understanding of outpatient journeys or experiences (3, 13, 35, 57).

#### **2.4.1. Improving Patient Experience**

Enhancing the clinic wait for all patient populations is viewed as a key driver of patient satisfaction and may be achieved in a variety of ways (44). Different research strategies for optimising patient experiences through ambulatory oncology have been reported in the literature. The most common objectives were to streamline clinic workflow and reduce patient wait times, thereby positively influencing patient satisfaction. Common approaches include process mapping, systems modelling, program planning or multi-method evaluations (to provide baseline evidence of clinic performance, prior to design and implementation of interventions). These methods are discussed briefly in the sections, below. Uniquely, one study developed a virtual chemotherapy unit to enhance their current cancer treatment services for paediatric patients (16). An earlier study conducted in Iran, was the only research found to use a sampling methodology by which to document a patient journey (41).

##### Process Mapping

Process mapping techniques used in several studies investigated patient journeys to gain fundamental understanding of the patient experience – the acquisition of patient perspectives helps to identify problems experienced only by patients, who can then participate in designing solutions (33). This method ensures a patient-centric focus, and commonly used mechanisms include direct observation, or retrospective and real-time data collection. Precise accounts of the end-to-end sequence through an outpatient oncology clinic were often used in creating flowcharts (35). Garcia-Alonso (2011) examined the steps in patient pathways through chemotherapy, particularly focussing

on patient-staff interactions, in order to improve patient care (61). An Australian study demonstrated the benefits of clinical redesign using process mapping, to target a range of clinical services (not paediatric oncology) in a state-wide program (33). In another study, process mapping aided in assessing the impact of a protocol-based software program on patient journeys, pre- and post-implementation (20). Lean-thinking principles were applied in some studies in which process mapping occurred, to identify non value-adding steps that could be eliminated in order to streamline workflow and minimise waste (3, 26, 33).

### System Modelling

Simulation modelling techniques were employed by healthcare organisations for the purpose of increasing operational efficiencies through a process of organisational redesign (59). Conceptual models are built using baseline information collected from the process or processes targeted for redesign (39, 59). In the studies retrieved through a search of the literature, patient experiences or journeys were initially analysed by observation of the stepwise procedure through an outpatient oncology episode, and the resultant data were tested using modelling software. Ahmed et al. (2011) used a simulation modelling technique for development of a scheduling template to improve clinic throughput and decrease patient wait times (40). A systems approach using a discrete event simulation (DES) model was reported by Suss et al. (2017) to effectively reduce patient wait times (39). Analysis of the patient journey through adult outpatient oncology units provided the data used in these simulation examples. Both studies avoided disruptions to daily clinic workflow, were cost-effective and used capacity planning to optimise clinic performance and decrease patient wait times (39, 40).

### Program Planning

Program planning involves establishing current practice, which can then be modified or improved. This technique was described by one study conducted in a paediatric outpatient clinic, which examined clinic workflow, patient volumes and treatment protocols (13). Issues in care delivery were established, and patients requiring shorter treatments were segmented into an express pathway. Clinic performance was improved without the addition of further resources, and the aim of decreasing patient wait times was achieved.

### Multi-Method Evaluation

Whilst most studies retrieved from the literature used more than one technique (i.e. mixed-methods) in their research examining patient experiences, to a lesser extent, researchers described employing a suite of methods in their evaluation and improvement of patient journeys or experiences. Blair et al. (2008) used a combination of parent and referrer surveys, patient mapping, staff interviews, and routine activity analysis to obtain a holistic view of a paediatric ambulatory care unit (57). In another study, Lingaratnum et al. (2013) used multidisciplinary process mapping of patient journeys, surveys, interviews, patient and staff tracking, and medical record audits, in addition to investigating electronic treatment records for the collection of baseline data (used for comparisons, pre- and post-intervention) (3). A study involving an adult outpatient oncology unit employed interviews, observations and process mapping to inform their clinical redesign process, however, data collection post-intervention was not available for comparison, at the time of reporting (35). None of the multi-method evaluation studies mentioned were conducted in a paediatric setting.

### Virtual Chemotherapy Unit

An innovative study conducted by Scavuzzo and Gamba (2004), detailed the creation of a virtual paediatric chemotherapy unit to facilitate the standardisation of the ordering process in chemotherapy (16). The routine surveillance and monitoring of chemotherapy administration processes identified a disparity between the paper-based ordering system operating in outpatient oncology, and the computerised process of ordering for inpatients. Previously, patients requiring admission for chemotherapy treatments had their treatment delayed until they were transferred from the outpatient to the inpatient system. Consequently, treatments began later in the day and were more prone to errors. Development of a Virtual Chemotherapy Unit provided coordination and streamlining of paediatric oncology services between the inpatient and outpatient units, with subsequent order entry safeguarding provided by the forcing functions of the computerised system. This unique use of rapid action change processes enabled the commencement of an outpatient chemotherapy procedure via the virtual unit, which then seamlessly integrated with in-hospital

operations. Additionally, treatment delays were minimised, thus increasing patient satisfaction with the service (16).

#### Time and Motion Sampling Study

A study conducted by Asefzadeh (1997) provided the only evidence of research using a sampling method (referred to in this study as Patient Flow Analysis) to quantify patient journeys through an outpatient paediatric service (41). Clinic staff manually recorded entry and exit times of patients moving between stations (Admissions, Intern, Paediatrician, X-ray and Laboratory) within the clinic. Data captured in this manner, revealed how time was spent during the outpatient visit, including duration of waiting periods and length of encounters with clinicians and other allied health professionals. This method allowed staff and clinic management to understand patient flow through the service and thus improve clinic performance (35).

#### Waiting Room and Other Interventions

Most studies in the published literature were shown to investigate patient experience for the purpose of improving the delivery of healthcare services. Waiting room interventions were designed to both enhance patient experience and improve clinic efficiency. Minimising patient wait times, or the perception of lengthy delays was a common goal. Hoffman and Futterman (1971) conducted a pre—post-intervention paediatric oncology study examining the waiting room experience (52). At the time of the study, a cancer diagnosis was often considered fatal — the impact of which was evident in the demeanour of parents (and negative behaviours of patients) waiting for oncology appointments (52). The study authors noted an appreciably unpleasant waiting room atmosphere, which impeded interaction or engagement amongst waiting individuals, prior to launching the intervention. Therapists were introduced into this environment to initiate a play program for the patients (and siblings), and to facilitate communication and social support for parents and family members. The use of therapists to promote coping effectively reduced social isolation by encouraging active engagement and participation, and by establishing social and emotional support between parents. This intervention helped to transform the waiting room experience from a distressing, passive, and isolating one into a more tolerable situation with inbuilt support mechanisms (52).

In a more contemporary study, Schneider and Workman (2000) introduced virtual reality equipment for paediatric oncology outpatients, using distraction as a coping mechanism (62). Distractions, acknowledged to facilitate coping in stressful situations such as receiving chemotherapy, are designed to shift attention from the unpleasant aspects of the visit, to more interesting stimuli. In their study, patients responded positively to the virtual reality experience. Participants were given access to the virtual reality headsets following commencement of their chemotherapy treatment. Feedback from patients indicated that it was a much more favourable way to pass the chemotherapy infusion time with some patients reporting that it didn't feel as though they had received treatment during their visit (62).

In a later study, positive distraction mechanisms employed by Pati and Nanda (2011) in a paediatric dental and cardiac outpatient setting, demonstrated beneficial behavioural modifications (43). This quasi-experimental study demonstrated the use of distractions using active imagery, to positively influence patient behaviours. Altering the environment of the waiting room resulted in observations of calmer physical behaviours during the waiting period, with an associated reduction in chaos (a significant contributor to stress). Pati and Nanda (2011) noted that use of a plasma screen TV to test an array of distraction conditions can be used to influence the perception of the waiting room experience, thereby enhancing patient satisfaction and their perceptions concerning the quality of care received (43).

In consecutive studies in an outpatient paediatric oncology clinic, the positive impacts of implementing systematic and behavioural staff interventions were demonstrable by comparing patient satisfaction with the service (42, 45). An initial study in 2015 used a questionnaire to analyse patient satisfaction with their outpatient experience and identify areas for improvement (45). The design of quality improvement initiatives resulted in systematic and behavioural interventions. A multi-modal approach was used: frequent review of survey data, peer-to-peer interactions between staff (sharing strategies and techniques), web-based instructional modules and targeted improvements for new patients (who were the least satisfied with the service) (45). In the latter study from the same outpatient clinic, a cross-sectional survey design was employed to determine the key drivers of patient experience ratings (42). Following the interventions described in the

previous study, patients most valued provider (doctor) communication, attitudes of the nurses and staff teamwork; wait times were of lesser consequence and did not appear to affect patient satisfaction to the same extent as in the earlier study (42).

## **2.5 Significance of Literature Review Findings**

Contemporary healthcare literature largely acknowledges the value of patient-reported outcome measures and experiences. The patient perspective has become integral for health care planning with regards to resource allocation, service improvement strategies and upholding a patient-centric focus, however, valid arguments are raised about the use of patient satisfaction as a proxy measure for perceived service quality (27, 63, 64). Anderson and Zwelling (1996) contend that patient satisfaction measures including perception of clinicians' attitudes, cleanliness of hospital facilities and wait times, may be broadly categorised as either technical or functional care quality measures (65). In their discourse, Anderson and Zwelling (1996) distinguished between these measures, proposing that technical quality refers to the quality of service provided, whereas the functional aspect describes the "manner in which the service is delivered," reflecting the qualitative nature of this indicator (p.9)(65). From an organisational standpoint, this has implications for clinical and management decisions, but at an individual level, patient's perspectives correlate more closely with the journey experienced and the subsequent medical outcome. Thus, the significance of evaluating patient experience in paediatric oncology is in their association with patient health outcomes. Authors of studies examining both oncology and general patient populations, assert that patients who are satisfied with their experience are more likely to follow treatment advice (23, 44). Brown et al. (2006) and Thomas et al. (1997) similarly emphasise that a patient's perception of care quality has treatment compliance repercussions, effectively influencing their clinical outcomes (4, 34). Davis et al. (2017), highlighting the research of Pascoe (1983) and Williams (1994), also report that better adherence and commitment to treatment advice together with increased appointment keeping is observed with greater levels of patient satisfaction, and that wait time may impact the overall experience for families navigating the childhood cancer journey (37). Understanding the fundamental role of patient experiences regarding treatment outcomes, helps to explain the focus



of research dedicated towards patient satisfaction, the waiting room experience and perceived quality of care. In the documentation of patient experiences or journeys through outpatient oncology, there has been ubiquitous acknowledgement that waiting is the least desirable aspect of the visit for patients and their families; Corsano et al. (2015) describing it as a “condition of high stress” (p.1066)(51). Minimising stressors and other associated negative emotions of those presenting in outpatient paediatric oncology, therefore, not only engenders positive downstream effects on health outcomes, but also facilitates superior clinical interactions and patient-clinician relationships, improving the perception of quality of care and patient satisfaction (4, 9, 13, 34, 51). Furthermore, paediatric patients report decreased pain and express calmer behaviours on exposure to positive distractions, which is indicative of lowered stress and anxiety associated with waiting periods (43).

## **2.6 Evidence Gap**

There is limited research about patient satisfaction or quality of care measures in the outpatient paediatric oncology context. Researchers noting the oversight of enquiry into the outpatient setting of paediatric oncology, petition for future research to fill this void (9, 13, 37). Furthermore, outpatient experiences in paediatric oncology in the Australian context, have been under-investigated.

Research of patient journeys and experiences in the published literature have predominantly focussed on adult oncology patients; current studies more often in an outpatient context. The research methodologies most commonly used in the collection of such data included techniques such as survey or questionnaires, process mapping, observations, interviews and multi-method evaluations.

The current study aims to examine the patient experience in paediatric oncology in an outpatient setting, with a focus on wait times, progression through treatment encounters and patient-clinician interactions.

### Justification for Study Methodology

Whilst much of the recent literature examining patient experiences in outpatient paediatric oncology have employed quantitative measures, one study was unique in its use of a manual paper-based time and motion study to quantify the patient experience (41). However, the collection of time data was used for managerial purposes and was obtained via manual recording of patient flow through the clinic by departmental staff (41). Additionally, it is important to note that this research was conducted several decades ago, and further, that examination of the patient perspective was not an outcome measure for the study.

Historically, work sampling and time and motion studies have been appropriated for the investigation of work distribution and task performance across a broad range of working environments. In healthcare settings, these techniques have favourable application in assessing clinical workflow and communication patterns (19, 66, 67). Earlier work sampling studies employed paper-based self-reporting or observational methods for obtaining measurable data (68-70). Whilst self-reporting techniques reduce task ambiguity and observer bias, the intrusiveness of recording alerts (to prompt data collection), are often poorly tolerated by staff and can result in incomplete data collection (69-71). Thus, observational methods are advantageous in their improved staff acceptance and the facilitation of greater quantities and higher quality of data that can be collected. However, observational methods are conducted at the detriment of being resource intensive (69, 70). With the introduction of digital technologies, there has been a shift from paper-based reporting methods, to recording via a digital interface (19). This improves efficiency, facilitating an increased capacity and complexity of data to be collected more accurately (19, 70). Traditionally, work sampling and time and motion studies in healthcare have focussed on changes in task performance and workflow patterns of clinicians subsequent to a workplace intervention (19, 67-69). Utilising time and motion study methodology to collect data from the patient perspective uniquely places this study in its research of outpatient paediatric oncology.

Measuring patient experience and what constitutes a good patient experience in the outpatient paediatric oncology context, is complex and challenging, and lacks procedural or methodological uniformity. No singular research method is exhaustive in its design; each has

inherent advantages and disadvantages (23). Whilst larger sampling sizes and comparison data can be obtained using surveys, simulations and other quantitative methods, contextual information and the patient voice is not able to be captured (72). The benefit of conducting qualitative research is in the acquisition of richer and more detailed information, which can better represent the reality of the patient/carer experience (23, 72). However, qualitative research is acknowledged as being more resource-intensive and time consuming, producing data less generalisable or comparable (23).

Employment of a mixed-methods study design harnesses the strengths of both quantitative and qualitative methods. The mixed-methods design according to LeVela and Gallan (2014), is preferable for measuring patient experience, as it affords cross-validation of combined quantitative and qualitative methods, providing a more comprehensive picture or overview (22). To date, there have been no documented studies in outpatient paediatric oncology using the mixed-methods approach described in the current study.

The current study will therefore employ a mixed-methods design including a direct observational time and motion study and semi-structured interviews to examine the patient experience in paediatric oncology in an outpatient setting. The focus will be on wait times, progression through treatment encounters and patient-clinician interactions.

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# CHAPTER THREE: METHODS

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### 3. Methods

In the previous chapter, a review of the literature in paediatric oncology affirmed that paediatric oncology is an under-researched field of study, with a substantive focus on general (adult) oncology services. The literature search revealed an absence of recent observational time and motion studies of outpatient paediatric oncology in either an Australian or international setting. The rationale underpinning the examination of patient experience is to garner understanding and awareness of patient perspectives for the purposes of monitoring service quality and improving health service delivery and clinical outcomes. The delivery of patient-centric care is an ideology which has gained traction in recent years and is contingent upon evidence-based design.

Chapter 3 outlines the methodology pertaining to research undertaken in an outpatient cancer clinic of a paediatric hospital in Sydney, Australia. Details of the study design, and descriptions of the sampling technique, data collection software, participant recruitment and qualitative approach are provided.

#### 3.1 Study Site

This study was undertaken in the cancer centre of an Australian paediatric hospital. The cancer centre is segmented into inpatient (acute care) and outpatient (treatment and management) service provision. The present study was confined to the outpatient oncology clinic.

##### Contextual Details of the Oncology Clinic

The Sydney-based hospital located in the Greater Western Sydney region, has a 340-bed capacity and encompasses a cancer centre accommodating up to 150 new patients per year. The cancer centre retains six Consultant Paediatric Oncologists in addition to several Fellow Oncologists and departmental Career Medical Officers (CMOs).

The clinic operating hours are 8:00am – 4:00pm. A patient list is generated daily by the reception staff, detailing consultation appointments, procedures (e.g. lumbar punctures and bone

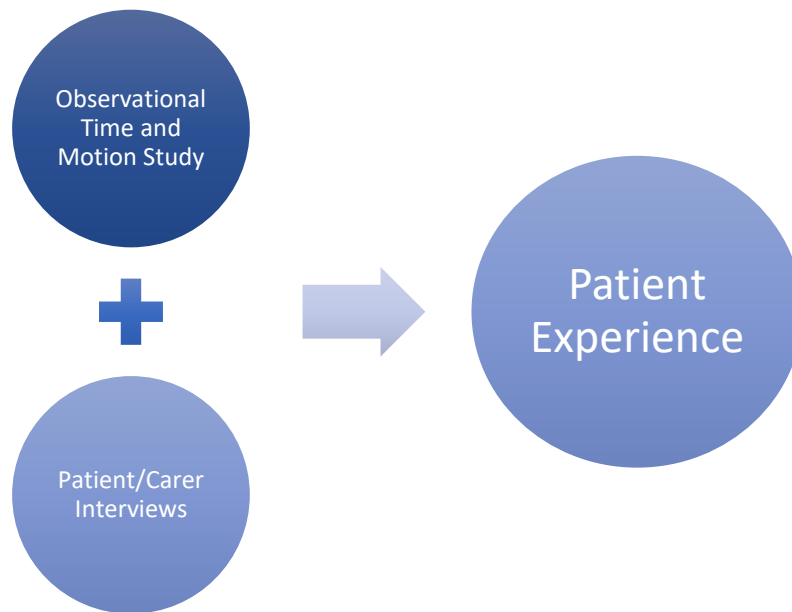
marrow testing or transplants), MRI bookings, and infusions (chemotherapy, platelets, antibiotics etc.). Appointment bookings are scheduled between 8:00am – 1:00pm, however, patients having procedures requiring anaesthesia are requested to arrive from 7:30am (at which time the nursing staff are available). All patients with a central venous line (CVL) requiring blood samples to be taken are requested to arrive half an hour prior to their appointment, and those patients with a port-a-cath are requested to arrive after 8:30am (at which time Phlebotomy staff from the Pathology department arrive to access ports).

The doctors in the oncology clinic work in three teams — Team A, B and C (Team B is the Bone Marrow team, who were not included in this study). Each patient has an assigned Oncology specialist within their designated team of clinicians, who acts as the primary point of contact. However, when clinicians are on call, they will attend to all patients in the clinic or wards, so patients may effectively receive care from any paediatric oncologist within the cancer centre. Teams A and C are comprised of three and four Consultant Oncologists respectively, and two Fellow Oncologists (who rotate teams every three months). CMOs (Career Medical Officers) are rostered on for several days a week in the clinic and are not attached to a particular team. Consultations are booked according to treatment protocol requirements for each patient, and the CMO or Team A/C doctor who is rostered on for the clinic that day, is the doctor who will provide the consultation.

### **3.2 Study Design**

The present study employed a mixed-methods design. Research conducted using structured patient (and carer) observations with a time and motion study technique, generated quantitative patient experience data. Unstructured observations and participant interviews were used to obtain qualitative data. The current research design is a formative approach for examining patient experience in this setting. The study collected evidence of wait times, patient-clinician encounters and the patient perspective.

A basic study approach is shown in Figure 1.



**Figure 1. Mixed-Methods Study Design**


### **3.3 Data Collection**

#### Data Collection Tool: WOMBAT

WOMBAT (Work Observation Method By Activity Timing) is a tool which can be used for direct observational studies, to capture time and motion data. The current study was undertaken using WOMBAT iOS Version 1.0. According to Westbrook et al. (2009) WOMBAT uses a “multidimensional work task classification system” (p.27)(19) which is designed for recording the work tasks and communication patterns of health professionals (69, 73). The current study adapted the WOMBAT task classification for recording patient timing and activity data, in order to capture the complexity of an outpatient paediatric oncology visit. All patient activities selected during observational episodes were automatically time-stamped and recorded in the WOMBAT template embedded on a tablet device.

Time and motion methodologies require defined task categories that are clear, measurable, distinguishable and mutually exclusive (69, 70). Figure 2 shows the dimensions and categories of the WOMBAT template used in the current study.

10:42 am Thu 10 Oct
87%


Activity Timing

<div>Tasks</div> <div>T1 - 10:42:42</div>	STAGE *			
	Before Dr Appointment	Doctor-Patient Consultation	After Dr Appointment	Treatment
	WHAT (PATIENT) * <span>M</span>			
	Waiting	Care/Treatment	Communication	Other
	WHERE (PATIENT) *			
	Observation Room	Consultation Room	Treatment Room	Reception Desk
	Waiting Area (Clinic)	Waiting Area (Outside Clinic)	Other	
	WITH WHOM (PATIENT) * <span>M</span>			
	Reception Staff	Doctor	Nurse	Other Health Provider
	Parent/Relative	Other Patient/Carer	Other	No one
<div>Interrupted</div>	PARENT <span>M</span>			
	What ▼	Where ▼	With Whom ▼	Not With Patient
	WHAT (CLINICIAN) <span>M</span>			
	Communication/ Care	EHR Task	Paper Documentation	Other
	INTERACTION <span>M</span>			
	Sharing Screen	EHR Use and Talking	Writing and Talking	Focused on EHR/Paper
	ACTIVITIES WHILE WAITING			
<div> <div></div> <div>Multitask / Interrupt</div> <div>Next Task</div> </div>				

Figure 2. WOMBAT Data Collection Template for Outpatient Paediatric Oncology Study



Dimension 1 of the WOMBAT template included four mutually exclusive patient activity categories (describing the four stages of the outpatient visit):

- Stage 1: Before Doctor Appointment
- Stage 2: Doctor-Patient Consultation
- Stage 3: After Doctor Appointment
- Stage 4: Treatment

The Wombat template similarly included mutually exclusive categories for the following patient dimensions: WHAT, WHERE and WITH WHOM. Multiple selections were possible for all dimensions in the template, except for categories in the STAGE and WHERE (Patient) dimensions. The first four dimensions of the WOMBAT template were required patient fields, thus a selection in each was necessary, prior to the commencement of a new activity.

The lower half of the template recorded parent and clinician (Doctor) activities which did not require mandatory selection. Note for parent activities “What” and “With Whom”, there are sub-categories in the template which are accessible by using a drop-down menu.

During Stage 2 observations, clinician behaviours regarding communication and use of the eMR, were documented, however, owing to the fluidity of the encounter, time intervals were not recorded. Observed clinician behaviours during encounters were documented using the WOMBAT template, and included:

- Communication/Care
- eMR task
- Screen sharing
- eMR use and talking
- Focussed on eMR
- Paper documentation
- Writing and talking
- Other.

Structured direct observations of patient/family units were conducted using WOMBAT. The researcher recorded patient/carer activities, categorising them according to observations made during each stage of the visit i.e. participants, nature of activity, location of activity and so forth. The WOMBAT template included a free-text dimension entitled “Notes (Activities While Waiting)” providing a facility for capturing additional contextual observations not otherwise specified for in the template.

### Semi-Structured Interviews

A semi-structured interview technique was chosen to complement the quantitative data obtained via the time and motion study. The use of qualitative data collection methods such as structured or semi-structured interviews, observations and focus groups, are purposeful in providing insight or understanding of a phenomenon such as patient experience (72). The face-to-face verbal exchange which epitomises the interview process is designed to elicit information from the participant, or interviewee (74). This method of data collection generates information in the form of words rather than numbers (as generated by quantitative methods).

Concern for the vulnerability of the study population guided the development of the interview procedure, which was therefore designed to be brief. Survey questions and interview material from the published literature (for general and paediatric patients) provided a framework for the current study. A set of questions was developed based on the study aims of examining patient experience in this paediatric setting. The areas of enquiry, therefore, reflected the interest in patient wait times and encounters with clinicians, with the objective of gaining a patient or carer perspective. Given the age of the patients, development of the questions was guided by the intention to approach either the patient’s carer or older patients. Table 3 shows the interview guide used in this study.

**Table 3. Semi-Structured Interview Questions**

<b>Interview Guide</b>
What is a typical day in outpatient chemotherapy like for you?
How long do you usually have to wait to see the doctor?
How long do you usually have to wait before chemotherapy is given?
Was the doctor you saw today your child's regular oncology doctor?
Was the doctor aware of your (child's) medical history? (Did the doctor know all about your child's condition?)
How long do you usually spend with the doctor? Did you spend enough time with the doctor?
Did the doctor use the computer?
Do you feel you can talk with the doctor while they use the computer?
How long do you usually spend interacting with the nurses?

### Unstructured Observations

Non-participant unstructured observations, which involved contextual observations of clinic routine, clinic flow and the clinic environment, were made throughout the pilot study and field study periods. Field notes pertaining to the observational episode were recorded in the lower section of the WOMBAT template, and additional contextual details were documented manually on paper. Opportunities to record observations presented during clinic operating hours whilst waiting for the arrival of suitable study participants, and during observational episodes.

### 3.4 Observer Training and Pilot Study

The researcher undertook training and conducted a brief pilot study, prior to the collection of research data to:

- (1) acquire skills in observational training;
- (2) achieve competency in the use of the WOMBAT software and tablet device; and
- (3) test the WOMBAT template for adjustments and tailoring specific to the paediatric oncology patient population.

Observer training was initially undertaken at Macquarie University, prior to attendance at the hospital. During this time, the researcher was introduced to the tablet device and WOMBAT software and began the process of familiarisation with the hardware and software. In the next phase, the researcher was introduced to the study environment, shown basic staff procedures and introduced to staff who were present in the clinic. Observer training commenced at the study site on July 9<sup>th</sup>, 2019, with supervised practice observations. The pilot study began the following day (July 10<sup>th</sup>, 2019), whereby both research student and supervisor conducted simultaneous but independent observations. This enabled the research student to acquire proficiency in the observational technique by commencing preliminary data collection whilst under supervision. The pilot study served to develop the researcher's proficiency in this methodology by facilitating familiarity and confidence with the data collection device and WOMBAT software. Patients were observed by the researcher during the training period and pilot study, and activities experienced during outpatient visits were recorded using the WOMBAT data collection template. Field notes were also documented during these episodes. Final modifications to the WOMBAT template were implemented after reviewing the data following completion of the researcher training and pilot study.

Observational sampling studies involving data collection by multiple observers are required to meet inter-rater reliability requirements. For studies conducted using multiple data collectors, it is recommended that inter-rater reliability between data collectors reaches a value above 85% for

accuracy in observational time and motion study techniques (19). During the pilot study for this research project, an inter-rater reliability of 91.3% was reached. Although this was not an essential requirement (as only one observer was conducting research during the study period), researcher competency was able to be established prior to commencing the study.

Data collection began following approximately 17.5 hours of observer training, and when the supervisor was satisfied that the researcher had attained competency in the observational sampling technique. An **Observer Training Record** is included in Appendix C.

### **3.5 Study Procedure for Outpatient Visits**

#### Participant Recruitment

The Department Head of the children's cancer centre was consulted to identify suitable participants for the study. Suitability criteria was based upon treatment protocol (IV infusions delivered via CVL or via port-a-cath), and stage of treatment (patients receiving chemotherapy treatments subsequent to their initial chemotherapy round). Potential study candidates included those patients scheduled for a routine outpatient appointment which included a doctor consultation and administration of treatment (e.g. IV infusions – chemotherapy treatments, blood products etc.). Patients ineligible to participate included those attending the clinic who were not scheduled to receive either treatment or a consultation with a doctor, and new patients (following diagnosis, newly diagnosed patients usually receive their first cycle of chemotherapy as hospital inpatients).

Staff members were informed about the study verbally and/or by email, prior to its commencement. Upon arrival at the clinic, participants were invited into the study by the clinic reception staff, after which, the researcher briefly explained the nature and purpose of the study. Written information about the study was provided to the parents and patients (if developmentally appropriate). Signed informed consent from parents and patients was obtained before observations were initiated.

### Time and Motion Study Procedure

Single family units (i.e. patients and accompanying family members) were shadowed by the observer through the entirety of their clinic visit. If parents or carers left the company of the child, the researcher remained with the patient. Sometimes patients remained in the playroom during part of the Doctor Consultation — in this circumstance, the researcher accompanied the parents or carers into the Doctor Consultation (as the researcher aimed to capture clinician use of the eMR system during these encounters). Timings for wait periods and patient-clinician encounters were recorded for each family unit throughout the scope of their visit. The locations of patient activities were also documented.

The researcher unobtrusively shadowed participants as they progressed through their visit, recording all patient activities occurring during this time. The researcher stood or was seated in close proximity to the patient and their carer/s. During bathroom breaks, the researcher waited in her current location for the patient to return; explanatory field notes were recorded in the WOMBAT template and observations continued (i.e. they were not suspended). Observation sessions concluded at the completion of the treatment stage: at the point in which the patient was disconnected from the IV; following administration of push chemotherapy; or after changing of the CVL (Central Venous Line) dressing.

The field study was undertaken from July 10 – August 6, 2019; observations were conducted on weekdays during the outpatient clinic's regular operating hours. Over 78 hours of observation data were collected.

### Interview Process

The qualitative component of this study obtained data from face-to-face semi-structured interviews conducted with parents, carers and patients. Study participant interviews were conducted in the final stage (Treatment) of the clinic visit, generally between the researcher and the patient's parent or carer/s. If a patient indicated their desire to be interviewed, the researcher conducted an initial interview with a parent or carer, and a subsequent interview was held between the researcher and patient. The treatment stage for patients scheduled for push chemotherapies

was typically comprised of a single chemotherapy injection and CVL/port care – and therefore, of minimal duration. Accordingly, interviews were conducted immediately following the end of the observation session for these patients.

### **3.6 Data Analysis**

#### Quantitative Study

Patient wait times were defined as the total time spent waiting during an outpatient visit. Patient-clinician encounters encompassed total time spent interacting with doctors or nursing staff throughout the visit. Wait time and interaction data were generated in stages and aggregated to obtain overall outpatient experience data. For the purpose of this study, outpatient visit data were captured during each of four stages, as follows:

- Stage 1: Before Doctor Consultation — interval from patient sign-in at reception to consultation with the doctor.
- Stage 2: Doctor-Patient Consultation — interval spanning duration of consultation.
- Stage 3: After Doctor Consultation — interval following consultation, and prior to administration of treatment.
- Stage 4: Treatment — interval spanning duration of treatment (including dressing changes and administration of IV infusions or push chemotherapies).

Outpatient visits encompassed a variable patient mix: the patients each had unique protocol requirements and treatment needs, which was reflected in the variability of the timings for observed participant sessions. For the purpose of this study, observation sessions were categorised according to treatment durations, as either Short or Long Treatments — treatments two hours or less were deemed Short, and treatments longer than two hours were characterised as Long. The purpose in categorising treatment durations was to examine the difference in wait durations between

Treatment types. Patients requiring Long Treatments typically booked earlier clinic appointments. Clinic staff aimed to expedite them through their outpatient visit, to avoid finishing late in the day.

Quantitative data analysis was conducted in Excel by a statistician familiar with the complex nature of continuous WOMBAT timing data. Descriptive statistics, including measures of central tendency (averages) and measures of frequency (proportions) were calculated. Durations of time captured from the observation sessions were used to calculate the sum of total time and average time patients spent in each stage of their visit (i.e. Before Doctor Appointment; Doctor-Patient Consultation; After Doctor Appointment and Treatment). Total and average times spent waiting and with clinicians (interactions with doctors and nursing staff) were also calculated for each stage of the observed visit.

The measurable outcomes for this study include:

- time distributions (time spent waiting, time spent with clinicians, time receiving treatment), and
- communication patterns (patient-clinician interactions).

### Qualitative Study – Inductive Thematic Analysis

Interviews were recorded (with consent), and later transcribed verbatim. Thematic analysis of the data corpus (entire data content from the participant interviews) using an inductive approach was undertaken to provide insight into the patient perspective of outpatient visits. Themes were identified during the analytic process.

Analysis using an inductive approach followed the basic six-step process outlined by Braun & Clarke (2006) (75):

#### Step 1: Data Familiarisation

Analysis began with data transcription and familiarisation with the transcripts. Recordings initially transcribed by the researcher, were subsequently transcribed using a professional transcription service. The researcher compared both transcripts, amending as necessary. Recordings



were listened to several times to develop familiarity of the content prior to commencing the coding process.

### Step 2: Generating Preliminary Codes

The coding process involved re-listening to the transcripts as often as necessary, to determine interviewee emphasis for certain words and phrases. Coding of the data was manually performed using a line by line process on paper (recording notes in the transcript margins). Interesting concepts and recurrent ideas were identified, and codes were systematically documented in an excel spreadsheet for all twenty-four participant interviews.

### Step 3: Generating Themes

This was an active process to sort and condense the data, thus grouping the codes. Duplications of codes were identified and removed, and candidate categories were generated. Links between candidate categories were used to group the data into categories, and further evaluation and condensation of categories was achieved using mind-maps drawn on paper. Refinement of the data from the mind-maps helped to organise the data into potential themes and sub-themes.

### Step 4: Reviewing Themes

Data refinement occurred during this review phase, in which potential themes were critically analysed for consistency and relatedness. This involved reviewing the coded data set and drawing another mind-map. Some of the potential themes were combined and others removed, until final themes were decided upon.

### Step 5: Naming and Defining Themes

Five final themes were identified from the data corpus. Some development was required in naming and defining the themes so that the core concept was identifiable. Themes generated from the data were influenced by the study aims, however, an analysis of the raw data determined the final thematic evaluation.

### Step 6: Final Analysis Reporting

The qualitative data was reported under theme headings, with explanatory details and supporting quotes from the participant interviews. Review of the data generated five final themes, which are presented in the Results chapter (Section 4.9.1).

## **3.7 Privacy and Security**

No identifying information from patients/carers was used for the purpose of this study. Participant privacy and confidentiality was protected by removing identifying information from the study documents and assigning specific study code numbers to each participant/family. Numerical identifiers were also assigned to participating doctors. All personal information collected during the study has been de-identified using numerical coding, which may only be linked by the study team at Macquarie University. Linking information is kept securely on a password protected computer at the Australian Institute of Health Information, Macquarie University. Research data collected for this study will be stored for 7 years after study completion.

## **3.8 Ethics Approval**

Approval for this study was given by the Sydney Children's Hospitals Network HREC (approval number: LNR/15/SCHN/171). The Ethics Amendment Approval document is included in Appendix A:

### **Ethics Approval**

The results from this investigation are presented in the following chapter.

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# CHAPTER FOUR: RESULTS

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## 4. Results

The previous chapter summarised the methodological approach used in this study for investigating patient experiences in outpatient paediatric oncology.

This chapter presents results from the investigation of an outpatient clinic at a children's cancer centre, conducted during the period from July 10 – August 6, 2019. The chapter begins by presenting quantitative results from the direct observational time and motion study, followed by qualitative results of participant interviews in the latter half of the chapter.

Patient Perspective of a typical day in the outpatient clinic:

*"I get my chemo, then I take my bloods...make slime and then I'm out of here."*

### 4.1 Study Participants

A total of 20 patients and accompanying carers/family members participated in this study, three of whom were observed on two occasions. Observational data recorded using the WOMBAT tool is uploaded to a server immediately following completion of the outpatient visit. Although data was collected for twenty-three episodes, on three occasions, problems occurred during the uploading process, and data was unable to be retrieved in time for analysis. Consequently, interview data from these three patients/family units was included in the study, however, their observational data was precluded from this study. Thus, quantitative data from 20 observational episodes, and qualitative data from 24 interviews are presented from this study (on one occasion, both carer and patient were interviewed in the same session).

Table 4 presents study participant data from each observational episode. Three patients/family units were observed more than once, but on no more than two occasions to minimise the potential psychological burden of being observed too frequently. Eight patients were accompanied by a single carer and twelve patients were accompanied by two or more carers/family members.

**Table 4. Study Participants: Patient Characteristics from Outpatient Visits (n=23)**

<b>Participant ID</b>	<b>Age</b>	<b>Gender</b>	<b>Appt Time</b>	<b>Who Else is Present</b>	<b>Consulting Doctor</b>
<b>100700 (Pilot)</b>	8 years	Male	8:30am	Father	Doctor 1
<b>110701#</b>	6 years	Male	9:00am	Mother	Doctor 1
<b>120702</b>	5 years	Male	10:00am	Foster Father (Carer)	Doctor 2
<b>150703</b>	6 years	Male	9:00am	Father	Doctor 3
<b>160704*</b>	3 years	Male	9:00am	Father, Mother, Baby	Doctor 4
<b>170705*</b>	8 years	Male	10:00am	Mother	Doctor 5
<b>180706#</b>	12 years	Male	9:00am	Mother	Doctor 6
<b>190707</b>	8 years	Female	10:30am	Mother, Nan	Doctor 7
<b>220708#</b>	9 months	Female	9.30am	Mother	Doctor 8
<b>230709</b>	15 years	Male	Before 12:00†	Mother, Stepdad	Doctor 3
<b>240710</b>	4 years	Female	8:30am	Mother, Father	Doctor 5
<b>250711</b>	2 years	Male	9:00am	Mother, Father, Grandmother	Doctor 6
<b>250712</b>	17 years	Male	10:00am	Mother	Doctor 7
<b>260713</b>	6 years	Male	9:00am	Father	Doctor 3
<b>260714*</b>	5 years	Female	11:00am	Mother	Doctor 6
<b>290715</b>	16 years	Female	8:30am	Father	Doctor 9
<b>300716</b>	13 years	Female	8:30am	Mother	Doctor 10
<b>310717</b>	1 year	Female	9:00am	Mother, Father	Doctor 5
<b>010818</b>	6 years	Female	9:30am	Mother	Doctor 11
<b>020819</b>	9 months	Female	9:00am	Mother	Doctor 2
<b>020820</b>	11 years	Male	11:00am	Grandmother (Carer)	Doctor 11
<b>050821</b>	4 years	Male	8:30am	Mother, Father	Doctor 3
<b>060822</b>	12 years	Male	8:30am	Mother, Grandmother	Doctor 3

\* Qualitative data only from these participants was included in the study.

† Patients are required to arrive before 12:00pm for blood collection and observations to be performed by the nursing staff.

#Patients observed more than once.

Appt is appointment.

**Table 4.1 Summary of Patient Characteristics (n = 23)**

<b>Patients/Carers (n=20)</b>	<b>Total</b>
Observations	23
Interviews	24
Interviewee (patient/carer)	4 (17%) 20 (83%)
Patient age (years) at observation (mean)	6.58
Patient sex (M/F)	14 (61%) 7 (39%)

## **4.2. Study Participation Rate**

Of twenty-three patients invited into the study (including the pilot study), twenty agreed to participate. This gave a total of twenty-three observations (including the pilot study) as three patients/family units were observed on two occasions each. The participation rate for this study was 86.9%.

## **4.3 Observed Process for Outpatient Chemotherapy Visits**

Conducting an observational study allowed the standard process experienced by patients in the clinic, to be determined.

Patients presented to the reception desk in the clinic, announcing their arrival. A pathology billing form for blood collection was signed by the patient or carer, before taking a seat in the waiting area (unless blood results were not required for the observed visit). There were two alternative clinic waiting areas for patients and family members: inside the clinic was a general waiting area furnished

with seating, a table with chairs, wall-mounted TV screen and three PlayStation units; this area also contained a playroom, supervised by a full-time child life therapist and part-time volunteer staff. A separate waiting area outside the main clinic was used by patients and carers who were unwell; effectively separating the patient population and minimising the risk of other patients to further illness. Nursing staff called each patient in turn to the Observation Room, and/or to a mobile Observation Station (situated near Reception), following a wait interval in either waiting area.

The Observation Room was used for blood collection and recording of weight and height measurements. Other vital measurements including blood pressure, temperature and oxygen saturation were taken here, or alternatively, at the mobile Observation Station. The Observation Station was similarly equipped with a laptop computer, BP cuff, thermometer and pulse oximeter, and was utilised for patient overflow when the clinic was busy. In most instances, these initial patient observations occurred in stages, interspersed by wait periods.

Patients typically waited in either of the waiting areas or the playroom, until they were called into the consultation by the doctor. Prior to the doctor consultation, some patients/family units chose to leave the clinic for short intervals once nursing observations had been completed.

Subsequent to the doctor-patient consultation, patients and carers experienced another waiting interval, during which time chemotherapy or other treatments (platelets, packed red cells etc.) were prepared by the pharmacy and/or nursing staff. Alternatively, if the patient was deemed unfit for treatment, they were sent home following the consultation. Chemotherapy (and other treatments), in addition to dressing changes, were attended to during the final stage of the visit. The treatment area was comprised of several rooms: individual treatment rooms for CVL or Port care (Port-a-Cath); a larger communal Treatment Room for chemotherapy administration, equipped with 5 treatment chairs, seating for carers/families, play equipment, and a wall-mounted TV; an operating suite for surgical procedures (lumbar puncture and bone marrow procedures), a recovery/treatment area used for patients returning from surgical procedures or for treatment of unwell patients, and several additional treatment rooms for patients requiring isolation.

Note: Patients with antibiotic resistance are segregated from all other patients and family units during outpatient visits and are accommodated in isolation rooms in the treatment area. These patients do not follow the regular process through the clinic for their visit.

A process map representing patient flow through the clinic during outpatient visits is displayed in Figure 3.



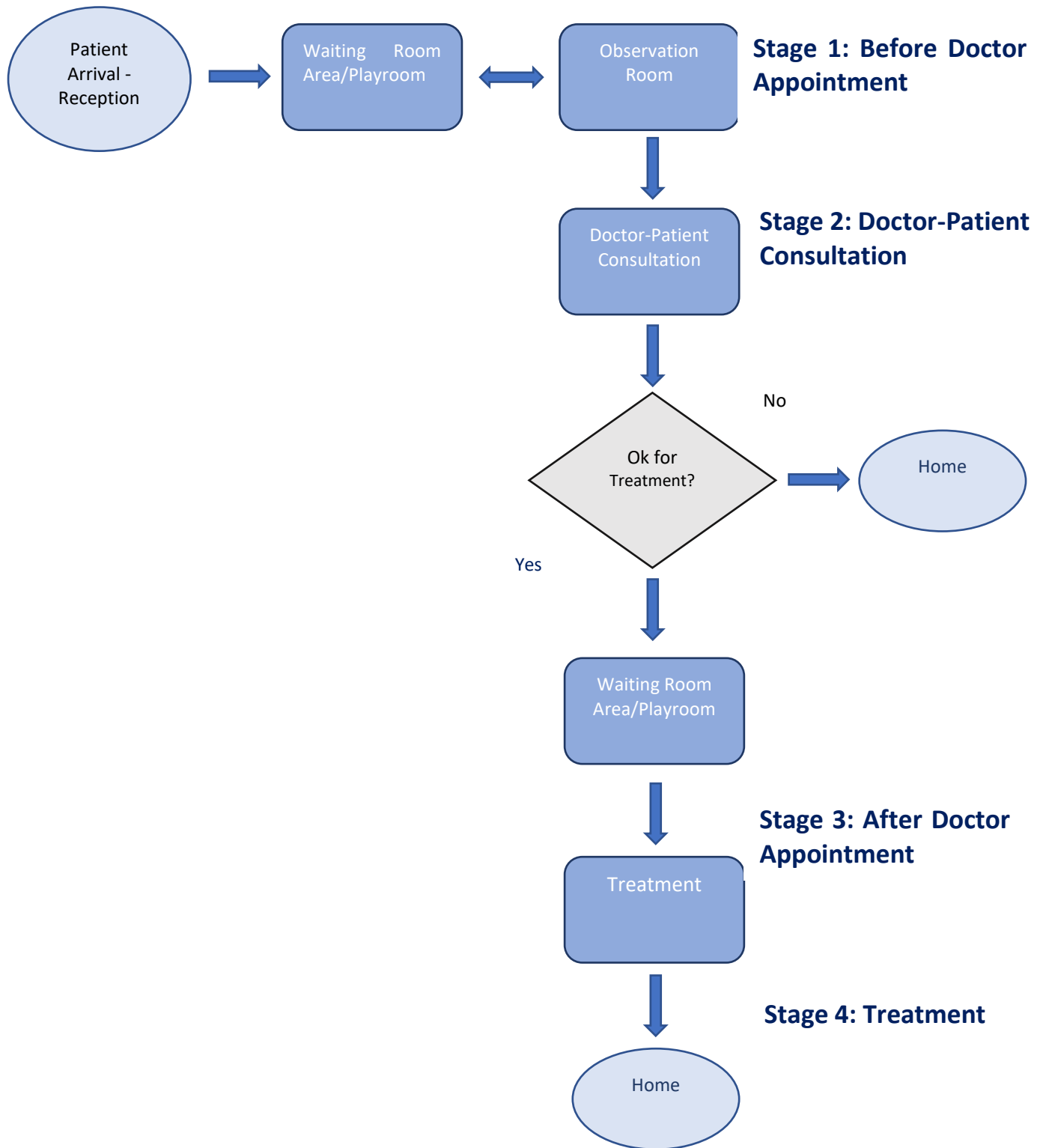


Figure 3. Process Map for Typical Outpatient Paediatric Oncology Visit

## 4.4 Outpatient Visits: Overview

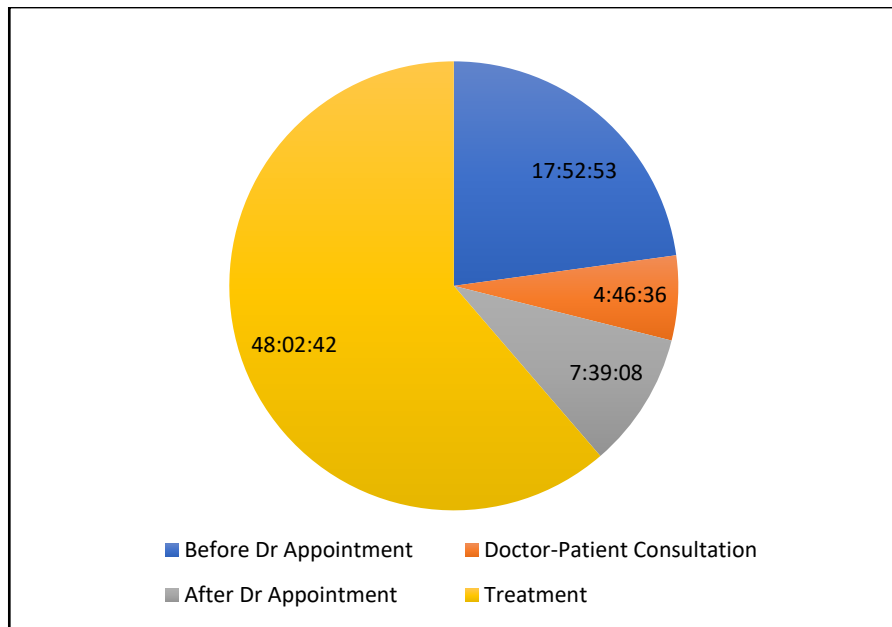
A total of twenty days of observations were conducted (excluding the pilot study). A summary of the quantitative data from the field study is presented in Table 5. Treatments were categorised according to duration (as described in Methods, Section 3.6 Data Analysis **Treatments**).

**Table 5. Summary Data from Field Study**

Outpatient Visits	Total
Observations (days)	20 days*
Total Observation Time (hrs)	78 hours 21 mins
Observation Sessions	20
No. of Patients/Family Units	17
No. of Long Treatments	10
No. of Short Treatments	8
No. of Visits with No Treatment	2

\*Number of Observation days (excludes pilot study). Note: Short Treatments are up to two hours, Long Treatments are two hours or more.

The overall time distribution for each stage of the twenty recorded observation sessions (n=20), is shown in Figure 4. Note that Stage 4 (Treatment) comprised eighteen observed treatment sessions, as two patients did not proceed to treatment due to clinical status.



**Figure 4. All Stage Analysis: Time Distribution (hours)**

Note: Treatment Stage (n=18).

Average times patients spent waiting and interacting with clinicians (doctors or nurses) over the twenty days of field study, are presented in Table 6.

**Table 6. Field Study Overview. All Stage Analysis: Waiting and Interaction Data (hours)**

All Observations (n=20)	Stage 1 Before Doctor Appointment	Stage 2 Doctor- Patient Consultation	Stage 3 After Doctor Appointment	Stage 4* Treatment	Total for All Stages
Av. Wait Time	0:45:26	0:02:07	0:21:47	2:16:07	3:25:27
Av. Time with Dr	0:00:04	0:12:13	0:00:06	0:00:18	0:12:41
Av. Time with Nurse	0:08:09	0:00:00	0:01:04	0:23:44	0:32:57
Av. Time with Clinician†	0:08:13	0:12:13	0:01:10	0:24:02	0:45:38

\*Stage 4 (Treatment) average is over 18 sessions as two patients did not proceed with treatment. Av. is average. † refers to doctors and nurses.

Overall time data indicated that the longest time spent in outpatient visits was during Stage 4 (Treatment), and the shortest was during Stage 2 (Doctor-Patient Consultation). Patient interactions with nurses during an outpatient visit were, on average, almost 33 minutes, and interactions with doctors were under 13 minutes. For an average outpatient visit of over four hours' duration, a patient spends 3 hours 25 minutes waiting and participates in an average doctor's consultation lasting just over 12 minutes.

#### **4.5 Outpatient Visits: Contextual Observations of Outpatient Stages**

For study purposes, outpatient visits were divided into four distinct stages (described in Methods, Section 3.3 Dimension):

Stage 1: Before Doctor Appointment: interval between patient check-in at reception until consultation with doctor. Many interactions occurred during this stage: primarily blood was collected, and vital signs were recorded. Encounters with allied health professionals and educators often took place at this time. The child life therapist greeted every patient and family in the waiting area and asked what materials they might like to play with during their visit. Younger patients were observed to frequent the playroom intermittently during this interval for individual or guided play activities; parents sometimes joined younger children in the playroom, or else took a seat in the waiting area. Older patients typically remained in the main waiting area with family members or carers and occupied themselves with their own devices (i.e. mobile phone or Ipad etc.). Stage 1 varied in length according to clinic flow: number of patients and appointment requirements. For patients with scheduled Short Treatments, Stage 1 often represented the longest waiting phase.

Stage 2: Doctor-Patient Consultation: patient encounter with an Oncology Consultant/Fellow or Career Medical Officer (CMO). This interaction provided the opportunity for the doctor, patient and parents/carers to identify any treatment issues and to assess patient health status. Prescriptions were issued and plans for the week/s ahead were discussed at this time. Younger patients usually sat with their parent/s or carer, though some played with toys, or used the colouring materials.

Stage 3: After Doctor Appointment: interval encompassing time after the doctor consultation, until administration of treatment. Following their consultation, patients and/or carers immediately reported to the reception desk with the appointment form (for billing and scheduling) to confirm their next booking. Patients returned to the waiting area and/or playroom, until a nurse called the patient in for treatment. The duration of Stage 3 depended upon clinic flow, resources and treatment requirements (for example, whether chemotherapy must be prepared that day, or if platelets, blood transfusions or other medications are necessary).

Stage 4: Treatment: process of treatment, including CVL or Port care, and administration of chemotherapy or other IV infusions. The duration of this stage was purely patient-driven (diagnosis/health status-dependent). The child life therapist would again visit each patient whilst they were in the treatment room and ask them if they needed anything to occupy them (toys, DVDs and so on).

#### **4.6 Outpatient Visits: Categorisation of Treatments**

Eight patients received Short Treatments, and although twelve patients were scheduled for Long Treatments, ten patients received Long Treatments and two patients did not proceed to treatment (No Treatment). Details of treatment categories, treatment durations, and length of visits are displayed in Table 7.

**Table 7. Treatment Categorisation, Duration of Treatment and Clinic Visits for Twenty Outpatient Episodes**

Patient ID	Treatment at Visit	Treatment Category	Treatment Duration (hrs)*	Duration of Visit (hrs)
#100701 (Pilot)	Yes	Long	2:44:51	3:21:46
#110701	Yes	Short	0:23:45	2:43:53
#120702	Yes	Short	0:14:58	2:23:01
#150703	Yes	Long	2:41:59	4:00:04
#180706	Yes	Short	1:36:00	3:13:01
#190707	Yes	Short	0:21:02	2:12:44
#220708	Yes	Long	3:57:54	7:33:37
#230709	Yes	Short	1:30:34	2:23:43
#240710	Yes	Long	4:48:01	5:30:04
#250711	Yes	Short	0:14:44	1:38:51
#250712	Yes	Short	0:10:24	1:54:20
#260713	No	No Treatment	-	1:01:18
#290715	Yes	Long	3:52:37	6:23:01
#300716	Yes	Short	0:08:23	1:42:04
#310717	Yes	Long	5:10:27	6:07:39
#010818	Yes	Long	3:34:55	5:55:11
#020819	No	No Treatment	-	1:08:08
#020820	Yes	Long	2:32:51	3:54:08
#050821	Yes	Long	5:49:50	7:41:14
#060822	Yes	Long	6:05:45	7:32:42
<b>Total</b>	<b>18</b>	<b>8 Short, 10 Long</b>	<b>-</b>	<b>78:21:19</b>

\*Treatment Durations include dressing changes (CVL/Port care) and chemotherapy administration. hrs is duration in hours.

## 4.7 Average Time Spent During Each Stage of Visit

The average times according to treatment category for Stages 1-4, are presented in Table 8. Patients scheduled for Longer Treatments tended to have appointments booked early in the day, to avoid finishing late in the afternoon. Note that patients in the No Treatment category were scheduled for Long Treatments. Average wait intervals for patients categorised as Long or No

Treatments in Stage 1 was 50:33 mins and 50:50 mins respectively, whereas patients scheduled for Short Treatments waited an average of 58:13 mins.

**Table 8. All Stage Analysis According to Treatment Type (hours)**

<b>Treatment Type</b>	<b>Stage 1 Before Doctor Appointment</b>	<b>Stage 2 Doctor-Patient Consultation</b>	<b>Stage 3 After Doctor Appointment</b>	<b>Stage 4 Treatment</b>
<b>Av. Short Treatment (n=8)</b>	0:58:13	0:16:18	0:25:15	0:36:42
<b>Av. Long Treatment (n=10)</b>	0:50:33	0:13:08	0:25:26	4:18:55
<b>Av. No Treatment (n=2)</b>	0:50:50	0:12:30	0:01:23	–
<b>Av. All Treatments (n=20)</b>	0:53:39	0:14:20	0:22:57	2:40:09*

\* Average is over eighteen sessions. Av. is average.

#### **4.7.1 Stage 1 Analysis: Before Doctor Consultation**

Table 9 presents timing and interaction data from Stage 1 of the outpatient visit, comparing Short with Long/No Treatments and overall treatments (All Treatments). Most patient interaction time was spent with nurses during this stage (i.e. whilst having blood taken and vitals recorded). Patients scheduled for Long Treatments spent over 17% of Stage 1 in nursing encounters compared with 12.5% for patients having Short Treatments. Patients spent the majority of their time in Stage 1 waiting; minimal or no time was spent with a doctor.

**Table 9. Average Lengths of Time and Proportion of Time Patients Spent with Clinicians (Doctors and Nurses) in Stage 1: Before Dr Consultation**

Observations	Short Treatments (n=8)	Long/No Treatments (n=12)	All Treatments (n=20)
Average Time with Nurse (hrs)	0:07:18	0:08:42	0:08:09
Proportion of Time with Nurse (%)	12.5	17.2	15.2
Average Time with Doctor (hrs)	0:00:09	0:00:00	0:00:04
Proportion of Time with Doctor (%)	0.3	0.00	0.1
Total Time with Clinicians† (%)	12.8	17.2	15.3
Average Wait time (hrs)	0:50:46	0:41:53	0:45:26
Proportion of Stage Spent Waiting (%)	87.2	82.8	84.7
Total Observation Time (hrs)	7:45:44	10:07:09	17:52:53
Proportion of Total Observation Time (%)	43.4	56.6	100.0

\*Note Long and No Treatments are combined (Scheduled as Long Treatments). hrs is hours, % is percentage. † refers to doctors and nurses.

#### **4.7.2 Stage 2 Analysis: Doctor Consultation**

This stage represents the patient-doctor consultation, thus no time was recorded with nurses. Table 10 shows that in an average twelve minute consultation, patients spent around two minutes waiting. Note that consultations for patients who had Long Treatments were approximately three minutes shorter than for patients with scheduled Short Treatments. Patient interactions with doctors fell below 100% during this stage, as doctors left the consulting room to retrieve prescriptions from the printer, and/or for brief consultations with other doctors or allied health professionals.



**Table 10. Average Length of Time and Proportion of Time Patients Spent with Clinicians (Doctors and Nurses) in Stage 2: Doctor Consultation**

<b>Observations</b>	<b>Short Treatments (n=8)</b>	<b>Long/No Treatments (n=12)</b>	<b>All Treatments (n=20)</b>
<b>Average Time with Nurse (hrs)</b>	0.00	0.00	0.00
<b>Proportion of Time with Nurse (%)</b>	0	0	0
<b>Average Time with Doctor (hrs)</b>	0:14:00	0:11:01	0:12:13
<b>Proportion of Time with Doctor (%)</b>	86.0	84.6	85.3
<b>Total Time with Clinicians† (%)</b>	86.0	84.6	85.3
<b>Average Wait (hrs)</b>	0:02:17	0:02:00	0:02:07
<b>Proportion of Stage Spent Waiting (%)</b>	14.0	15.4	14.8
<b>Total Observation Time (hours)</b>	2:10:20	2:36:16	4:46:36
<b>Proportion of Total Observation Time (%)</b>	45.5	54.5	100.00

hrs is hours, % is percentage. † refers to doctors and nurses.

#### **4.7.3 Stage 3 Analysis: After Doctor Appointment**

In Stage 3 (After Doctor Appointment), patients waited for their scheduled chemotherapy/IV infusions (see Table 11). Patients had minimal interactions with clinicians during Stage 3.

**Table 11. Average Length of Time and Proportion of Time Patients Spent with Clinicians (Doctors and Nurses) in Stage 3: After Doctor Consultation**

Observations	Short Treatments (n=8)	Long/No Treatments (n=12)	All Treatments (n=20)
Average Time with Nurse (hrs)	0:01:17	0:00:56	0:01:04
Proportion of Time with Nurse (%)	5.1	4.3	4.7
Average Time with Doctor (hrs)	0:00:03	0:00:08	0:00:06
Proportion of Time with Doctor (%)	0.2	0.6	0.4
Total Time with Clinicians† (%)	5.3	5.0	5.1
Average Wait time (hrs)	0:23:55	0:20:22	0:21:47
Proportion of Stage Spent Waiting (%)	94.7	95.0	95.0
Total Observation Time (hrs)	3:22:01	4:17:07	7:39:08
Proportion of Total Observation Time (%)	44.1	55.9	100

hrs is hours. % is percentage. † refers to doctors and nurses.

#### 4.7.4 Stage 4 Analysis: Treatment

During Stage 4 the greatest discrepancies exist between clinician interactions and wait periods for Short and Long Treatments. Although patients spent nearly double the time interacting with nurses during Long Treatments (i.e. 30 mins for Long, and 15 mins for Short Treatments), proportionally, this represents a much shorter time distribution than for scheduled Short Treatments (i.e. nearly 12% of the stage for patients with Long, versus over 40% interaction time for patients with Short Treatments). Table 12 shows the average times and proportions of times patients spent waiting and interacting with clinicians (doctors and nurses) during this Stage.

**Table 12. Average Lengths of Time and Proportion of Time Patients Spent with Clinicians (Doctors and Nurses) in Stage 4: Treatment**

Observations	Short Treatments (n=8)	Long/No Treatments* (n=10)	All Treatments* (n=18)
Average Time with Nurse (hrs)	0:15:13	0:30:32	0:23:44
Proportion of Time with Nurse (%)	41.5	11.8	14.8
Average Time with Doctor (hrs)	0:00:18	0:00:19	0:00:18
Proportion of Time with Doctor (%)	0.8	0.1	0.2
Total Time with Clinicians† (%)	42.3	11.9	15.0
Average Wait time (hrs)	0:21:10	3:48:04	2:16:07
Proportion of Stage Spent Waiting (%)	57.7	88.1	85.0
Total Observation Time (hrs)	4:53:32	43:09:10	48:02:42
Proportion of Total Observation Time (%)	43.4	56.6	100

\*Note Treatment average is over 10 sessions for Long/No Treatments, and over 18 sessions for All Treatments. hrs is hours, % is percentage. † refers to doctors and nurses.

Graphic representations of patient interactions with nurses and doctors compared with wait times for different treatment types are included in Appendix E: **Quantitative Analysis — Graphs and Charts**.

## 4.8 eMR use and Communication Patterns

Undertaking a direct observational study enabled the study of computer use and clinician behaviours during patient-clinician encounters. Accessing the patient eMR was fundamental to (nearly all) patient-doctor consultations, with one exception. On this occasion, the patient occupied an isolation room for the entirety of the visit, and so a brief consultation was conducted at the patient's bedside. A computer was not accessed at that time. In all other observed visits, doctors checked blood results, ordered scripts, scheduled procedures and checked medical histories by accessing the patient eMR.

In most instances, doctors communicated with patients and/or carers whilst accessing the patient eMR or during paper documentation. Doctors were frequently observed to share results (displayed on the screen) with patients and their carers. Although patient histories are accessible through the hospital eMR, patients/carers also keep a paper record, in the form of an oncology diary. This is generally brought into the clinic for appointments (a requirement for appointments, though occasionally is forgotten), and information is exchanged during these encounters between patients and the consulting doctor.

## **4.9 Qualitative Analysis**

Over the duration of the study period (and including the pilot study), a total of twenty-four interviews were conducted. Interview Durations are shown in Appendix F (**Table 20. Length of Interviews**).

Information elicited from the twenty-four interviews revealed that most patients had experienced a consultation with a doctor who was not their assigned oncologist; this was apparent in eighteen of the twenty-three outpatient visits. Regardless of which doctor provided the consultation, many carers and patients considered that a basic awareness of the patient's medical history facilitated a meaningful interaction. Consultation durations were generally reported by patients and parents/carers as being adequate. Summary information about consultations are presented in Appendix F (**Table 21. Patient-Doctor Encounters**).

### **4.9.1 Thematic Analysis**

An analysis of the qualitative data identified five distinct themes which influenced the patient/carer experience within the outpatient context.

#### **Theme 1: Care Discontinuity and Provision of Care**

On the day of observation, patients and parents/carers reported having appointments with oncology doctors other than their assigned oncologist. This aspect of the outpatient visit was found to induce a level of uncertainty or unpredictability, which was expressed by comments such as:

*"It ranges so actually every chemo we'll potentially see a different doctor...so Dr 6 is his normal doctor, his specialist, yeah, but we had Dr 4 for the beginning of treatment and then I think they rotate teams so we often pick up a different group from time to time as well...When we come back we may see one of the many others and they've got to play catch-up with what's been happening to our child, so it's one of the many challenges of being a public system." (#160704, Father [Male, age 3])*

Although each patient's care was managed by a Consultant Oncologist or Fellow, each consultation could potentially be with any doctor from the team, or with a Career Medical Officer (CMO). The modus operandi for the provision of care by clinic doctors was explained by carers:

*"So there is no usual doctor. So Dr 1 is our specialist, he is the guy assigned to overlook our case, or when you come into the clinic it's basically you put in the bloods and whichever doctor is doing that team, you will see them." (#100701 Father [Male, age 8])*

Some carers and patients referred to our 'proper doctor' and 'my actual doctor' highlighting a disparity in confidence or assuredness, as a result of receiving care from a range of clinicians. Many carers expressed concern, frustration or stress associated with this apparent fragmentation of care, commenting:

*"Well, I've only seen that doctor once before. There's been other doctors that I felt didn't know and had to look it up and had to log in and ask a lot of questions that weren't necessary...whereas they could have just looked it up, yeah? But today was not too bad." (150703 Father [Male, age 6])*

*"Yeah sometimes I feel I'm in there too much because they're trying to wrap their head around it as well and if it was our normal oncologist...they know exactly what's happening and how it's working and we can ask them questions. It would have been really redundant today to ask the doctor about my child going forward because she wasn't on top of it...It was a very vanilla consultation... I think that it was obvious from her conversation, not only her conversation — by the way she had to refer to*

*the previous clinical notes and his medication schedule and the protocols that were in place, because she didn't know what they were.” (#120702 Father [Male, age 5])*

Other parents were more confident in the provision of care by oncologists within their team, stating that:

*“Because I know that they all talk to each other, I’ve only got to run into one out there and they’ll talk to me, and they all talk together, they work close together.” (#170705 Mother [Male, age 8])*

## Theme 2: Communication and Provision of Information

Exchange of information amongst clinicians within the oncology team was apparent to parents and carers. The concept of team care was mentioned by several parents and carers, and whilst some admitted to preferring their own oncologist, they were generally satisfied with the care received. The demonstration of familiarity that team doctors had with their child’s medical history proved reassuring, with parents/carers stating:

*“...sometimes when we come in it’s another doctor, but they are all interconnected anyway.” (#240710 Mother [Female, age 4])*

*“It’s all documented. He (my son) asks questions, and always — you never know who’s around, but they all are — there’s three teams here, and they all have meetings, and every morning they have a meeting at 8am, and they’re all...on the same page.” (#180706 Mother [Male, age 12])*

Communication during consultations was of paramount importance. Patient-clinician encounters were revealed as a source of information exchange often resembling a question and answer session:

*“I don’t know if she read all the things, but the feedback I had, was she could answer my questions, which is what you need...I feel, at the clinic...every time I have a good answer.” (#010818 Mother [Female, age 6])*

Having an accessible digital record (eMR) was perceived to facilitate communication during patient-clinician encounters and was found to be an integral part of the consultation. This patient appreciated the ease of information retrieval, explicating:

*"I speak a lot to them (the doctors), and ask questions. And with the computer they can just flick that up on the screen and tell me the answers. It's pretty easy...it makes it quicker, the questions quicker, because if it was all papers and all that, they would have to go and look for them. Then that would take longer, so the computer is a lot easier."* (#230709p Patient [Male, age15])

Parents and carers felt that computer use during consultations was an important source of information that aided their understanding. One parent commented:

*"they have little moments where they'll show you something on the computer which is good because it makes you feel involved, that they're showing you what they're talking about, for example if they use a massive word that makes no sense to you they open it up and show you on that which is a great tool to have because we can then understand..."* (#250711 Mother [Male, age2])

A few of the parents and carers were reluctant to converse with doctors while they were accessing the eMR or using a computer, for example:

*"...like when they are looking at results and everything, I don't talk to them because I want them to get it right."* (#170705 Mother [Male, age 8])

Not all carers shared the view that the computer was essential to the consultation. One parent was found to have an alternative view regarding the use of computers and the eMR during consultations, noting:

*"No, Dr 7 doesn't tend to (use the computer). I haven't seen the others. Dr 1 tries to update that. It doesn't seem to- it doesn't strike me as something that's embedded as the natural way to do things around here for any of them. It's something that they're still coming to terms with and they remember to do it*

*because they know they have to do it as opposed to something that's an integral enabling part of providing their care, that's not how it is."* (#250712 Mother [Male, age 17])

Whilst patient consultations were perceived to support communication and information exchange between clinicians and patients and carers, the potential to omit contextual information was an issue raised by several parents/carers. Familiarity and trust developed in the initial treatment phase was not necessarily fostered during appointments with successive clinicians. Parents spoke about subsequent consultations being less meaningful:

*"Depending on ... what doctor you access on the particular day who has more knowledge of — sometimes you get a doctor you don't know. So, it's a bit hard then to talk about the girls because you've got no ongoing connection with that person. Whereas, obviously today, Dr 6 was available, so it was more in-depth..."* (#260714 Mother [Female, age 5])

*"Sometimes they have to look it up...Sometimes we just have to remind the doctors what's happening."* (#100701 Father [Male, age 8] Father [Male, age 8])

Parents and carers raised a separate issue regarding communication, describing unexplained waits. On occasion, they experienced extended clinic delays, which they found frustrating. This exacerbated feelings of uncertainty and annoyance. Parents or carers would eventually ask the reception staff, as these parents recounted:

*"You just go and ask because we have been here that long we just go and say what's going on?"* (#100701 Mother [Female, age 6])

*"I think sometimes, (it's) bad to ask why I'm still here."* (#010818 Mother [Female, age 6])

### Theme 3: Service Quality and Meeting Patient Care Needs

Clinicians were generally reported as meeting and sometimes exceeding the care requirements and expectations of both patients and carers. Service quality in terms of staff care,



was expressed as the most positive aspect of attending the clinic. This extended beyond technical care provided by the doctors and nursing staff and was inclusive of allied health professionals who provided patient and family support. Most carers reported being given ample time during consultations to receive the necessary care for their child:

*"I think they (the doctors) are guided by the number of questions or things we want to know, too... other times we've picked their brain for quite an extensive period of time because things weren't going quite right, we didn't know what was happening next and you want to know those things so I've never felt like we're rushed or they don't give us the time.....in dealing with the teams, the teams are fantastic so it's a good experience."* (#160704 Father [Male, age 3])

*"I feel I can get every question that I want out, yeah. I can take the time..."* (#220708 Mother [Female, age 9 months])

One parent had an alternative view about consultations provided in the initial period following her child's diagnosis, commenting that although current appointments were adequate, earlier appointments during that time needed to be longer:

*"I do now because I'm confident with the system and who is here but earlier on in this, no, not at all, I wouldn't have felt that."* (#250712 Mother [Male, age 17])

The technical competence of the nursing staff was appreciated by many carers, inspiring confidence and assurance in a situation which was continuously evolving. Parents and carers were lavish in their praise of nurses and the staff in general, remarking:

*"They're (the nurses) brilliant! So, they change -they have the central line changed and dressed every week...make it look so easy...as well as administering the chemotherapy to the stand, as well as checking the observations as well from the patient, and cleaning up after chemo. So there is a little bit of hands on interaction with the nurses, and I find them all fabulous...the service here is sensational for us."* (#180706 Mother [Male, age 12])

*"Everyone's very good, very busy, very...we can literally say we love them; we do. They're very caring. You can rely on this place." (#190706 Mother [Female, age 8])*

Whilst the technical competence of the nursing staff was espoused by many patients and carers, the psychological care and support was also highly regarded. Several parents and carers described strong bonds between patients and staff, alluding to feelings of assurance, faith and confidence that their child's well-being was paramount:

*"It's always, we always feel like, we always say to them it's our second home, since November last year. Yeah, we always feel welcome. And they're always approachable. And they always seem to know what they're doing." (#240710 Mother [Female, age 4])*

*"You kind of get that little, like that – not friendship, but you know, that little bond with certain nurses." (#260713 Father [Male, age 6])*

*"...every nurse has this bond with her, and it doesn't worry me if they're happy to hold her, but with her, every minute pretty much is with a nurse or a doctor, or someone. So we're very lucky, very lucky." (#220708 Mother [Female, age 9 months])*

The ease of accessibility to the clinical staff was of significance to several carers who commented:

*"I know where to find them (doctors) if I need them and I'm happy not to have them if I don't." (#250712 Mother [Male, age 17])*

*"...if there are problems or if I have questions or my wife has questions, they're (the nurses) easy to find and ask a quick question, yes. They've been pretty helpful." (#290715 Father [Female, age 16])*

#### Theme 4: Lack of Autonomy

A dependency on external influences within the clinic was mentioned by many carers. Some parents/carers spoke about staff and resourcing constraints which impacted their visits:

*"...then the doctor orders what happens. They will go to the room, they will give you the counts and the doctor orders what we'll do and then we'll walk around to the ...treatment room, unless the chemo's not ready or the nurses aren't ready, we just wait again."* (#170705 Mother [Male, age 8])

*"...depending on if there's a space available, within one to two hours we'll wait to have a space and time, depending on what chemotherapy the child's having."* (#180706 Mother [Male, age 12])

As recipients of the outpatient service, patients and families commented on being influenced by clinic flow during their visits, and a dependency on predisposing clinic factors. Parents/carers talked about potential impacts on their outpatient experience including visit duration, lengths of waiting times, clinic resourcing and staff. One carer noticed that "it all happened pretty seamlessly today" (#230709), which proved to be a better experience than most other reported experiences:

*"Today, I was a bit, mmm, someone forgot about us because it was a long wait."* (#010818 Mother [Female, age 6])

*"You kind of get your favourite doctors and the unfavourite doctors. So, those unfavourite doctors don't tend to pre-order those bloods. So, we have to order them again and have to wait. Whereas normally most of the doctors will order it prepared ready for that day. So, that's the only time we'll have to wait. We wait like an hour."* (#260713 Father [Male, age 6])

The uncertainty of clinic waits was one of the most difficult challenges patients and carers faced at every outpatient visit. The range of waiting times varied considerably from visit to visit, which exacerbated feelings of dependency, inconsistency, uncertainty and frustration in carers and patients. Comments included:

*“Well, it varies, it really varies as to how many people are in clinic, how many people got here before you et cetera so, look, it varies from an hour to sometimes two, two and a half, three hours. It really depends...” (#120702 Father [Male, age 5])*

*“It could be a couple of hours to twelve hours, you never really know...Yeah, I have just worked out that if you think the worst and I always plan that I’m going to be here for twelve to fifteen hours, anything less is a bonus...I mean of course if you could reduce the amount of time waiting then it would be amazing.” (#110701 Mother [Male, age 6])*

The perception of wait times, however, varied according to individual patient/carer experiences. Some patients enjoyed the playroom activities, and when asked how long the wait was before her doctor’s appointment, one patient clearly underestimated it to be:

*“Maybe about 15 minutes.” (#190707 Patient [Female, age 8])*

This patient was quickly corrected by her parent, who amended by stating:

*“Longer than that. It all varies because it depends, we may get blood taken first, or we’ll get our height and weight checked first, so it’s depending on that, we wait for that. We come back, wait again, bloods, wait for those results, wait for the doctor to actually look at the results then call us in, go back to the waiting room, then go to the room to get chemo. So it depends.” (#190707C1 Mother [Female, age 8])*

Outpatient visit wait time was influenced by the patient’s health status and other complexities associated with the patient condition. These circumstances could negatively impact perceived wait periods, as evidenced by:

*““Ours has been a little bit not consistent because of the port and the issues that we were having with her port. We have to – there were days when they couldn’t give her the chemo because they couldn’t access the port. So, then we’d come in on days – I think one day we were here for five hours waiting.” (#300716 Mother [Female, age 13])*

Coping with clinic life for some patients' families meant arriving earlier or later than the scheduled appointment time, or avoiding the busier days, as this carer explained:

*"Monday. Monday, and I think Wednesdays, they're busy, busy days. Well, that's, they're the days I really avoid. I don't like making appointments on Mondays. I don't like making appointments on Tuesday or Wednesday. Thursday or Friday, that's when they start to calm down..."* (#020820 Mother [Female, age 9 months])

#### Theme 5: Oncology-derived challenges and Quality of Life Impacts

Acclimatising to clinic life as an outpatient family was a digression from previous family routines that some parents and carers described. This was accompanied by a sense of resignation and acceptance that patients and carers expressed towards their 'new normal':

*"We have had previous experiences where we have come in and waited all day, we have been in here like at 8:30 and we have walked out of the door at 4:30 and we spent most of the time just waiting in the waiting room, and that's just staffing arrangements and trying to get seen."* (#100701 Father [Male, age 8])

*"There's going to be two years of this so you've just got to settle in...That's the new norm so that's what you do."* (#150703 Father [Male, age 6])

Paediatric oncology is acknowledged as having a high level of complexity. Parents and carers demonstrated an understanding of this:

*"Yeah, and today waiting for the blood, because it was decided last minute that he was going to have a blood transfusion and they had to do so much. It's not as simple as opening the fridge and getting it out — I can appreciate it."* (#110701 Mother [Male, age 6])

Chemotherapy has numerous impacts on patients — physical, social and emotional. Some of the treatment consequences were difficult for the parents or carers to manage, and other situations proved onerous for everyone:

*"I think the worst is when they have steroids, fasting (for) lumbar puncture or bone marrow. Is a nightmare." (#010818 Mother [Female, age 6])*

*"I have to be quite honest — I do get a bit frustrated because it is a big, big day and he gets...very agitated because he just doesn't like it. He doesn't like sitting here being hooked up or anything like that for hours, and he just doesn't like — because when all this is finished, he is going to be quite sick, he's going to end up vomiting, and everything like that, and all he wants to do is sleep then." (#020820 Grandmother [Male, age 11])*

Long chemotherapy treatments were identified as being particularly arduous for patients and carers alike. Some of the carers spoke of paying bills or doing work on their laptops, although they often found the clinic environment to be distracting. One patient had his own coping mechanism for enduring long visits:

*"...when I'm in here, I tend to sleep, just to pass the time." (#230709p Patient [Male, age 15])*

The challenges of being an oncology outpatient family are compounded by having to travel and/or live away from the comforts and relative normality of being at home. A few families talked about these challenges:

*"It's probably quite time consuming, as you can imagine. I suppose — particularly if you live in a regional area, it's the wait time that's mainly difficult. And you can't always access Ronald McDonald House for accommodation which would then make it extremely financially difficult because it takes such a long time in the day to do one treatment. It's not really feasible to drive two hours from a regional area and then two hours home in one day. (#260714 Mother [Female, age 5])*

Some of the care coordination was managed by carers, who were required to organise some of the tests and home nursing visits. This was yet another confronting experience one parent described:

*"It's been as pleasant as it can be, if you know what I mean, we haven't had any disappointments. I'd say because we're so far away...we do have to organise stuff...and that is the only difficult part sometimes..."* (#150703 Father [Male, age 6])

Additional patient and carer quotes have been included in Appendix G (**Table 22: Qualitative Analysis — Themes and Subthemes**).

A final quote concludes this chapter. According to one patient, the best part of the outpatient visit (#230709p) Patient [Male, age 15]:

*"Leaving!"*

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## CHAPTER FIVE: DISCUSSION

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## 5. Discussion

This chapter discusses findings from the study, looks at the strengths and limitations of the methodological approach, and compares results from the present study with findings from similar research in the existing literature.

### 5.1 Key Findings

The central objective of the present study was to examine the outpatient experience in a paediatric oncology clinic, with a focus on wait times, patient-clinician interactions and progression through the outpatient visit. Results from the direct observational time and motion study determined that an average visit to the outpatient clinic was more than four hours long, with patients (and family members) attending a doctor's consultation of just over twelve minutes. Patients spent a substantial part of their visit waiting and were found to engage in interactions with clinicians (doctors and nursing staff), for less than a fifth of the time during an average outpatient visit. Consultation duration was generally reported as being acceptable by most patients and parents/carers, however, the waiting time was perceived as unpredictable and long. Parents and carers were found to be satisfied by the provision of care offered by the clinic, viewing the nursing and other clinic staff with high regard. Interactions with treating doctors were reported as being meaningful by most patients and carers, with clinician use of computers during consultations generally considered as integral to the visit.

Accordingly, a paediatric oncology outpatient visit at this clinic primarily involved a cumulative lengthy wait interspersed by encounters with clinicians (nursing staff and doctors). Patient interactions with nursing staff occurred with greater frequency than patient interactions with doctors, such that during an average outpatient visit, patients were found to interact with nurses for more than twice the length of time than with doctors (around 33 minutes compared with 12.5 minutes, respectively). These results reflect the divergent roles clinicians fulfilled within this oncology clinic setting. Nursing responsibilities involving direct patient contact were centred around the practicalities of chemotherapy administration – such as taking blood samples, checking vital

signs, preparation for drug administration, administering infusions, observing and monitoring the patient during infusions and attending to wound care (CVL and port care). These duties, whilst intermittent and often brief, occurred with relative frequency during Stages 1 (Before Doctor Appointment) and 4 (Treatment), of outpatient visits. Oncology doctors generally interacted with patients during consultations (Stage 2), and only briefly and infrequently throughout the rest of the outpatient visit. Consequently, total patient interactions with doctors were more limited than encounters with nurses.

Overall, the quantitative and qualitative findings identified several key factors which influenced the outpatient experience, including wait times, patient-clinician relationships, communication of information, lack of autonomy and chemotherapy impacts.

## **5.2 Waiting in the Outpatient Clinic**

Patients in this study were categorised as having Short or Long Treatments (less than, or greater than 2 hours). Those patients scheduled for Short treatments spent proportionally more time waiting during Stage 1 (Before Doctor Appointment), than patients having Long Treatments. These results suggest that patients receiving Long Treatments were prioritised at the clinic. Conceivably, clinic staff prioritise these patients in the initial phase of the visit (Stage 1: Before Doctor Appointment), to ensure that Long Treatments are completed in a reasonable time frame, and within clinic operating hours.

A paediatric oncology study by Hendershot et al. (2005) similarly defined outpatient treatments according to duration, however, only push chemotherapy and intramuscular IV injections were characterised as treatments of short duration (13). Although exact outpatient timings were not reported, an outpatient visit encompassing a short treatment was described as averaging 3-4hrs. Outpatient visits in the present study were quantified in terms of patient wait periods, timing of patient-clinician encounters and overall visit durations. Results from the current study indicated that seven of the eight visits of the Short Treatment type, were less than 3hrs in duration, which was shorter than the approximated length of outpatient visits reported in the Hendershot study (13).

In a general (adult) oncology study using an ethnographic methodological technique, observations of outpatient visits revealed that patients received twenty-minute doctor consultations and waited for up to three hours for chemotherapy treatments to be prepared (59). This was longer than the average consultation duration determined in the present study.

During the Doctor-Patient Consultation in Stage 2, on average, patients receiving Long Treatments spent less time in consultation with the doctor, than patients receiving Short Treatments. Interestingly, all patients were found to spend a small proportion of time during the Doctor Consultation waiting, which was unanticipated (i.e. when clinicians leave the room to speak with other health professionals, or to retrieve prescriptions from the printer located at reception). Consultations appeared to be largely patient-driven, with doctors seemingly guided by the number of questions asked by patients or carers. Parents and carers reported that consultation lengths were variable, according to need. Whilst consultations at this clinic averaged over 12 minutes in duration throughout the field study period, parents and carers identified times over the course of their child's treatment, when consultations were much lengthier. Parents and carers appreciated being given as much time as they needed during consultations, without feeling rushed or pressured by time limitations. The duration of consultations, therefore, were reported as largely satisfactory, however, there were some exceptions. A few carers felt that consultations with doctors (not their assigned oncologist) were too long, and one parent suggested that earlier consultations following their child's initial diagnosis needed to have been longer because of the complexity of the situation and unfamiliarity with the oncology clinic. This view is consistent with findings from a study of general outpatient populations, which determined that newer patients expected more time in consultations, whereas the quality of consultations was of greater importance than duration, for follow-up patients (24). In the paediatric oncology setting, patients and parents have indicated a preference for receiving more generalised information during initial consultations, followed by more comprehensive information in subsequent consultations (76). Furthermore, clinicians exhibiting a caring manner and willingness to communicate are valued more highly by patients, than the length of encounters (48).

Proportionally, patients spent the most time waiting (95%) during Stage 3 (After Doctor Appointment). Waits averaged nearly 22 minutes for this interval, which was less than the estimated average wait reported in an adult study of chemoradiotherapy patients (56 minutes between their scheduled appointment and chemotherapy treatment) (34). Clinician interactions were limited in Stage 3, and minimal differences were observed between the two treatment types (i.e. Short and Long Treatments). This wait period is an essential component of the outpatient visit, during which preparations for chemotherapy (and other infusions) are made. However, the length of the interval may be impacted by other factors such as clinic flow and resource constraints (such as availability of treatment chairs) (13, 39, 59).

The other research study found to document patient wait times and clinician interactions, was undertaken by Asefzadeh et al. (1997) in an outpatient paediatric clinic (41). Patients in this study were found to wait an average of 77 minutes for a 3.4-minute doctors' appointment. Consultation times for the present study were almost four times the consultation duration reported for the study by Asefzadeh (1997), although shorter than the average twenty-minute consultation reported by Lamé et al. (2016) (41, 59). Differences in consultation durations could reflect the nature of the service provided and patient populations studied; longer consultations were reported for adult oncology patients in the study by Lamé et al. (2006), and shorter consultations were documented in both paediatric studies (41, 59). Furthermore, the more recent two studies report longer doctor consultations, which may be indicative of the complexity of outpatient oncology (7, 11, 77). Adult patients may also wish to engage in further dialogue with their physician, and there may be a diminished sense of urgency in proceeding to chemotherapy treatment, in comparison to parents of paediatric oncology patients.

As expected, the majority of outpatient time for patients scheduled to have Long Treatments was spent receiving chemotherapy or other infusions (i.e. during Stage 4: Treatment). This contrasted with patients receiving Short Treatments, who spent proportionally more time in the initial stage of the outpatient visit (Stage 1: Before Doctor Consultation). Patients and parents found Long Treatment durations challenging; depending on wellness, patients either slept, played or watched DVDs to occupy their time.

Wait times were a predominant concern for most outpatient attendees. The unknown wait duration was one of the most challenging aspects of the outpatient visit. In an average outpatient visit, patients and family members faced nearly 3.5 hours of waiting, which included over one hour before treatment commenced for that visit, and more than 2 hours during treatment. Younger patients (and siblings) were well catered for during wait intervals, thus positively influencing outpatient visits for patients and carers alike. Occupying young children during these visits can effectively minimise parental/carers stress (13). The outpatient clinic employs a full-time child life therapist (assisted by part-time volunteer staff), who co-ordinates play and helps to constructively occupy children's wait time. Some parents commented that their child enjoyed coming to the clinic for play time guided by the child life therapist. Patients also expressed enthusiasm about the playroom activities. Older patients (adolescents and teenagers) were not seen to engage with this or other programs, consequently finding wait times more tedious. Other organised programs and events offered in the clinic were mostly targeted toward the younger age group, however, educational support was available to all patients (Back on Track program), in the form of organised tuition. Patient uptake of this program, however, was contingent upon health status. Whilst the clinic catered well for the younger age groups it seemed to afford little opportunity to engage older patients during wait intervals. Acknowledgement of the idiosyncrasies of this paediatric patient sub-population was highlighted in an investigation of an established inpatient adolescent cancer unit in the UK (60). The oncology unit, designed specifically to accommodate adolescents, employed specialist staff skilled in the treatment and care of adolescent oncology patients. The study emphasised the importance of acknowledging the unique challenges faced by teenagers with cancer, and the value of delivering developmentally and age-appropriate care (60). Oncology patients of this age group clearly benefitted from and appreciated being treated as a separate patient population, deriving mutual support and a sense of normality from being accommodated with other adolescents. Features of the unit which highlighted its strengths included the physical environment, effective multidisciplinary teamwork, the availability of skilled staff with expertise in adolescent oncology care, and the mutual support provided by their peers (60).

Addressing patient/carers concerns regarding unacceptable wait durations could be undertaken in various ways. Rondeau (1998) suggests that healthcare services may consider re-

engineering the service delivery process by either adding or removing a number of discrete steps within the service process. Using the methodological approach of discrete event simulation modelling (DES) embedded in a soft systems methodology framework, Lamé et al. (2016) contends that service evaluation can be performed at various stages of the redesign process. Outpatient clinics (such as the one presented in this study) exhibiting extended waiting periods could conduct DES modelling in conjunction with qualitative data collection to assess and improve service deficiencies.

Whilst wait time was emphasised as a negative aspect of the clinic, the perception of wait time differed according to individual circumstances. Patients were found to significantly underestimate the wait time when they were occupied. These results may be indicative of the concept that time seems to pass more quickly when patients are constructively engaged. Time discrepancies observed in the current study may reflect wait periods perceived as either enjoyable or tedious. Wait periods spent in discomfort, apprehension, or in circumstances resulting in extended delays (e.g. during times of impeded clinic flow or port access difficulties), caused outpatient attendees to perceive the waits as much lengthier. Variations in perceived wait times compared with actual wait times in the current study corroborates the propositions of Maister (1985) quoted by Rondeau et al. (1998), that occupied waits appear shorter than unoccupied waits, and anxiety and uncertainty in waiting is perceived as lengthier than a finite, known wait (44). In another study, Leddy et al. (2003) suggest that “A key component to wait time is perception” (p.139)(55).

### **5.3 Patient-Clinician Relationships and Perceived Care Discontinuity**

Clinical consultations were a focal point in the examination of patient-clinician encounters. As part of the public hospital system, the outpatient clinic is subject to staff rostering and resource constraints (including staff rotations), contributing to the perceived unpredictability and inconsistency of care experienced by patients and family members (an apparent fragmentation of care). Most patients participating in this study were not seen by their assigned oncologist on the day of observation, and parents/carers explained that they may potentially be seen by a different

oncologist at every visit. Some patients minimised their potential for care discontinuity by arranging appointments on their doctors' known assigned clinic days.

The significance of patient-clinician relationships has been well-documented in the literature and has further significance for oncology patients who experience higher acuity levels (37). The successful patient-clinician relationship is comprised of many elements, including effective communication, trust, familiarity, empathy, clinician behaviours and inter-personal skills (9, 45, 49). The concern regarding care continuity was problematic for some carers and parents of the present study, and was expressed as frustration, annoyance, or worry. Parents and carers spoke about contextual details that only their regular doctor was aware of, describing consultations in which basic needs were met, however, meaningful, in-depth conversations were not possible. A systematic review investigating patient-clinician relationships in oncology, highlights the value patients assign to the continuity of consulting with the same doctor at outpatient visits, and the underlying link to perceived care quality (9). It may be necessary for patients to attend the outpatient clinic often, however, encounters with oncologists may be relatively brief and less frequently attended (9). Evidence suggests that paediatric patients prefer care continuity from the same doctor where an established familiarity prevents them from having to repeat information about their condition (76). In the investigation of communication preferences, Zwaanswijk et al. (2007) identified patient and parent concerns regarding potential adverse impacts on patient health resulting from fragmented care (76). Misgivings included the inability to detect minor variations in patient health due to a lack of familiarity, and the increased likelihood of miscommunication when receiving care from multiple doctors. Patients and carers in the present study similarly indicated a preference to attend consultations with their assigned doctor, however, were generally satisfied with the care received at the clinic.

The outpatient clinic in the present study has devised a system of team care to maintain quality of care for their outpatients. Provision of Team care is facilitated by regular team meetings, and universal access to the patient eMR for Team doctors (Consultant Oncologists and Fellows). Usual clinic practice dictates that doctors access patient files immediately prior to a consultation, thereby familiarising themselves with each patient history. Theoretically, working in teams, in

conjunction with having access to patient eMRs, should obviate the need for patients to be restricted to seeing one oncology doctor for all appointments, and minimise care discontinuity.

Although meaningful interactions were recounted by most parents/carers, there remained a preference for experiencing greater consistency in their child's oncology care. Whilst the provision of care from doctors retained some level of uncertainty, patients and carers expressed considerable confidence, adoration and appreciation of the nursing staff. Nursing staff may act in an interpretative capacity for patients and their families, reinforcing information given by the doctor in a more informal setting than the consultation (78). According to Björk et al. (2006) nurse familiarity may also play a vital role in patient cooperation (79). The present study has demonstrated that patients and carers have additional opportunity to interact with nursing staff throughout their visits and thus develop familiarity. Consequently, nursing interactions can exert considerable influence on overall patient experience during outpatient visits, which may contribute towards bridging the perceived gap in care provision (9).

The clinic environment, encompassing the staffing, scheduling, resourcing and clinician expertise, is a key determinant of the patient experience – patients and their families are reliant on care, communication and teamwork to provide an optimal clinical outcome (37, 42). Generally, parents and carers were appreciative of the service provided at the clinic, holding clinicians and staff in high regard. Notwithstanding the inconsistencies experienced through exposure to different clinicians, most study participants were confident in the quality of care provided (technical and emotional). A strong sense of teamwork was mentioned by several parents, with this generating faith and reassurance in care provision. In paediatric oncology, attributes such as teamwork, provider communication, and clinic cheerfulness have also been demonstrated to influence overall patient experience (37, 45).

## **5.4 Communication and Provision of Information**

The complexity of paediatric oncology necessitates the communication of difficult concepts. Clinicians must explain diagnoses, management and potential health impacts to patients and carers, clarifying complicated treatment protocols and chemotherapies (9, 76). Detailed patient



information, including protocol information, treatment plans, test results and notes, are entered into the eMR, which is readily accessible to all treating clinicians. Regular team meetings in conjunction with accessible current patient records facilitates the sharing of essential information amongst clinicians and enables treatment to be provided by various medical staff. This is particularly significant in oncology, as patients' health status is often in flux.

Exchange of information is a critical component of the outpatient oncology visit and is an integral part of each clinician interaction. Development of an ongoing, trusting relationship and familiarity between patients and clinicians can foster effective, reciprocal communication and enhance patient engagement (48, 49). One of the fundamental benefits of an ongoing patient-clinician relationship is the facilitation of communication between patients and clinicians (49, 76). Attending consultations with alternative team doctors proved challenging for many outpatient attendees, who felt that consultations were difficult without an ongoing connection. This view is consistent with the communication preferences of paediatric patients in the study by Zwaanswijk et al. (2007)(76).

#### Computers Facilitating Communication During Consultations

Patients and carers considered computer use and accessing the eMR as beneficial to the consultation, serving both as a source of information and facilitator of information exchange. The introduction of digital technologies (such as eMRs) into medical practices and hospitals has provoked considerable debate in the published literature regarding implications for the patient-clinician relationship. Many studies have addressed the matter of computer use during consultations, however, few studies have investigated the patient perspective in the paediatric population (80). Recent studies of family medical clinics have looked at clinician use of eMRs during consultations and found that most patients embrace this practice (49, 50). Not all parents and carers in the present study felt comfortable speaking to doctors whilst they were using a computer, stating that they preferred not to interrupt, as it was important for the doctor to get it right when reviewing results. This view was shared by patients in a recent study of general medical practices in Lebanon, which assessed the use of eMRs during consultations (50). A small number of patients exercised the choice not to speak to doctors whilst using the computer, as they also felt concerned about the potential

for doctors to make errors (50). In the present study, observations of clinicians during consultations revealed that doctors usually angled their computer screens for the benefit of patients and carers, and generally maintained a reasonable balance between focussing on the computer and being attentive to the patient and their carers.

#### Provision of Information

The provision of information was satisfactorily addressed during patient-clinician encounters, however, was found lacking in the greater clinic environment. Some carers spoke about unexplained delays during outpatient visits, and having to ask reception staff about the nature of the delay when information was not forthcoming. According to a study conducted by Davis et al. (2017), being informed about clinic delays was one of several factors influencing overall patient experience and satisfaction with service quality in paediatric oncology (37).

### **5.5 Lack of Autonomy**

Attendees of the outpatient clinic are confronted with having to adjust to a new 'clinic life.' This involved exposure to external influencing factors, which determined an altered routine, structured around the oncological treatment pathway. The unpredictability of the patient's condition coupled with limited choices about treatment decisions and a dependency on others to deliver essential care, effectively diminishes opportunities for autonomy or normalcy.

Families in these circumstances experience a high degree of stress, uncertainty, dependency and added complexity. Clinical decisions are governed by disease progression and treatment consequences. Clinic visits, therefore, involve an element of unpredictability resulting from factors such as health status, communication, clinic flow and resourcing (staff and clinic). New patients and their families exist within the confines of the clinic routine, which is dictated to them, although some find ways to exercise a modicum of control over their situation. Participant interviews revealed that the outpatient experience in paediatric oncology exposes patients and their parents/carers to a degree of uncertainty. Many carers expressed frustration about their lack of autonomy within this context: unpredictability of waiting times, clinic flow, clinic volume, the consulting doctor, visit duration, provision of information, and most significantly — patient health status (potentially

influencing each outpatient visit). Whilst many of these uncertainties are unavoidable, some ambiguity around clinic delays could be alleviated by providing more information to outpatients (37).

## **5.6 Oncology Derived Challenges and Quality of Life Impacts**

### **Loss of Normalcy**

Becoming an outpatient family involves the loss of normalcy — with the former quality of life being compromised. Essential outpatient visits represent a disruption to normal daily routines and events, often for extended periods of time (sometimes many years). The impacts of this can be considerable, particularly for rural and regional families who travel significant distances to attend the clinic as outpatients. There can be a loss of autonomy, identity, normality, and often social and financial losses, which are in addition to the burdens of physical and behavioural changes experienced by the patient. Temporary loss of social connection was a further hardship for adolescents, and regional or rural families. These results are similarly reflected in a study of paediatric oncology patients in Argentina, in which children recounted the impacts their condition had, on their everyday lives (81).

Many carers and patients were resigned to their situation and assimilated to new clinic routines, accepting their new norm. However, other families experienced difficulty in adjusting to a prescribed routine, arriving at the clinic opening time (regardless of their booking time), whilst other families arrived later than their scheduled booking. Parents and carers spoke about avoiding certain days of the week, and only booking appointments on less busy clinic days. Exerting some control over their situation created an opportunity for some patients and their carers to minimise clinic time and maintain some sense of normality and quality of life.

### **Complexity of Oncology**

As discussed, patients and carers exhibited different coping mechanisms for lengthy wait periods. Parents demonstrated some tolerance and understanding towards delays in the outpatient process, citing reasons such as waiting for blood samples to come back from pathology, and availability of treatment chairs for chemotherapy. Parents and carers displayed an appreciation and

understanding of the complexity of paediatric oncology. One parent spoke about blood transfusions as being much more complicated than just retrieving them from the fridge. Other parents were careful not to interrupt the doctor while they were accessing patient records during consultations.

The lengthy delays experienced in outpatient paediatric oncology can be partly explained by the work carried out by staff on the patient's behalf. Whilst Suss et al. (2017) explain this aspect of patient waits as "value-added waiting time" (p.533)(39) during which patients are non-participatory, Lamé et al. (2016) refer to "idle patient times" (p.9)(59) to describe the wait intervals between patient care events. As some wait time is inevitable (such as the interval described in Stage 3: After Doctor Consultation), it cannot be eliminated. Unexplained delays (discussed earlier), however, were more challenging to contend with, causing patients and their family members some anxiety and frustration.

### Chemotherapy Impacts

The issue of chemotherapy side-effects was raised by several parents, particularly those impacts associated with steroid treatments. Changes in physical appearance were stressed as being problematic for teenaged patients, however the behavioural changes were cited as being more troublesome to manage. Parents and carers confessed to lacking appropriate skills for managing steroid-induced emotional fluctuations, revealing that they did not feel adequately prepared or equipped to deal with their child under these conditions. This issue has perhaps been overlooked by clinicians, representing a potential gap in communication and information provision, which would be beneficial to address.

A further challenge in paediatric oncology witnessed during observational episodes and articulated by some parents and carers, was the distress of CVL dressing changes. Nurses attend to CVL care on a weekly basis for patients with central venous lines, to minimise the potential for infection (a serious concern for this patient population). This was clearly one of the most distressing, yet unavoidable elements of outpatient visits for most patients and carers. Active and passive distraction mechanisms have been used for pain management in paediatric patients during procedures such as wound dressings (82, 83). Distraction mechanisms such as engagement with serious gaming, music therapy, interactive toys, auditory and audiovisual distractions, for example,

can effectively divert a child's focus from painful procedures (82, 83). Research by Nilsson et al. (2013) demonstrated that serious gaming elicited a sense of control over the wound dressing procedures in addition to reducing distress and pain behaviours. Restoration of some sense of control may engender feelings of patient autonomy, Whilst the use of serious gaming may not be suitable for wound care in paediatric oncology patients, other distractive mechanisms could feasibly be offered.

Ideally, investigation of superior wound dressing techniques or materials may provide an alternative to the current method of practice at the clinic which patients, carers and nurses clearly found traumatic. The physical impacts of chemotherapy on paediatric patients is widely recognised, however, identification of emotional and psychosocial symptoms stemming from cancer therapy has been suggested as a responsibility of clinic nursing staff (84).

## **5.7 Strengths of Study**

Utilising a mixed-methods approach for this study was beneficial in providing quantifiable evidence of paediatric oncology outpatient visits and presenting the patient/carer perspective of this experience. Patient flow and clinic processes were examined from the perspective of patients and their carers, as well as timing data of activities during outpatient visits. This is the first study to apply a time and motion study method using a validated sampling tool, for the investigation of patient experience in the outpatient paediatric oncology setting.

Contextual data was obtained through the combined use of an observational methodology and the undertaking of participant interviews. Qualitative research methodologies are advantageous in facilitating understanding of the positive or negative aspects of a health service, as well as service appropriateness (60). Observational methodologies are beneficial in avoiding disruption to daily clinic operations and are advocated when investigating child participants (20, 79). In addition, qualitative methods enable the examination and "understanding of activities in their context" which is invaluable in gaining greater detail and depth of information about clinical services or processes

from a patient perspective (p.4)(59). The opportunity for patients and carers to articulate their views was fundamental in examining their outpatient visits. Patient and carer responses elicited a depth of detail not attainable solely through observations – thus disclosure of patient expectation and lived experience is foundational in understanding the efficacy and perceived quality of the services provided (24).

## **5.8 Limitations of Study**

The parameters of the study governed the selection criteria for suitable participants; potential participants included patients undergoing active chemotherapy treatment (accompanied by their parents or carers) scheduled to receive both a doctor's consultation and chemotherapy (or other IV infusions) on the day of observation. This limited the number of potential participants who could be approached during the interval of field study. Furthermore, the number of potential observational episodes per day were restricted due to the clinic booking schedule, as patients were only able to secure appointments between 8:00am – 1:00pm. As there was only one observer conducting the time and motion study and participant interviews, observational episodes were limited to a maximum of two per day.

The sample size was small owing to the participant inclusion criteria and the relatively short period of field study. In conjunction with the unique characteristics of the study population, the sample size limits the potential for comparison or generalisation to other patient populations. There are no equivalent studies with which to compare quantitative results from the present study, however, the data may be foundational in providing a baseline for future research in the field.

Inductive thematic analysis undertaken by a single researcher provided a further study limitation, potentially creating bias or error, with a resultant lack of validity and rigour for the qualitative component of the study. According to Thomas (2006) and Roberts et al (2019), having a second coder to provide consistency checks and inter-rater reliability, establishes validity – a component of trustworthiness, to the data analysis (85, 86). In addition, this study was limited to a

single study site. Results may be found to differ according to the size and location of the outpatient service.

Finally, potential interviewer biases may have been introduced through the undertaking of interviews by the same researcher conducting the observational time and motion study (80).

## **5.9 Recommendations and Future Directions**

The study findings identified several potential avenues for future research in the field of outpatient paediatric oncology.

Gauging the physical, emotional and psychosocial impacts of the various factors influencing the patient experience remains challenging. A combined approach using quantitative and qualitative measures could focus on eliciting the patient voice to evaluate outpatient experiences in paediatric oncology. The use of patient interviews, in conjunction with validated survey and reporting instruments appropriate to this patient population, could prove beneficial to investigating ways of ameliorating some factors found to influence patient experience in this setting. Jibb et al (2018) suggest that patients experiencing a lack of autonomy can benefit from inclusion in their treatment and care processes, in addition to being provided with information about their condition and the opportunity to ask questions.

Similarly, research incorporating patient feedback data could be used to establish baseline evidence of patient expectation in this setting, as compared with experience of the actual outpatient visit (24).

Noted earlier in Section 5.2 (p74), adolescent patients were less well catered for than younger patients in the clinic during wait periods. Evidence suggests that positive distraction mechanisms can help alleviate boredom, stress and anxiety during wait times, thereby positively enhancing the waiting experience and overall patient/carer perceptions of outpatient visits (43). Consideration of potential interventions targeted towards the engagement of adolescent patients could enhance the experience of this patient population in outpatient oncology clinics.

Conclusions drawn from the observation of clinic processes and supported by qualitative evidence acquired from the patients and carers, has led to the following suggestions:

1. Patients and their families would appreciate and benefit from investigation of clinic waiting periods to improve outpatient experience and reduce unnecessary waits.
2. Examination of the wound dressing procedure to minimise the distress of patients, carers and nursing staff would greatly enhance the outpatient experience.
3. Positive distraction mechanisms additional to those provided for younger patients (by the child life therapists) could be investigated, particularly for older children, especially the adolescent patients.
4. Provision of information by clinic reception staff regarding unexpected delays would avoid uncertainty of extended waits, thereby enhancing the outpatient experience.



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## CHAPTER SIX: CONCLUSION

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## 6. Conclusion

This study examined the outpatient experience in paediatric oncology, which was achieved using a direct observational time and motion study technique, paired with semi-structured interviews. A time and motion sampling technique using the WOMBAT tool provided quantitative data of patient wait times and patient-clinician interactions experienced during a visit, while interviews provided vital information from the patient/carer perspective. A mixed-methods approach contributed to a more holistic understanding of the patient/carer perspective in outpatient paediatric oncology. Key factors influencing the outpatient experience included the unpredictability of wait durations, patient-clinician relationships, communication, lack of autonomy and the complexities of oncology.

Waiting during outpatient visits in paediatric oncology is inevitable, with some wait intervals unavoidable, i.e. prior to treatment administration when staff are engaged in work on behalf of patients (time during which patients are non-participatory). Wait times were largely perceived as being unpredictable and long. Unexpected or unexplained waits during outpatient visits were viewed as frustrating, negatively impacting upon the patient/carer experience. Improvements in information provision by clinic staff may increase the perceived quality of care, thus improving satisfaction with the service and positively enhance the patient/carer experience.

Consultation durations were considered adequate and interactions were predominantly viewed as meaningful. Some misgivings were expressed about the provision of clinic consultations, with patients and carers articulating a preference for continuity of care with their assigned oncologist. Although clinic consultations are provided by multiple doctors using a coordinated team approach, the loss of contextual details and familiarity of an ongoing patient-doctor relationship was concerning for some parents/carers. A perceived fragmentation of care reinforced the uncertainty and unpredictability of outpatient visits, with potential underlying implications for patient compliance, cooperation and the development of trust within patient-clinician relationships.

The experience of an outpatient paediatric oncology visit, whilst coloured by uncertainty, primarily involving lengthy waits, was tempered by the quality of service provided and patient-staff

interactions. Staff expertise and care were highly regarded by patients and carers, engendering confidence and assurance in the quality of care provided at the clinic. Encounters with clinic staff (nurses, reception staff, allied health professionals and doctors) were highlighted as one of the more positive aspects of outpatient visits. Patient/carers familiarity with nursing staff, in conjunction with their acknowledged technical expertise, was found to influence and enhance the outpatient experience, potentially bridging the perceived disparity in care continuity.

Most patients and carers positively viewed the use of computers and the electronic medical record (eMR) during doctor-patient consultations, as a source of information and facilitator of communication. Effective communication between patients, carers and doctors is essential in paediatric oncology, and accessing the patient eMR was considered integral to the consultation by most study participants.

This study has contributed to the knowledge of outpatient paediatric oncology by quantifying patient wait times and patient-clinician interactions, thereby establishing the patient progression through an average outpatient visit. The qualitative component of the study has further provided a comprehensive patient/carers account of this experience, which is fundamental in establishing patient expectations, service issues and areas for improvement. Further studies examining patient experience in the paediatric oncology outpatient setting could similarly employ mixed methods research using appropriate self-reporting instruments in concert with qualitative methods, for capturing the patient voice with the aim of informing clinical practice. Patient-centric evidence of a service such as this one, can ensure service efficacy when underpinned by information about service impacts, patient-appropriateness and service quality not otherwise elicited from qualitative measures.

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# APPENDICES

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## Appendix A: Study Documents

### Ethics Approval

This study has been approved by the Sydney Children's Hospitals Network HREC (approval number: LNR/15/SCHN/171).



**Contact for this correspondence:**

**Research Ethics Office**

Research Ethics Administration Assistant

Phone: (02) 9845 1253

Facsimile: (02) 9845 1317

Email: [SCHN-ethics@health.nsw.gov.au](mailto:SCHN-ethics@health.nsw.gov.au)

Corner Hawkesbury Road  
and Hainsworth Street  
Locked Bag 4001

Westmead NSW 2145

Sydney Australia

DX 8213 Parramatta

Tel +61 2 9845 0000

Fax +61 2 9845 3489

<http://www.schn.health.nsw.gov.au/>

ABN 53 188 579 090

18 June 2019

Professor Johanna Westbrook  
Centre for Health Systems & Safety Research  
Australian Institute of Health Innovation (AIHI)

Dear Professor Westbrook,

**HREC Reference: LNR/15/SCHN/171**

**Project title: Assessing the effects of an eMR in paediatric oncology on workflow, workload, efficiency and patient outcomes**

**Site/s: The Children's Hospital at Westmead  
Sydney Children's Hospital, Randwick**

I acknowledge receipt of your project amendment submitted 16 May 2019, requesting approval for:

**(1) Addition of Personnel**

*Kalissa Inshaw / Master of Public Health Student / BSc(BiolSc) / Student Researcher.*

**(2) Change to Participant Group**

*Addition of patients/carers as participants in the study. As patients are under 18, they will only be included in the study with the consent of their carer and whilst with their carer (i.e. the patient must be in the presence of their carer).*

**(3) Addition of a Survey / Questions**

*Addition of interview questions relevant to the patient/carers, to obtain their views on the impact of eMR on efficiency (i.e. waiting times) and communication (i.e. interactions with clinicians). (Interview Guide attached)*

**(4) Protocol Amendments**

*Protocol amendments reflect the addition of patient/carers to the study. No change in research methods or tools used (i.e. direct observations using WOMBAT and interviews).*

**(5) Change to Information Sheets or Consent Forms**

*PICF for patients/carers to voluntarily participate in the study*

The amendment/s was reviewed at the meeting of the Executive Committee of the Sydney Children's Hospitals Network Human Research Ethics Committee (SCHN HREC) at its meeting held on 30 May 2019 and the response to the request for further information by the Executive of SCHN HREC on the 17 June 2019.

I am pleased to advise that the documents reviewed and approved at the meeting were:

<i>Documents Reviewed</i>	<i>Version</i>	<i>Date</i>
Amendment form		16 May 2019
Appendix - Carer Interview Guide	V1	Received 16 May 2019
Study Protocol	V3	16 May 2019
CV - Kalissa Inshaw		16 May 2019
Covering Letter - SCHN HREC – LNR/15/SCHN/171		05 June 2019
Email cover letter		05 June 2019
PICF Patients and Carers	V2	16 May 2019
Young Person PIS	V1	05 June 2019

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

This letter constitutes ethics amendment approval ONLY. A copy of this letter must be forwarded to the Research Governance Officer at each site for governance approval.

This application has been assessed in accordance with, and meets the requirements of the National Statement on Ethical Conduct in Human Research (2007).

Should you require any further information, please do not hesitate to contact the Research Ethics Office at [SCHN-ethics@health.nsw.gov.au](mailto:SCHN-ethics@health.nsw.gov.au) or on (02) 9845 1253.

Yours sincerely,

Associate Professor Sarah Garnett  
**Chair, Sydney Children's Hospitals Network Human Research Ethics Committee**  
**Sydney Children's Hospitals Network Human Research Ethics Committee**

CC Dr Mirela Prgomet

## **Working with Children Check (WWCC)**

Number: WWC0286684V

## **Police Check**

Reference Number: **98D75FB701**





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## National Coordinated Criminal History Check Certificate

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Check Results Report		Report Run Date/Time: 08/05/2019																																					
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<p><b>AUSTRALIAN CRIMINAL INTELLIGENCE COMMISSION</b></p>																																							
<p><b>LIMITATIONS ON ACCURACY AND USE OF THIS INFORMATION</b></p> <ol style="list-style-type: none"> <li>This nationally coordinated criminal history check provides a point in time check about the applicant for an authorised nationally coordinated criminal history check category and purpose. Information obtained through this check should not be used for any other purpose.</li> <li>The accuracy and quality of information provided in this nationally coordinated criminal history check depends on accurate identification of the applicant which is based on information, including aliases, about the applicant provided in the application and the comprehensiveness of police records.</li> <li>While every care has been taken by the Australian Criminal Intelligence Commission (ACIC) to conduct a search of police information held by it and Australian police agencies that relates to the applicant, this nationally coordinated criminal history check may not include all police information about the applicant. Reasons for certain information being excluded from the nationally coordinated criminal history check include the operation of laws that prevent disclosure of certain information, or that the applicant's record is not identified by the search process across the agencies' relevant information holdings.</li> <li>This nationally coordinated criminal history check may contain any of the following information about an applicant:               <ol style="list-style-type: none"> <li>charges;</li> <li>court convictions;</li> <li>findings of guilt with no conviction;</li> <li>court appearances;</li> <li>good behaviour bonds or other court orders;</li> <li>pending matters awaiting court hearing;</li> <li>traffic offence history.</li> </ol> </li> </ol> <p>(Disclosable Court Outcome).</p> <ol style="list-style-type: none"> <li>If this nationally coordinated criminal history check contains a Disclosable Court Outcome, the entity submitting the application is required to:               <ol style="list-style-type: none"> <li>notify the applicant of the nationally coordinated criminal history check;</li> <li>provide the applicant with a reasonable opportunity to respond to, or validate the information, in the nationally coordinated criminal history check.</li> </ol> </li> <li>To the extent permitted by law, neither the ACIC nor Australian police agencies accept responsibility or liability for any omission or error in the nationally coordinated criminal history check.</li> </ol> <p><b>NATIONALLY COORDINATED CRIMINAL HISTORY CHECK PROCESS</b></p> <p>The information in this nationally coordinated criminal history check has been obtained according to the following process:</p> <ol style="list-style-type: none"> <li>the ACIC searches its data holdings for potential matches with the name(s) of the applicant;</li> <li>the ACIC and the relevant Australian police agencies compare name matches with police information held in Australian police records;</li> <li>the relevant Australian police agency identifies any police information held in its police records and releases the information subject to relevant spent convictions, non-disclosure legislation or information release policies; and</li> <li>the ACIC provides resulting information to the entity submitting the application.</li> </ol> <p><b>Organisation: AUSPOST</b> <b>Office: CONSUMER</b></p> <p><b>CHECK DETAILS</b></p> <table border="1"> <thead> <tr> <th>Submitted</th> <th>Batch ID</th> <th>Status</th> <th>Result</th> <th>Match Date</th> <th>Release Date</th> </tr> </thead> <tbody> <tr> <td>08/05/2019</td> <td></td> <td>Closed</td> <td>No Disclosable Court Outcomes</td> <td>08/05/2019</td> <td>08/05/2019</td> </tr> </tbody> </table> <p><b>Type</b> Volunteer  <b>Category</b> Employ/Probity/Licence  <b>Purpose</b> researcher, education, macquarie park, NSW, Supervised contact with vulnerable</p> <p><b>SUBJECT DETAILS</b></p> <table border="1"> <thead> <tr> <th>Name(s)</th> <th>Primary</th> <th>INSHAW, KALISSA JEANETTE</th> </tr> </thead> <tbody> <tr> <td>Previous</td> <td></td> <td>BROOKE COWDEN, KALISSA JEANETTE</td> </tr> <tr> <td><b>Additional Identifier</b></td> <td></td> <td></td> </tr> <tr> <td><b>Birth Date</b></td> <td></td> <td>1972-05-13</td> </tr> <tr> <td><b>Gender</b></td> <td></td> <td>Female</td> </tr> <tr> <td><b>Birth Place</b></td> <td></td> <td>eastwood, NSW, Australia</td> </tr> <tr> <td><b>Address(es)</b></td> <td>Residential</td> <td>4 Heatherbrae Place, Castle Hill, NSW 2154, Australia</td> </tr> <tr> <td></td> <td>Postal</td> <td>4 Heatherbrae Place, Castle Hill, NSW 2154, Australia</td> </tr> </tbody> </table>				Submitted	Batch ID	Status	Result	Match Date	Release Date	08/05/2019		Closed	No Disclosable Court Outcomes	08/05/2019	08/05/2019	Name(s)	Primary	INSHAW, KALISSA JEANETTE	Previous		BROOKE COWDEN, KALISSA JEANETTE	<b>Additional Identifier</b>			<b>Birth Date</b>		1972-05-13	<b>Gender</b>		Female	<b>Birth Place</b>		eastwood, NSW, Australia	<b>Address(es)</b>	Residential	4 Heatherbrae Place, Castle Hill, NSW 2154, Australia		Postal	4 Heatherbrae Place, Castle Hill, NSW 2154, Australia
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1 of 1

## Appendix B: Literature Review

### Summary Table

**Table 13. Methodologies for Examining Patient Experiences**

Source	Type of Study	Methodology	Strengths/Limitations of Study
Ahmed Z, Elmekawy T, Bates S. Developing an efficient scheduling template of a chemotherapy treatment unit: A case study. The Australasian Medical Journal. 2011;4(10):575-88.	General Chemotherapy Unit	The simulation modelling method obtained the observational data of patient journeys through different treatment stages, to improve throughput and decrease patient wait times. Simulation experiments informed the design of an efficient scheduling template, thus optimising clinic performance. This maximised the numbers of patients served, whilst minimising wait times and used the resources which were available.	<u>Strengths</u> : Using simulation modelling, system performance was assessed without interruption to daily operations to the oncology service provided. This enabled testing of multiple potential scenarios, and the development of a scheduling template which matched patient arrivals to available resources. In addition, the scheduling template may more broadly be applied to other oncology clinics. <u>Limitations</u> : Simulation modelling predictions are reliant on the quality of the model, which in turn is reflected by data quality. (Bellanti, 2011)
Asefzadeh S. Patient flow analysis in a children's clinic. International Journal for Quality in Health Care. 1997;9(2):143-7.	Paediatric Outpatient Department	Patient Flow Analysis (a sampling methodology) was performed using a manual technique — recording the times of arrival and exit from each station (service provided) within the clinic, visited by a patient. Data was then analysed using a computer to determine length of encounters and wait times.	<u>Strengths</u> : Advantages of using a manual sampling technique for this study was simplicity, quick to perform, cost-effective (significant for use in developing countries), easy to learn and easily transferable. <u>Limitations</u> : as with all manual techniques, inaccuracies due to human error are potential study limitations. This study was conducted over 20 years ago, therefore somewhat dated.
Ben-Tovim DI, Dougherty ML, O'Connell TJ, McGrath KM. Patient journeys: the process of clinical redesign. The Medical Journal of Australia. 2008;188(S6):S14-S7.	Hospital or Treatment Centres (NSW Health) – Emergency and Elective Care	Process Mapping of patient journeys was used for the purpose of clinical process redesign to improve patient flow and reduce delays. Patient involvement occurred at the mapping and solution phases. A comprehensive understanding of the patient experience was obtained by examination of the horizontal pathway of patients, during their visit -encompassing	<u>Strengths</u> : Following the stepwise process of the patient journey enables a view of the process from the service-user perspective. <u>Limitations</u> : Study findings are individualised to each hospital or treatment centre, therefore not broadly applicable. This was a general medical study in emergency and elective care, and not paediatric.



Source	Type of Study	Methodology	Strengths/Limitations of Study
		multiple departments and/or disciplines.	
Blair M, Gore J, Isaza F, Pajak S, Malhotra A, Islam S, et al. Multi-method evaluation of a paediatric ambulatory care unit (PACU): Impact on families and staff. Archives of Disease in Childhood. 2008;93(8):681-5.	Paediatric Ambulatory Care Unit (PACU)	Multi-method evaluation of a paediatric ambulatory care unit, using a combination of parent and referrer surveys, staff interviews, routine activity analysis and patient journey mapping by direct observation (both quantitative and qualitative techniques). This ensured that a range of service objectives could be assessed using different perspectives.	<u>Strengths</u> : A multi-method evaluation of the service provided a comprehensive, holistic view. <u>Limitations</u> : Analysis was undertaken after the PACU began operations, thus a before and after comparison was not performed; the final A&E survey sample was small, introducing potential for selection bias; as assessment was restricted to one site, the results may not be generalisable. Although paediatric, this study was not conducted in outpatient oncology.
Brown AD, Green E, Sandoval GA, Sullivan T. Factors that influence cancer patients' overall perceptions of the quality of care. International Journal for Quality in Health Care. 2006;18(4):266-74.	Adult Outpatient Oncology Service	A 6-month survey was conducted to provide insight into how the patient experience could be improved.	<u>Strengths</u> : large, multifacility sample, representative of a population of around 70,000. Survey tool was previously validated by the National Research Corporation for cancer patients (sample of 5,000 patients). <u>Limitations</u> : low valid response rate for survey (40%). Study findings are limited to the instrument used (however, results were found to be comparable to other studies). This was an adult outpatient study, and not paediatric.
Corsano P, Majorano M, Vignola V, Guidotti L, Izzi G. The waiting room as a relational space: young patients and their families' experience in a day hospital. Child: Care, Health & Development. 2015;41(6):1066-73.	Paediatric and Oncology Ward of a Day Hospital	Mixed-methods approach: survey instruments (ERI, and Child Drawing) were employed as sampling tools, in addition to conducting semi-structured interviews with patient family members. This study investigated patient experience in the waiting room with regards to children's emotional states, and families' perceptions of waiting.	<u>Strengths</u> : This study provides useful suggestions for future improvements in the organisation of day hospital waiting rooms for children and their families. <u>Limitations</u> : Adult perceptions were based on only 3 questions; as a tool, ERI is limited and repetitive - patient's emotional states may be better measured using narrative tools; the study was executed on a single day and may not be representative of perceptions regarding usual clinic routine.
Davis J, Burrows JF, Ben Khallouq B, Rosen P. Predictors of patient satisfaction in pediatric oncology. Journal of Pediatric	Outpatient Paediatric Oncology Clinics	Surveys issued to care givers of patients of four outpatient clinics, over a 3-year period, to determine overall patient satisfaction and the likelihood of recommending the practice.	<u>Strengths</u> : Survey used a cancer-specific approach with tailoring of questions for the paediatric oncology outpatient experience. <u>Limitations</u> : potential response bias due to the voluntary nature of the survey; low sample size (however,

Source	Type of Study	Methodology	Strengths/Limitations of Study
Oncology Nursing. 2017;34(6):435-8.			this was addressed by using data spread across four clinics); retrospective study with data collected over 3-year duration, thus findings from specific survey items require careful interpretation.
Hendershot E, Murphy C, Doyle S, Van-Clieaf J, Lowry J, Honeyford L. Outpatient chemotherapy administration: decreasing wait times for patients and families. Journal of Pediatric Oncology Nursing. 2005;22(1):31-7.	Outpatient Paediatric Oncology Clinic	Mixed-methods approach: surveys issued to patient families and clinic staff, followed by interviews with patient's care givers. Primary study goals were to decrease wait times, better utilize nursing resources and improve clinic flow. Investigations were made by observations and examination of clinic flow, patient volumes and treatment protocols. Data collected was used in programme planning for the development of a pilot study.	<u>Strengths</u> : Use of qualitative and quantitative data provided a comprehensive analysis of clinic services; identification of care delivery issues and segmentation of the patient cohort created efficiencies of service without affecting clinic costs or resources; segmentation of patient cohort by treatment need, is a tailored solution which can be applied to other patient populations. <u>Limitations</u> : survey responses from participating families of the pilot study may represent potential response bias.
Lingarathnam S, Murray D, Carle A, Kirsas SW, Paterson R, Rischin D. Developing a performance data suite to facilitate lean improvement in a chemotherapy day unit. Journal of Oncology Practice. 2013;9(4):e115-e21.	General Chemotherapy Day Unit	Multi-method approach: this multidisciplinary process entailed mapping of patient journeys, staff and patient surveys, staff interviews, staff & patient tracking, medical record audits and investigation of electronic treatment records. A 4-month diagnostic phase preceded the stepwise interventions (allowing collection of baseline data for comparison).	<u>Strengths</u> : Multi-method evaluation using the principles of lean thinking, gave a more holistic view, with an appreciation of different aspects of the oncology service provided - helping to identify the aspects of the service which worked well, resource availability and areas needing improvement; process mapping served to improve multidisciplinary teamwork, and provide a patient perspective. <u>Limitations</u> : Potential response bias in survey questions, due to patient eagerness to please. An adult outpatient oncology study, not paediatric.

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Title of your thesis / dissertation	Examining the patient experience in a paediatric oncology outpatient clinic
Expected completion date	Oct 2019
Estimated size(pages)	50
Requestor Location	Ms. Kalissa Brooke-Cowden 4 Heatherbrae Place  Castle Hill, NSW 2154 Australia Attn: Ms. Kalissa Brooke-Cowden
Total	0.00 AUD

## Appendix C: WOMBAT Training

### Observer Training Record

**Table 14. Observer Training Record**

<b>Date</b>	<b>Duration (hrs)</b>	<b>Proposed Duration (hrs)</b>	<b>Activity</b>
20/3/19	0.5	0.5	Study overview including background of method and protocol
22/05/19 05/07/19	1.0 2.0	2.5	Instruction in tablet App use and explanation of definitions with practice scenarios
02/07/19	1.0	1.5	Introduction to study site and key personnel, clinical areas, documentation, methods of communication and equipment
07/07/19 07/07/19	1.0 1.0		Practice Sessions familiarising with tablet use
09/07/19	7.5	1.0	Teaching Session (observation of trainee by experienced Observer/trainer)
10/07/19	3.5	2.0	Inter-rater reliability tests (0.5hrs) x2 plus de-briefing
<b>Total:</b>	<b>17.5</b>		

## Appendix D: Definitions for Outpatient Paediatric Oncology Sampling Study

### STAGE Dimension: Before Doctor Consultation

#### Patient Activity Categories

Mandatory Field – This section must be selected during observation.

**Table 15. Patient Activities**

Stage Dimension	Includes
Before Doctor Appointment (Wait time)	Time recorded from signing consent form until called into appointment with doctor  Communication with staff  Observation room activities/Vitals – phlebotomy (taking blood sample), weight, height, BP, temperature, pulse/oxygen  Playroom Activities  Leaving Clinic (within hospital environment)

## WHAT Dimension

### Patient Interactions (equivalent to work tasks category)

**Mandatory Field – This section must be selected during observation.**

**Table 16. Care/Communication – any activity directly related to communication or receiving care**

Includes	Excludes
Reception e.g. returning yellow form following consultation (for future bookings)	Documentation by health professional or allied health professional
Physical examination or review – includes port/IV care, weight & height measurements, BP, temperature checks, pulse/oxygen, heart and lung checks, abdominal palpation, mouth ulcer check, gland check, etc.	
Phlebotomy (taking blood sample)	
Medication-related activity	
Chemotherapy treatment	
Accompaniment/assistance in transit	
Providing and checking medical history (includes looking up results in eMR)	
Communication	
Receiving assistance or comfort	

Note: all communication with a health professional or allied health professional is regarded as care.

**Table 17. Wait Period Activities.**

<b>Waiting</b>
Bathroom breaks
Leaving clinic (e.g. walk to shop/café, visiting Starlight Express etc.)
Food or drink breaks
Using device
Reading
Playing (toys, PlayStation, Ipad or phone)
Watching TV
Playroom Activities (e.g. drawing, colouring, playing with slime, playing with toys or games etc.)

## WHO Dimension (Who is the patient interacting with?)

**Mandatory Field – This section must be selected during observation.**

This includes non-verbal communication as well – e.g. nodding, pointing, hugging someone etc

**Table 18: Patient Interactions**

With Whom	Location
<b>Reception staff</b>	Direct interaction with clerical staff at Reception Desk
<b>Nurse(s)</b>	Direct interaction with a nurse or nurses of any classification
<b>Doctor(s)</b>	Direct interaction with a doctor or doctors of any classification
<b>Pharmacy</b>	Direct interaction with a member or members of the pharmacy team
<b>Allied Health Staff</b>	Direct interaction with any member of the allied health team including Social Worker, Psychologist etc.
<b>Relative</b>	Direct interaction with family member
<b>Other</b>	Direct interaction with anyone not explicitly defined including staff members e.g. Therapists, Educators (Back on Track staff), ward clerks
<b>No one</b>	No direct interaction with another person, observed patient is by her/himself



## WHERE Dimension

Mandatory Field – This section must be selected during observation.

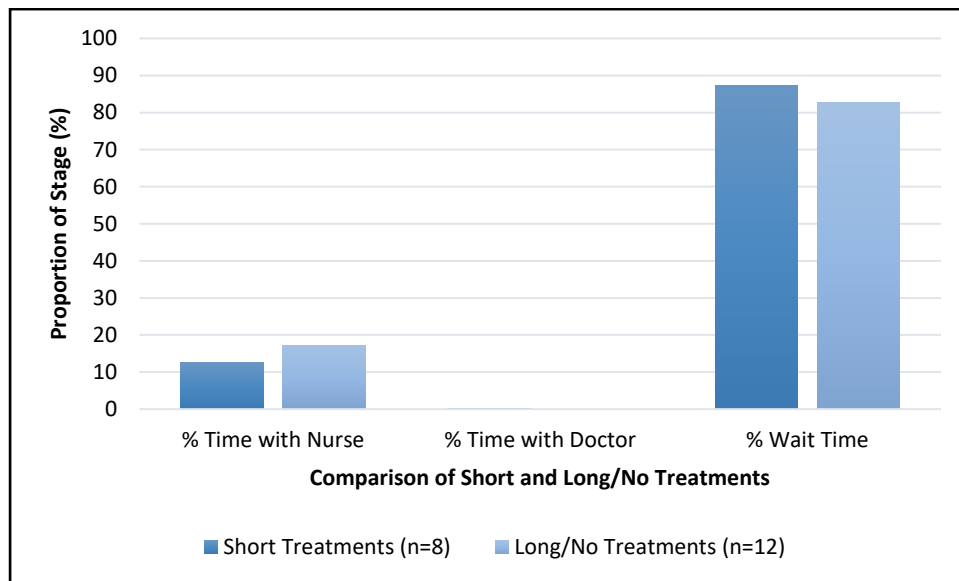
**Table 19: WHERE Dimension - Location of Activity**

<b>Outpatient Oncology Unit</b>	Patient is in the outpatient clinic area. Includes playroom.
Observation Room	
Consultation Room	
Treatment Room	
Reception Desk	
Waiting Area (Clinic)	
Waiting Room (Outside Clinic)	
Other	Patient is in area not otherwise specified e.g. cafeteria

## Appendix E: Quantitative Analysis — Graphs and Charts

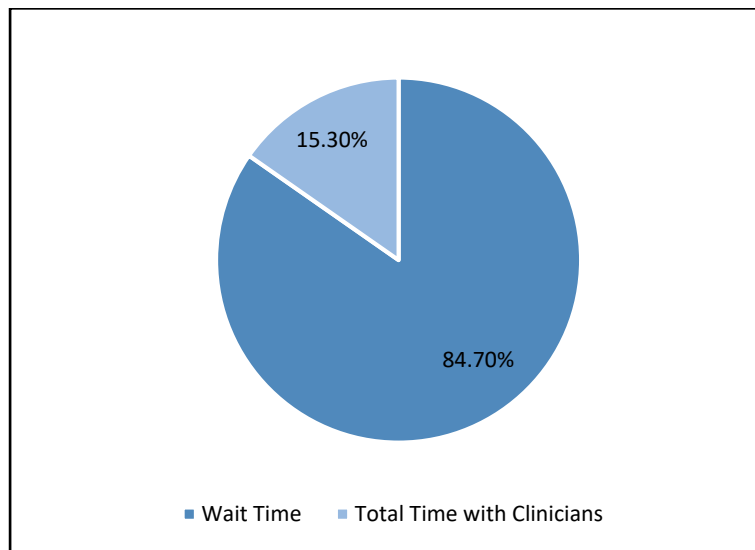
### Stage 1 (Before Doctor Appointment)

Figure 5 highlights the amount of time patient spent waiting in Stage 1 compared with time spent interacting with nurses or doctors.



**Figure 5. Stage 1 Analysis: Distribution of Time Comparing Short and Long Treatments**

In Figures 6, the time during Stage 1 (Before Doctor Appointment) that patients spent waiting is compared with patient interactions with clinicians (doctors *and* nurses).

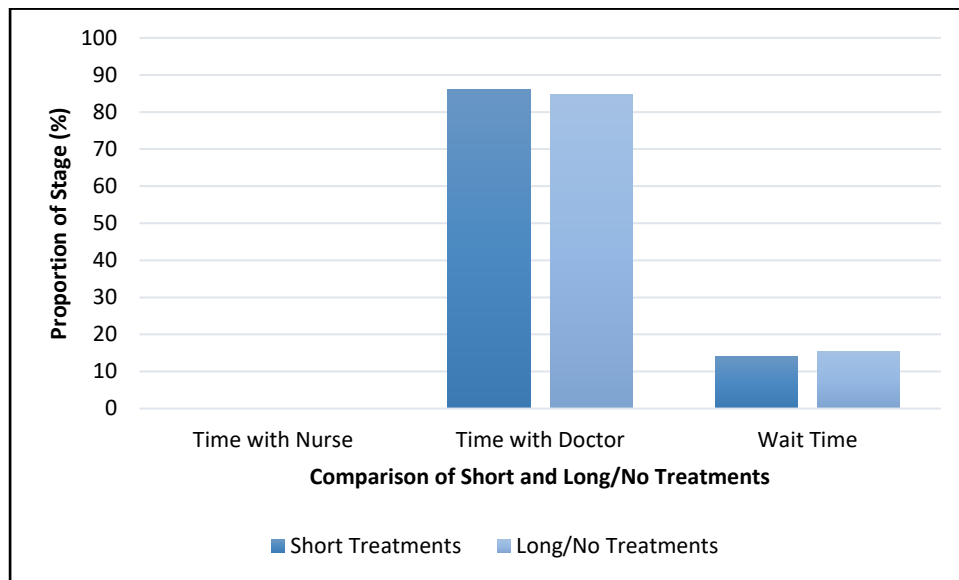


**Figure 6. Stage 1 Analysis: Patient Time Distribution for All Treatments (n=20)**

Note: Clinicians include doctors and nurses.

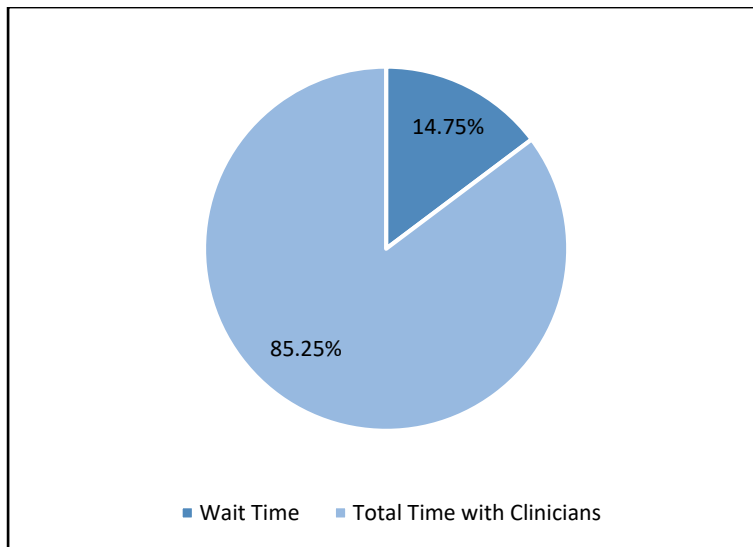
## Stage 2 (Doctor-Patient Consultation)

Figure 7 shows the time distribution during the patient-doctor consultation. There is a minimal difference in patient-doctor interaction time between patients having Long compared with Short Treatments.



**Figure 7. Stage 2 Analysis: Distribution of Time Comparing Short and Long Treatments**

In Stage 2 (Doctor-Patient Consultation) the majority of patient time is spent interacting with the doctor, however, part of the consultation is spent waiting (e.g. whilst the doctor retrieved prescriptions, conferred with other clinicians etc.). The time distribution is presented in Figure 8.

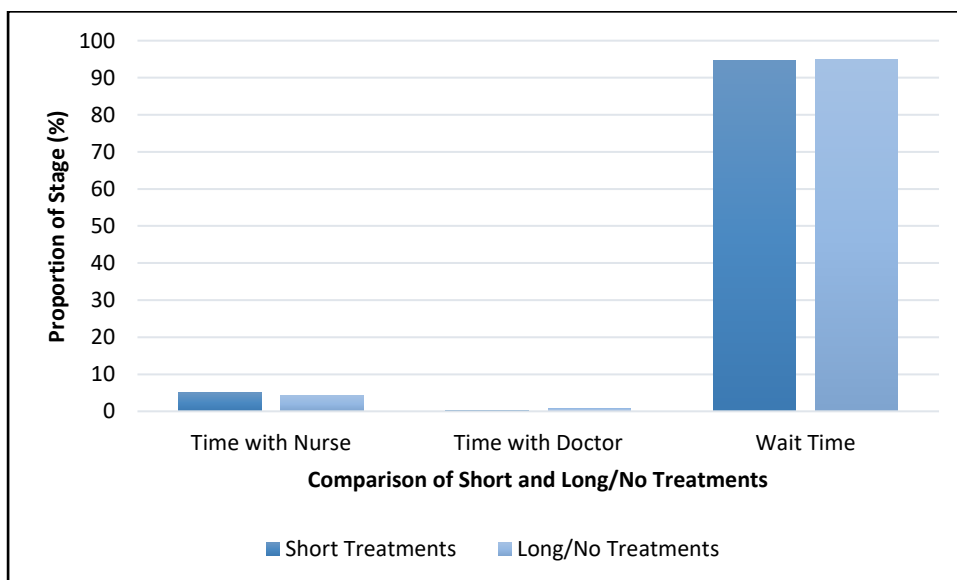


**Figure 8. Stage 2 Analysis: Patient Time Distribution for All Treatments (n=20)**

Note: Clinicians include doctors and nurses.

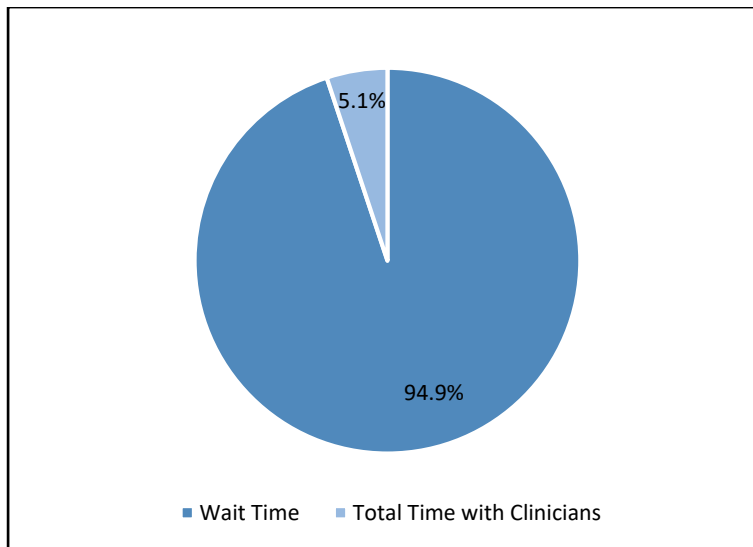
### Stage 3 (After Doctor Appointment)

In Stage 3 (After Doctor Appointment) patients spent the majority of their time waiting (illustrated in Figure 9).



**Figure 9. Stage 3 Analysis: Distribution of Time Comparing Short and Long Treatments**

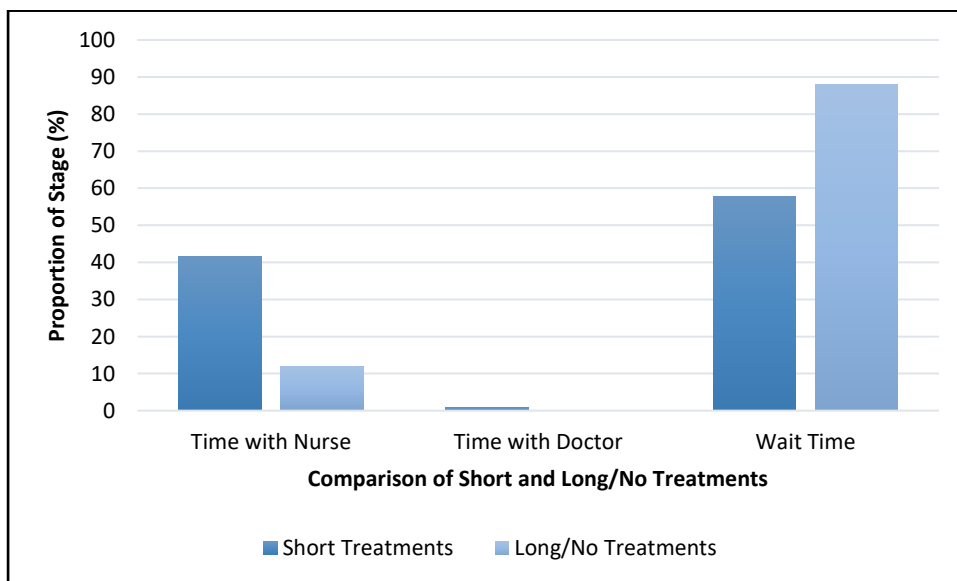
Figure 10 shows minimal interactions occurring between patients and clinicians during Stage 3 (After Doctor Appointment).



**Figure 10. Stage 3 Analysis: Time Distribution for All Treatments (n=20)**

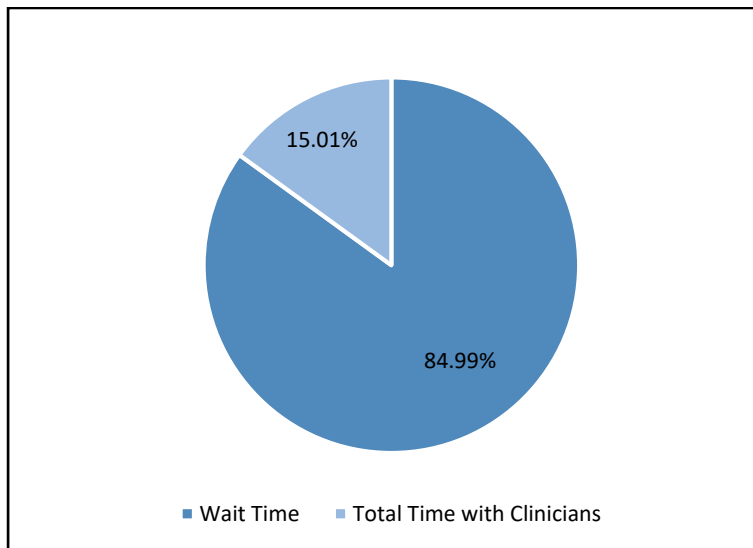
Note: Clinicians include doctors and nurses.

In Stage 4 (Treatment), the proportion of time patients interacted with nurses was much higher in those receiving Short Treatments compared with Long Treatments (see Figure 11). Administration and monitoring of chemotherapies is performed by nursing staff; doctors rarely enter the treatment room during chemotherapy. Patients receiving Long Treatments spend proportionally more of this stage waiting than patients with Short Treatments.



**Figure 11. Stage 4 Analysis: Distribution of Time Comparing Short and Long Treatments**

In Stage 4 (Treatment), patient interaction times with clinicians as compared with wait times is demonstrated in Figure 12.



**Figure 12. Stage 4 Analysis: Time Distribution for All Treatments (n=18)**

Note: Clinicians include doctors and nurses.

## Appendix F: Qualitative Analysis

### Duration of Interviews

Table 20. Length of Interviews

Participant	Duration of Interview (mins)
#100700 (Carer)	10:38
#110701 (Carer)	3:50
#120702 (Carer)	7:02
#150703 (Carer)	05:31
#160704 (Carer)	05:23
#170705 (Carer)	05:36
#180706 (Carer)	06:39
#190707 (Patient, Carer 1 & 2)	03:27
#220708 (Carer)	05:07
#230709 (Carer)	04:04
#230709 (Patient)	04:29
#240710 (Carer)	06:18
#250711 (Carer)	02:52
#260713 (Carer)	03:28
#260714 (Carer)	04:24
#290715 (Carer)	11:58
#300716 (Patient and Carer)	06:39
#310717 (Carer)	02:24
#010818 (Carer)	12:09
#020819 (Carer)	01:35 (2 <sup>nd</sup> Interview)
#020820 (Carer)	10:54
#050821 (Carer)	02:40
#060822 (Patient)	02:52



## Patient-Clinician Encounters

**Table 21. Patient-Doctor Encounters**

Patient ID	Assigned Consultant	Familiar with Patient history	Adequate Consultation Duration
#100701 (pilot)	No	Yes	Too long
#110701	No	Yes	Yes
#120702	No	No	Yes
#150703	No	No	Too long
#160704	No	Yes	Yes
#170705	No	Yes	Yes
#180706	No	Yes	Yes
#190707	No	Yes	Yes
#220708	No	Yes	Yes
#230709c	No	Yes	Yes
#230709p	No	Somewhat	Yes
#240710	Yes	Yes	Yes
#250711	Yes	Yes	Yes
#250712	No	Yes	Yes*
#260713	No	Yes	Yes
#260714	Yes	Yes	Sometimes
#290715	Yes	Yes	Yes
#300716	Yes	Yes	Not sure
#310717	No	Yes	Yes
#010818	No	Yes	Yes
#020819	No	Yes, mostly	Yes
#020820	No	Yes	Yes
#050821	No	No	Yes
#060822	No	Yes	Yes
Means	21.7% Agree	78.3% Agree	83.3% Agree

\*Note: #230709c refers to Carer, #230709p refers to Patient.

## Appendix G: Thematic Analysis

**Table 22: Qualitative Analysis — Themes and Subthemes**

Themes	Subthemes	Selected Quotes
<b>1. Care Discontinuity and Provision of Care</b>	Fragmentation of Care	<p><i>"She's also an oncologist you just— I think there's four on the team, on our team, so you see which ever one you're put down to." (#170705)</i></p> <p><i>"Her oncologist is quite (often) away, we don't see her, like, every check. Usually, like this doctor today was very, very long time, probably, the second time she saw (my child). Yeah, probably. Or maybe the first, because you see a lot at the clinic." (#010818)</i></p> <p><i>"...she said that she had spoken to the proper doctor and I did see his regular oncologist down the hallway and she apologised for not being able to come today. But she was on duty, on rounds, doing rounds and on call, so yeah." (#110701)</i></p> <p><i>"...it depends on which doctor you see. If you see your regular oncologist (#120702)</i></p> <p><i>"My child's regular is Dr 5, she's usually — I haven't really had her, probably the last three I've had a fill in doctor, but I had a meeting with her last week just to clarify because things are coming across a bit different to what she was saying, so my social worker actually got a meeting to speak with our actual doctor." (#220708)</i></p> <p><i>"Ah, Dr 7 is reasonably normal. There's probably, oh, three or four that I would see. I mean, Dr 1 is our specialist doctor but his team, there's Dr X, Dr 7 – we saw Dr 11, I think, last week so there's just familiar people that we see, as opposed to one." (#250712)</i></p> <p><i>"...there's times where we have seen a new doctor for the first time and they tend to ask us a lot more questions because they're trying to find out about his history..." (#160704)</i></p>
	Effective provision of care	<p><i>"Because I know that they all talk to each other, I've only got to run into one out there and they'll talk to me, and they all talk together, they work close together." (#170705)</i></p>
<b>2. Communication and Provision of Information</b>	Information exchange within teams	<p><i>"They can see everyone else's notes, and whatnot, they can bring it all up." (#230709c)</i></p>
	Communication within Consultations	<p><i>"...the doctor gave me time to ask questions, so I have no question to ask." (#050821)</i></p>

Themes	Subthemes	Selected Quotes
	Loss of contextual information	<p><i>"She's not as updated, but she gets the general idea. She does cover 90% of the bases. She will ask a bit more, whereas my regular one will know straight off. But she covers herself, but she doesn't know straight away. If that makes sense." (#020819)</i></p> <p><i>"I think she (the doctor) knew a bit, but not as much as my actual doctor." (#230709p)</i></p>
	Computers Facilitating Communication in Consultations	<p><i>"Obviously they read up – knowing about the eyesight and stuff like that. So she must have read up on it." (#190706)</i></p> <p><i>"Because they need those records for everything else within the hospital, because everything's linked." (#190706)</i></p> <p><i>"So they do to a degree and catch up on his file and I think that does work quite well under this circumstance because generally they have an awareness or they can find the answer if we're talking about something that they're not up to speed on with his case." (#160704)</i></p>
<b>3. Service Quality and Meeting Patient Care Needs</b>	Confidence and familiarity	<p><i>"...extreme confidence and the nursing system — it is great, yeah." (#120702)</i></p> <p><i>I really – I don't enjoy coming here, but I think the people here are nice. Especially the play therapist — she's beautiful. She's always looking after him. So, I really enjoy it — seeing that. (#260713)</i></p> <p><i>"The nurses are really good here." (#260713)</i></p> <p><i>"...the staff are really lovely." (#110701)</i></p> <p><i>"They don't push you out the door, or anything like that, they listen to you, answer what they can." (#190706)</i></p>
<b>4. Lack of Autonomy</b>	Lack of Control	<p><i>"So a lot of the time we see Dr 11, which is good, or we have seen some of the other doctors. So we don't know who we are going to get. There is no control over that." (#100701)</i></p> <p><i>"an hour and a half to 2 hours. Depends, sometimes we can do like this morning where it's just 45 minutes, and sometimes it can be really (a lot) longer. Usually it takes an hour and a half to see the doctor." (#310717)</i></p> <p><i>"Like I said before, I've been here in and out for two and half hours, but I've been here for six...so it all depends on the day, of how many people are here, what time we get here, and stuff like that." (#190706)</i></p>
	Exerting some control	<p><i>"Okay, so there are two different types of days in Outpatient Chemo. The first day is basically if we have to consult, then we try and get in as early as we can, get the bloods taken as soon as possible before the pathology list builds up. So that basically means we want to come in around 8:00, get the bloods done</i></p>

Themes	Subthemes	Selected Quotes
		<p><i>asap and hopefully see a doctor by 9:00 and then get out so we can go off to school.” (#100701)</i></p> <p><i>“We try and come on Wednesdays, cause it’s her clinic day.” (240710)</i></p>
<b>5. Oncology-derived Challenges and Quality of Life Impacts</b>	Resignation	<p><i>“Yeah, it depends on — you can tell when you’re going to be here awhile. Because if — when you walk in the place is packed...so they can’t do it any quicker, so you’ve just gotta wait your turn.” (#230709c)</i></p>
	Dependency	<p><i>“Oh, it will very much depend on when the bloods are done and then when the bloods will be back so it could be half an hour or it could be one hour, so it’s not too bad.” (#150703)</i></p> <p><i>“Depends on if there’s problems or not...depends on how the child’s feeling.” (#170705)</i></p> <p><i>“Apparently last time the drugs weren’t here, the chemo drugs, so that’s why it took a lot longer last time but we were told this morning that the drugs are already here so shouldn’t have to be waiting for preparation of the drugs.” (#290715)</i></p>
	Chemotherapy Impacts	<p><i>“But I think – more than the physical. This kind of sickness, I think it’s the mental that needs a little bit of help, because the physical is the physical, but being at an age where she – the age that she’s at, I think, you know, the physical side effects that it’s creating is having more of an effect on her than the – yeah.” (#300716)</i></p> <p><i>“And aggressive, it’s Dexamethasone which really does give mood changes yeah, not like Prednisone, where they are grumpy, no — cranky.” (#100700)</i></p>
	Rural and Regional Families	<p><i>“I think probably one of the hardest things would be is like me you’re doing it by yourself...” (#220708)</i></p> <p><i>“So, yeah, really we have to be down here for one week which is all we’re planning for this time. Out of the month that’s not too bad really. So it’s working pretty well but getting home definitely made a big difference for her and seeing her friends and stuff. No, overall considering the news, it’s been pretty smooth really, she’s been handling it really well since.” (#290715)</i></p>

Themes	Subthemes	Selected Quotes

## Appendix H: Glossary of Terms

Terms	Definitions
Acuity	high nursing care requirements. A measurement of the intensity of nursing care required by a patient.
Adjuvant chemotherapy	after a primary treatment is given to treat the cancer, chemotherapy can be used as an additional therapy to destroy any remaining cancer cells that may be undetectable on scans.
Central Venous Catheter	– a type of central venous access device (CVAD) also referred to as a central venous line. This is a catheter (small, plastic tube) inserted into a large vein in the chest or neck, through which bloods and fluids can be administered painlessly. Specimens (bloods) may also be collected through this conduit.
Palliative Care	refers to an interdisciplinary approach used to improve quality of life for persons with serious illnesses, and their families. It involves the provision of emotional support and treatment of symptoms.
Provider	includes all people who provide healthcare-related services.
Push Chemotherapy	administration of intra-venous chemotherapy into an IV via a syringe. This process can take up to 10-15 minutes to administer all of the chemotherapy, and administration is often through a CVL or Port.

