

**FROM THEIR PERSPECTIVES:  
CHILDREN AND YOUNG PEOPLE'S EXPERIENCE OF A  
PAEDIATRIC HOSPITAL ENVIRONMENT AND ITS  
RELATIONSHIP TO THEIR FEELING OF WELL-BEING**

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### **STATEMENT OF ORIGINALITY**

This thesis is my original work and has not been submitted, in whole or in part, for a degree at this or any other university. Nor does it contain, to the best of my knowledge and belief, any material published or written by another person, except as acknowledged in the text.

Katherine G. Bishop

### **APPROVAL OF THE HUMAN ETHICS COMMITTEE**

The Scientific and Ethics Committee of the Children's Hospital at Westmead granted approval for this research. (Project No. 2004/040)

The Human Ethics Committee of the University of Sydney also granted approval for this research (Ref. No. 7661).

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## **ABSTRACT**

This study was conducted to increase our understanding of children and young people's experience of a hospital environment and to identify the salient attributes of the physical environment in their experience. There were three specific aims: to describe children and young people's experience of a hospital environment and identify what constitutes a supportive paediatric environment; to examine the role of the physical environment in patients' feeling of well-being; and to highlight the capacity of participatory research with children and young people to inform evidence-based paediatric design.

At this stage, there has been very little healthcare design research carried out with populations of children and young people. Well-being research with children and young people in paediatric environments that identifies the potential supportive attributes in this environment is also very limited. Historically research on children's health and well-being has been dominated by a focus on the prevalence of disorders, problems and disabilities. More recently, in response to the change to health promotion, positive attributes have been included in well-being and satisfaction measures. At this stage, there are still many fewer positive measures.

Within the body of literature that exists in healthcare, healthcare design research, and well-being research, there are only a small number of participatory studies that focus on children and young people's experience of hospitalisation, and an even smaller number that include children and young people's experience of hospital environments. The picture that is created by the research that exists is patchy. There is a need for a more holistic understanding of children and young people's experience of hospitalisation and of hospital environments from their own perspectives.

Based on these gaps in current knowledge, two research questions were developed. The first was concerned with describing children and young people's experience of the sociophysical environment of a paediatric hospital. The second question was concerned with understanding the role of the physical environment in children and young people's feeling of well-being in a hospital environment. In addressing these questions, the intention was to identify attributes within the hospital setting which collectively

comprise a supportive environment for children and young people and which contribute to children and young people's feeling of well-being in a paediatric setting.

The current study was conducted as an exploratory qualitative case study and carried out at the Children's Hospital at Westmead, in Sydney, Australia. Using participatory research techniques, the sequence of the study included two pilot studies and the main study. The focus was on understanding the experiences of longer-term patients of a paediatric hospital environment. In the main study 25 children and young people, aged between 9-18 years, who had been in hospital for at least a week completed semi-structured interviews in which they talked about their response to the environment of the hospital and their experience of hospitalisation.

Data analysis was completed using a combination of concept mapping and thematic analysis techniques. Preliminary findings were used as the basis of a further member-checking task carried out with a further six children and young people before conclusions were reached.

The findings reveal that children and young people's experience of a paediatric setting involves a number of major areas of influence including their personal situation, their social experience, their interaction with the physical environment, opportunities and characteristics of the organisation, and the effect of time. The findings also reveal that children's feeling of well-being within this experience is linked to their ability to feel comfortable in the environment, to maintain a positive state of mind, and to remain positively engaged with the experience and the environment.

This research reveals a dynamic relationship between children and young people and a paediatric environment that children and young people actively manage and shape. It reveals some of the key considerations in children and young people's experience of hospitalisation. It also reveals why these considerations are important and what role they play in patients' experience and feeling of well-being. These findings provide the basis for further research and they have implications for future design and research practice in paediatric healthcare settings.

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## **PART A: INTRODUCTION AND CONTEXT**

### **CHAPTER 1**

#### **INTRODUCTION**

“Is it ok if I take my teeth out for the interview?” asked Josie<sup>1</sup> matter-of-factly. “Yes” I said, “of course, that’s fine,” trying to hide my surprise. I was certainly surprised by the question, but more so by the matter-of-fact way that it had been asked. Josie was a young girl who had been in hospital for some weeks having survived a bad accident in which she had lost most of her front teeth. She had new teeth by the time we met but she was having trouble speaking clearly with them in place.

Continuing to consider Josie’s question long after the interview, I realised that it neatly encapsulated the level of drama, trauma and life-changing event that children in hospital can face and be expected to cope with, sometimes without any preparation. Depending on the circumstances, going to hospital has the potential to be an extraordinary, or a collection of extraordinary experiences in children and young people’s lives.

As a child I had orthopaedic problems which dominated the first few years of my life. As part of this experience, I was hospitalised for a couple of long periods of a month on one occasion and for three and a half months on another. These admissions occurred when I was aged between 17 months and three and a half years old. My memories are fractured fragments but those that remain are etched strongly in my mind. I suspect this is because most of them have the capacity to evoke a strong emotional response.

I have memories of feeling isolated and alone. I knew the ward was full of children but there was almost no social interaction between us because no opportunity was created for my age group to socialise. My nurses were often stern with me, most offering little warmth and comfort.

The central memory of my experience is of the endless, endless waiting for visiting time. My mother was allowed to visit me for two hours a day. I have visions of myself

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<sup>1</sup> All names are pseudonyms

asking every passing nurse how long it was until visiting time. When the hour finally arrived it was with very mixed emotions that I greeted her every day. It brought immense joy but it also filled me with overwhelming dread, knowing that her arrival also signalled the beginning of the end of her visit in the same moment. It was a terrible daily cycle of pain for both mother and child, which has left a lasting impression on both of us.

I spent a lot of time looking down on green linoleum floors through the metal bars of my cot, restless with boredom. On several occasions I resorted to throwing my mercury thermometer out of my cot to watch the balls of mercury running across the floor, for simple entertainment. My punishment involved being wheeled into the bathroom at the end of my ward where I would be left in isolation for a while to contemplate the error of my ways.

I remember my cot being placed in several different positions in a large, rectangular dormitory ward. Sometimes I was perpendicular to a dimly lit wall and at other times I was parallel to a wall of windows which ran from the floor to the ceiling. Sometimes the room felt dark and at other times I felt covered in light which corresponded to these different positions. Overall the impression of the space is of texture-less, bland surfaces. Apart from the green floor which was khaki green, there was no colour in the ward.

I am able to verify my memories of the physical environment with my mother who confirms their accuracy. My own story provides an example of the potency of the physical and social environments in children's experience of hospital, even for children as young as I was.

It is unlikely that the hospital was designed deliberately to be an environment stripped bare of stimulation for young children. It is also unlikely that the visiting protocols were designed to deliberately inflict daily cycles of pain on mothers and young children. It is most likely that the potential impact of hospitalisation and the hospital environment for children and their families were simply not considered, or were considered of little importance in relation to meeting the medical needs of patients.

The link between my research and my own experience is not as direct as it may seem. However, I am sure that it was my own experience as a young child, which gave me my interest as an adult in assisting children in challenging circumstances.

The specific motivation to complete this research came later on in my life. During the completion of a tertiary degree in visual arts, I began designing toys for children who were blind. For approximately the next ten years, custom-designing play environments for children with special needs was the focus of my working life.

Because there was very little research, or knowledge from other's experiences to guide my decision-making as a designer, I spent many hours as a participant observer with many of the groups of children with whom I worked. I needed to learn how they interacted with their environment, and to identify the key environmental attributes in relation to each group of children and their particular abilities.

Working with the children themselves was a very effective way of learning about their needs in relation to their environments. I became very interested in understanding the role of the physical environment in supporting and facilitating these children's ability to participate in the world around them. This work also led to my interest in participatory design and research. There seemed to me to be no more direct and rewarding way to understand children's experience and needs than from children and young people themselves.

In combination, all these elements in my background influenced the particular research project chosen, and the way that it has been carried out. Ultimately I decided to focus on the experience of children and young people in a healthcare setting because there is limited research available from children and young people's perspectives in this context, and because of the potentially traumatic nature of this experience in their lives. If there are any circumstances where children with special needs, (even if the classification is only temporary), need a supportive environment, it is during a visit to hospital.

### **Rationale**

Qualitative healthcare research and healthcare design research, which focuses on the response of children and young people to healthcare environments, is very limited. This

reflects a number of considerations. Firstly, qualitative research is relatively new to nursing and medical science disciplines and there are still reservations about this kind of research in medical circles. Secondly, gaining access to children and young people to carry out participatory research with them in hospital can be very difficult, involving permission from many levels of 'gatekeepers' (Hood, Kelley & Mayall, 1996; Stalker, Carpenter, Connors & Phillips, 2004).

Beyond, these considerations there are still questions surrounding the competence of children and their capacity to provide reliable data, which influence the acceptability of participatory research. In the past, researchers have been very cautious about carrying out research solely with child participants (Faux, Walsh & Deatrick, 1988; Miller, 2000). These concerns centre on the question of the reliability of children's data, the depth and quality of that data and the ultimate ability to be able to answer research questions based on that data alone. In healthcare research, this cautiousness is still evident in studies where children and young people have been involved. They can be one of a number of groups and their voice can be obscured by surrounding adults' interpretation of their experience (Eiser, 2000).

Although patient-centred-care models have become the accepted models of care in the last few decades, the experience of children and young people and their families in healthcare environments is still largely one of disempowerment, particularly for children (Alderson, 1993; Bricher, 1999). "Adults are presumed competent to make health care decisions; children are presumed incompetent without any validation as to whether the child has the knowledge and ability to make the decision" (Bricher, 2000, p. 277).

Bricher (1999) studied nurses' perception of the importance of patient trust and revealed a discrepancy between what nurses understood to be in the children's best interest and what they actually practiced. She found that nurses considered building trust with children was essential for smooth functioning and good relationships with the children, yet maintained that breaching trust for medical reasons was essential. "What did not appear evident to the nurses was the dichotomy that they viewed trust as really important, but considered breaking trust to be essential" (p. 451).

This reticence in clinical practice to respect children's competence is evident in the lack of participatory research with children in healthcare contexts also. The absence of children's voice in research illustrates a lack of appreciation of children's capacity to provide valuable insights from their own experience. It also reveals a lack of appreciation for the evidence that does exist that children and young people are not passive recipients in the experience of hospitalisation but instead, are actively involved in managing it and in shaping it (Carney et al., 2003; Hutton, 2003, 2005; Moules, 2004).

Finally the reticence to acknowledge the evidence of children's competence in a hospital environment reveals a lack of appreciation of the evidence as something positive that healthcare professionals, healthcare policymakers and designers of paediatric environments can engage with. Policy, design, and healthcare management for children and young people can only be strengthened by the input of children and young people themselves. Children's own input minimises the assumptions being made by adults about what children and young people need in these circumstances, and increases the likelihood of designing supportive hospital environments, from children and young people's perspectives.

In contrast to healthcare research, social science research has embraced participatory research with children and young people. Since the late 1980s, there have been shifts in children's research from research which was consistently *on* children, to research *with* children, and more recently research *by* children (for discussions see Alderson, 2001; James & Prout, 1990, and Kellett, 2005). Children have gone from being objects of research, to being subjects of research, to being considered autonomous social actors and agents in their own lives, and in research (Christensen & Prout, 2001).

Within the social sciences, the idea of children and young people having critical and unique perspectives on their lives, which are invaluable to our understanding of those lives, has been embraced. Whilst this research has met with criticism because some ethical and methodological aspects are contentious, its value to knowledge and insight into childhood and children's lives is increasingly recognised. This is evident in the rapidly increasing use of participatory research with children and young people.

In the context of healthcare design research, the history of research with children and young people is limited but formative. The work of Lindheim, Glaser and Coffin (1972) made many recommendations for paediatric design. They discussed a patient-centred model of care, known as the Planetree Model, which emphasised creating a home-like environment for patients. They made a series of recommendations, which encompassed the need to provide adequate cognitive stimulation, access to recreational and learning activities, opportunities for social contact and self-care management, opportunities for personal space, privacy and confidentiality, and individual control.

Rivlin and Wolfe (1985) conducted a long-term study in a psychiatric hospital for children and young people. They clearly identified children's sensitivity to the nature of their institutional environment and their need for environmental control. They also identified the need for privacy, confidentiality, control over time management, and activity choice.

Recent research revealed that children and young people's response to hospitalisation is linked to environmental perception, empowerment, situational influence, self-determination, social support, privacy, and personal control (Hallstrom & Elander, 2003; Ishibashi, 2001; Moules, 2004; Runeson, Hallstrom, Elander & Hermeren, 2002; Sharma & Finlay, 2003). Key environmental attributes identified include: age-appropriate activities and spaces; having access to school; a need for privacy and community; the importance of bright colours, soft furnishings, age-appropriate art work, and the removal of bland décor (Blumberg & Devlin, 2006; Hutton, 2002, 2003; Miller, 2003; Tivorsak, Britto, Klosterman, Nebrig & Slap, 2004).

Although offering insights into the experience of children and young people in a paediatric setting, this research provides an incomplete picture of the experience as a whole. There is only limited evidence of what constitutes a holistic healing environment in a paediatric setting (de Vos, 2006).

The amount of healthcare design research has increased greatly since the late 1990s, but little of it has been carried out with children and young people (Rubin, Owens & Golden, 1998; Ulrich & Zimring, 2004). Whilst many of the parameters of a supportive

environment for both adults and children may be similar, this is not an assumption we should make without research with children and young people themselves.

For example, Blumberg and Devlin (2006) identified that having pictures of nature on wardroom walls was an unpopular form of artwork for adolescents. However, having pictures of nature on walls is a recommendation that is widely followed in hospitals around the world (based on research with adults) (Ulrich, 1984; 1992b). Likewise, assuming that adolescents and children prefer the same environmental attributes is problematic. Blumberg and Devlin (2006) also identified that adding chalkboards in adolescents' bed areas was unpopular with adolescents yet this is a design recommendation for children's hospitals. Instead, adolescents prioritised the need to be able to personalise their own space with their own posters as their way of influencing the aesthetics of their environment.

Only through research with children and young people themselves can we be sure that we are creating hospital environments that meet their needs. Blumberg and Devlin's (2006) research illustrates the risk of assuming that what suits adults will also be correct for children and young people. It also highlights the fact that the needs of children and young people are likely to differ from each other, at least to some extent.

A more holistic understanding of what constitutes patient's experience and feeling of well-being in a paediatric setting for both children and adolescents is required. In addition there is a need to focus on understanding how the physical environment is involved in children and young people's experience and their feeling of well-being. This means providing more than a list of the key environmental attributes for these age groups. It means trying to identify what role these attributes play, how patients use them, and for what purposes in their experience. To be able to assemble the key attributes in a hospital environment effectively, there has to be a greater understanding from children's perspectives of how they use them and what for.

### **Purpose**

In response to the discussion above, the purpose of this study is to increase our understanding of children's experience of a paediatric hospital environment. It is also to identify the salient attributes of the physical environment in their experience, and the

involvement of these attributes in children's feeling of well-being whilst in hospital to enable recommendations to be made to those developing supportive paediatric environments for children and young people.

### **Aims**

There are three specific aims for this study. The first aim is to arrive at a description of the experience of hospitalisation and what constitutes a supportive environment, through the experience of children and young people themselves.

Whilst the use of participatory research is limited within healthcare research, there is a strong tradition of participatory research within environment-behaviour research. This body of research clearly indicates that children and young people are competent to talk about, and document their environment and their experiences within it, in a capacity that is useful to designers, planners and policy makers (Hart, 1997; Moore, 1990; Spencer & Blades, 2006).

The second aim is to increase our understanding of the involvement of the physical environment in patients' feeling of well-being in a paediatric setting. Historically medical research has overlooked the role of the physical environment (Devlin & Arneill, 2003). At this stage, we know a little from children and young people as to what the significant attributes of the physical environment are within their experience of hospitalisation, but we know less about what functions they may have and what may be the significant characteristics of each attribute identified. Without this evidence, we do not have the information needed to support the creation of supportive paediatric environments. Environments which we can confidently claim meet the needs of children and young people in these circumstances.

Children's well-being research has also overlooked the role of the physical environment (Pollard & Lee, 2003). The second aim to explore the involvement of the physical environment in patients' feeling of well-being also reflects the conviction that the physical environment is playing a major role in children's experience and their ability to manage their response to hospitalisation. This conviction is supported in particular by research into children and young people's place preference, and emotional self-regulation (Korpela, 1992; Korpela & Hartig, 1996). Although not carried out in a

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healthcare setting, this body of research establishes links between children and young people's use of the environment, and managing their emotional self-regulation.

The third aim is to highlight the capacity of participatory research with children and young people to inform evidence-based paediatric design. In relation to the design of children's environments of all kinds, there is still a gap between the practice of adult designers and planners and the opportunity for children and young people to inform those processes, either through participatory design or research. Hopefully in time this will be altered by the growing weight of evidence which demonstrates the value of these processes in the success of children's environments.

This study will add to the growing chorus of evidence that illustrates that children and young people are active shapers and managers in their own lives, with the capacity to give evidence which can inform those making decisions that will affect children and young people's lives. Evidence from this study will be used as a basis for the development of recommendations for those creating paediatric environments. It will also be used to encourage others to complete participatory research with children and young people in a healthcare setting.

## CHAPTER 2

### **THEORETICAL DIRECTIONS IN ENVIRONMENT-BEHAVIOUR APPROACHES TO HEALTH PROMOTION, WELL-BEING AND RESTORATION**

This research is embedded in three principal areas of literature and seeks both to be informed by current knowledge in each of these areas, and to fill gaps in that current knowledge. Chapter 2 is concerned with relevant theoretical concepts from environment-behaviour research, and with relevant theoretical directions in health promotion, well-being, and restoration. Chapter 3 is concerned with healthcare and healthcare design research, and focuses ultimately on research with children and young people. Chapter 4 is concerned with the history of participatory research and the philosophy behind it, and focuses on the experience of participatory research in healthcare and healthcare design research, and environment-behaviour research.

#### **Person-Environment Fit and Environmental Congruence**

Michelson (1970) stated in relation to urban planning that:

Departures from past practices in physical development are increasing. A great deal of money, private and public, is staked on the appropriateness of innovations. Given the state of knowledge on man and his environment, however, these decisions have had to be made largely on the basis of concerned observations and good guesses (p. 198).

In relation to children's environments, more than thirty years on, this statement still remains largely true. Many of children's environments are developed by adults with little reference to research or to the opinions and experience of children themselves.

However, Michelson and Michelson (1980) said later, in relation to children's environments specifically, "everything that they use or could potentially use need not be made to order, anymore than birds eat only cultivated berries" (p. 5). Somewhere along the spectrum between guess work and over-prescription lie workable solutions to children's and young people's environments. The question is what do these environments look like and how do they function in children's lives? What are the possible governing principles which can go some way toward describing the

relationship between children and their environments? What kinds of environmental solutions are we aiming for anyway?

Possible answers to these questions include environments which could be described as supportive or congruent with children's needs and well-being in each circumstance, and environments where children and young people can experience person-environment fit. Even though these concepts were not developed specifically in relation to children and young people's environments, environmental congruence and person-environment fit are two overarching concepts which offer useful conceptualisations of the potential relationship between children and their environments.

Some of the early models of environmental congruence proposed by ecologists prioritised the role of the environment in shaping patterns of human behaviour, without giving sufficient weight to the influence and involvement of the psychological processes of the individual (Barker, 1968; Wicker, 1979). In these models, settings are seen to be predictive of the behaviour of individuals. However, as Kaplan (1983) states, this fails to take into consideration the purposes and inclinations of individuals which make these settings a more or less satisfactory context. "The fact that an individual behaves as expected cannot be considered an exhaustive analysis of the existing level of congruence" (p. 314).

Environmental congruence, as it is discussed by Michelson (1970), includes both *mental congruence* and *experiential congruence*. Mental congruence equates to an individual's perception that an environment is conducive to his or her personal needs, functions and life-style. Whereas experiential congruence equates to how well the physical environment actually accommodates the behaviours of a social group.

Michelson (1970) is concerned with experiential congruence and he advances a model of congruence which is based on the understanding that "states of variables in one system coexist better with states of variables in another system, than with other alternative states" (p. 26). This is what he calls his *intersystem congruence model*. This model assumes that interplay exists between individual and social factors and the physical features of settings, which will influence the congruence of the designed

environment, and that within this interplay some sets of variables will align more readily than others.

A congruent environment, however, does not guarantee the experience of fit for an individual. Designers will create environments which they believe are congruent in all the ways that they can anticipate for the needs and activities of the relevant user group, however, this does not ensure the experience of fit for an individual. “An environment that proves congruent in terms of the intended behaviours of a targeted population may not fit a person who was not targeted but is there anyway, or an unanticipated personal need of a targeted person” (Zimring, Carpman & Michelson, 1987, p. 920).

Zimring et al. (1987) discuss the concept of person-environment fit in the following way:

Every person has a range of needs at any given minute such as psychological needs for social interaction or solitude, stimulation or relaxation, safety or challenge, and physiological needs for food, water and physical comfort. All of these must be satisfied within a permissive physical setting, although the setting does not determine most of the activities (p. 920).

As their discussion of person-environment fit continues, person-environment fit is achieved when the needs of an individual and the characteristics and opportunities of a setting are matched. When they are not matched they suggest it is likely that energy will be spent either modifying personal needs or modifying the environment, seeking a better fit. In the process there could be the experience of misfit or incongruence which has the capacity to induce physiological or psychological stress and undermine an individual’s feeling of well-being.

For Alexander (1970) the list of potential factors contributing to person-environment misfit also provides the list of criteria for fit. As he argues, the concept of what is ‘a good fit’ is “flimsy and insubstantial” (p. 48). In looking for a good fit:

we are searching for some kind of harmony between two intangibles: a form which we have not yet designed and a context which we cannot properly describe....If we agree to treat fit as the absence of misfits....our theory will at

least have the same nature as our intuitive conviction that there is a problem to be solved (p. 48).

In this conceptualisation, Alexander is trying to make components of the concept of a good fit tangible for designers. In so doing, he emphasises attributes of the physical environment as these are the attributes over which designers have control. A flaw in this conceptualisation is that the physical environment is likely to be only one of a series of influential factors in person-environment fit. In creating a form that anticipates all the possible misfits for a user group, the designer cannot guarantee fit between an individual and a setting because the experience of fit is more complex than soundness of the physical form. However, Alexander's (1970) discussion highlights the nebulous nature of the concept of person-environment fit. The discussion necessarily leaves the reader asking whether the concept of person-environment fit is, after all, a useful conceptualisation for the designers of environments, and children's environments in particular?

The strengths of the person-environment fit concept as defined and described by Zimring et al. (1987) are that the concept is holistic and anticipates the complexities of people, the variation of environments, and the interaction between them. This is useful, even if the discussion does not include a definitive description and detail of the relationships involved. The discussion is also useful in that it suggests a focus and a desirable endpoint for all those involved in the design of children's environments which is the experience of person-environment fit. A preliminary definition of an environment that is supportive of individual well-being is also established as being one in which it is possible for an individual to experience person-environment fit, however that may be defined and detailed.

Kaplan's (1983) discussion of the concept of person-environment fit (or compatibility and incompatibility as he calls it), dwells on the concept of a supportive environment and on the link between a supportive environment and person-environment fit. He says whilst supportiveness is not simple to define,

as a first approximation consider the implications of an environment that is high in compatibility. Such an environment would not grant an individual complete control over important outcomes, but it would make it possible for an individual

to strive toward such outcomes or goals. This perspective focuses on eliminating the barriers that currently make it hard for people to help themselves (p. 323).

Kaplan's description has overtones of Alexander's (1970) approach in that minimising barriers is similar to minimising misfits. However, Kaplan's (1983) notion of supportiveness and its assessment centres on the perception of the individual, whereas Alexander's concept of a good fit centres on the nature of the physical environment. Kaplan (1983) argues that supportiveness should be understood as the extent to which people can act meaningfully on their personal plans and inclinations. Therefore the supportiveness of an environment can be measured in terms of people's perception of its capacity to enable them to pursue their goals and plans effectively.

As Kaplan (1983) suggests, in any environment it would be valuable identifying the elements in the physical environment that are associated with higher or lower levels of perceived supportiveness. This is because experiencing unsupportive environments for any length of time is likely to be detrimental. Time in an environment that is perceived as unsupportive is likely to undermine individual well-being. In Kaplan's (1983) words, "in time, resilience will decline, irritability will increase, and ultimately impacts on health and well-being are unavoidable" (p. 329).

The concept of environmental congruence, the concept of person-environment fit and the concept of a supportive environment are useful for this study in which one of the aims is to describe what constitutes a supportive environment for children and young people in a paediatric hospital.

### **Well-being, Health Promotion and Social Ecology**

Stokols (2000) states that prior to the 1970s the focus on individual and population health consisted entirely of the treatment of disease. This led to the development and dominance of disease prevention strategies that became a powerful focus in community health management. However, in the last ten years, wellness promotion has expanded to "encompass not only the immediate causes of morbidity and mortality but also the more fundamental determinants that reside in the political, social and physical environments" (Jamner & Stokols, 2000, p. 1). Community health is now understood as a concept that extends well beyond the prevention of disease. It is a set of health priorities that should

be negotiated with all levels and areas of the community, rather than being just the premise of healthcare institutions.

The change to health promotion has led to much more comprehensive and holistic definitions of what constitutes individual and community health and well-being. These changes have been accompanied by an increasing interest within health research in prevention and health promotion research, alongside problem-based research (Stokols, 1996).

In summarising health promotion research, Stokols (1996), identifies three key orientations, including research that promotes:

1. *Behavioural change*, which encourages individuals to modify their behaviour
2. *Environmental enhancement*, which requires both identifying environmental stressors and eliminating them, as well as providing environmental features which are known to support individual well-being
3. *An interdisciplinary approach*, which has the capacity to recognise the roles of the individual, the organisation, and the sociophysical environment in shaping well-being. This forms the basis of the social ecological approach to health promotion as defined by Stokols (1992, 1996, 2000).

A social ecology analysis of health promotive environments emphasises multifaceted and multidimensional levels of interactions between individual or collective behaviour and the health resources and constraints that exist in specific environmental settings. This conceptualisation is understood as being the context of individual well-being. In the social ecological approach, the physical and social features of settings directly influence the health of their occupants, and in reverse, the occupants of settings influence the healthfulness of their surroundings through their actions. Well-being is understood as the result of a “dynamic interplay among diverse environmental and personal factors” (Stokols, 1992, p. 8). The social ecological approach has the capacity to provide the theoretical framework for a holistic conceptualisation of individual health and well-being.

Stokols (1996) argues that social ecological models are becoming increasingly popular in health research in response to the recognition that health challenges require an integrated examination of psychological, organisational, cultural, community planning, and regulatory perspectives. The social ecological perspective provides a framework for understanding the complex and dynamic interaction and interconnection between the individual and their environment and the relationship of this to individual well-being. This provides a basis for understanding health promotion.

**The origins of the social ecological perspective.** Human ecology provides the theoretical base from which social ecology has evolved. Although human ecology gave greater attention to biological process and the geographical environment, the basic tenants of ecology still persist. Ecology itself is fundamentally interested in the interrelations between organisms and their environments (Barker, 1968; Stokols, 1992; Wicker, 1979).

From the outset, human ecologists assumed that:

- Every organism exists in a complex network of relationships with other organisms
- All organisms are affected by internal (within individual) and external (contextual, socio-cultural) forces
- All organisms act in a way to achieve a harmonious working relationship with their environment, selectively distinguishing between features that are appropriate for their needs and those that are not (Wicker, 1979).

Lewin (1951) was one of the first psychologists to suggest that to understand the behaviour of individuals or groups, the nature of their environments should be examined.

Barker and Wright (1971) became interested in developing an ecological viewpoint, based on Lewin's ideas. They concluded through their early work with children in the Midwest of North America that the behaviours of children could be more accurately predicted from knowing the situations the children were in than from knowing the individual characteristics of the children. It was therefore important to learn more about the contexts in which behaviours occurred (Barker, 1968; Barker & Wright, 1971). This

led Barker and Wright (1971) to describe and define the notion of the *behaviour setting*. Behaviour settings constitute the immediate sociophysical environments that surround an individual or group. They are active, organised and self-regulating environments and are considered the most significant influence on an individual's behaviour (Barker, 1968; Barker & Wright, 1971; Wicker, 1979).

Bronfenbrenner (1979) was another early theorist whose work influences contemporary social ecology. His systems theory of human development also represents a development of Lewin's (1951) early ideas. Bronfenbrenner (1979) defines the ecological environment as a "set of nested structures, each inside the next like a set of Russian dolls. At the inner most level is the immediate setting containing the developing person" (p. 3). Ultimately, he describes a system of nested structures in which the individual is centrally placed, and which includes the immediate, local and cultural environments, all of which have the capacity to influence individual development both directly and indirectly. His theory encompasses environmental interconnectedness and its impact on psychological growth. He conceives of levels of interconnection and cycles of mutual influence between the environment and the individual which can impact development. He also argues that it is the environment as it is *perceived* by the individual that may count more than the environment as it can be objectively described.

Many of these concepts are present in contemporary social ecology and are useful in providing a conceptual framework for understanding patients' feeling of well-being and patients' experience in a hospital environment. The idea of individual experience being central in a series of nested and connected structures, where the individual and the environment are involved in a dynamic relationship consisting of cycles of mutual influence, is a useful conceptualisation for patient experience. Also useful is the idea that the environment as perceived by the individual may be more potent in individual experience than the environment as objectively defined. This may be a relevant conceptualisation for understanding an individual's feeling of well-being in a hospital environment. It is also likely that 'feeling of well-being' will be a subjective response to situational factors and the circumstances surrounding an individual as he or she perceives them to be in their immediate environment.

**Stokols' social ecological model of health promotion.** Many of the ideas outlined above, including person-environment fit and environmental congruence still persist in contemporary social ecology as defined by Stokols (1992). Stokols' social ecological model, defined in relation to health promotion, encompasses core assumptions about the dynamics of human health and the development of effective strategies to promote personal and collective well-being that clearly reflect their origins. These core assumptions included:

- Well-being is influenced by multiple interacting facets of both the physical and the social environments coupled with personal factors. Efforts to promote well-being should be focused on understanding this dynamic interplay between the factors involved, including environmental, biological or behavioural factors, rather than examining these factors in isolation.
- Analyses of health and well-being should take into consideration the multidimensional and complex nature of human environments. Not only do environments consist of tangible physical and social properties or objective qualities, they also encompass subjective or perceived qualities. These qualities can be studied as separate attributes or in terms of their relationship to other elements. "The health promotive capacity of an environment represents the cumulative impact of multiple environmental conditions on occupants' physical, emotional and social well-being, over a specified time interval" (Stokols, 1996, p. 285).
- Time in the environment also has the capacity to alter individual well-being.
- As with the environment, participants can be studied at several levels also, either as individuals or as representatives of social groups. In social ecology, a study would include the individual or group experiences as well as an assessment of the surrounding environmental health in order to assess the healthfulness of settings. Assessing the person-environment fit and the congruence of the environment in relation to the individual is part of an overall assessment of healthfulness of settings (Stokols, 1996).

- People-environment interrelations are characterised by cycles of mutual influence (Stokols, 1992, 1996). The physical and social features of settings directly influence the health of their occupants and in reverse, the occupants of settings influence the healthfulness of their surroundings through their actions.
- As in Bronfenbrenner's (1979) systems theory approach, there are levels nested within levels of this kind of interaction, which are interdependent on each other and influential on collective well-being. "A core principle of social ecology is that the environmental contexts of human activity function as dynamic systems". (Stokols, 1996, p. 291)

Stokols (1992) discussed the environmental elements involved in the complex interaction between person and environment in relation to two concepts: *environmental scale* which concerns the intrasetting factors that influence individuals' health and well-being, and *contextual scope* which concerns defining the temporal, spatial and socio-cultural units to be used in any research analysis. These two concepts encompass the levels of environmental and temporal dimensions of well-being. Stokols argued that researchers must be explicit about the range of settings and the time periods encompassed by their analyses, and the way in which the attributes of settings and conditions work in combination to influence individual and collective well-being. This reflected his understanding that well-being is context specific.

*Environmental scale* ranges from specific intrasetting factors that can influence occupants' health, to the ways multiple settings and situations in a person's life such as school, home, and work, combine to influence an individual's well-being. The scale of environmental units that should be considered in individual well-being, beginning with the individual and moving out from them to include greater socio-cultural considerations are:

- *Situations* which are sequences of individual or group activities occurring at a particular time and place
- *Settings* which are geographical locations in which various personal or interpersonal situations occur on a regular basis

- *Life domains* which are the different spheres of a person's life such as family, education, recreation, and employment
- *Overall life situations*, which consists of the major domains of an individual's life during a particular period (Stokols, 1992).

*Contextual scope* refers to the scale of contextual units to be used in the research analysis. Two types of units identified by Stokols (1992) were relevant for this study. They included:

- *Spatial scope* which represents the broadest extent of the places, processes and events occurring in the individual's geographical environment
- *Temporal scope* refers to the broadest timeframe that events, processes and places will be analysed (Stokols, 1992)

Within the current study, Stokols' (1992) social ecological framework of health promotion and terminology are not used explicitly or strictly. However, all these components are variously described and defined throughout the study as they are all relevant parameters for this research.

Stokols' (1992) model also encompassed the analysis of individual and collective behaviour. The 'social' in social ecology indicates that there is still an emphasis on the individual and his or her role as active agents in their own well-being in this approach. Stokols (1992, 1996; Stokols, Grzywacz, McMahon & Phillips, 2003) identified the need for research to address the joint influence of personal and environmental factors in health promotion and to consider the behavioural outcomes of groups or individuals in relation to the specific contextual environment.

Within Stokols' model, the emphasis is on providing a conceptual framework that will enable the complexity of person-environment interrelations involved in individual well-being to become evident. Individual well-being is clearly understood as a complex concept, which centres on the experience of the individual in relation to a range of life domains, situations and settings. It represents a dynamic interplay of both human and environmental factors in any context and it recognises the influence of time in the environment, and the role of individual perception.

Although the emphasis in the current study is on understanding what comprises children and young people's *feeling of* well-being, rather than on their well-being in a hospital setting, Stokols' social ecological approach also provides the basis for an initial conceptualisation of the components that may be involved in a patients' feeling of well-being. Stokols' approach potentially provides the framework for understanding the complexity of person-environment interrelations which will be part of both individual well-being and feeling of well-being in a paediatric hospital environment. Potentially, feeling of well-being is likely to be associated with an individual's perception of, and emotional response to, their own situation which will be comprised of a series of domains, situations and settings in their immediate environment. It is also likely that an individual's response to the setting, and their experience of it, will vary across time in the environment and therefore, that time will be a factor in feeling of well-being as it is in well-being.

**Social ecology as a model for the study of child health and well-being.** The use of social ecological models in child health and well-being research has increased significantly in response to the emphasis on health promotion (Brown, 2002; Earls & Carlson, 2001; Kazak, Segal-Andrews & Johnson, 1995; Parker, Baldwin, Israel & Salinas, 2004).

In discussing the social ecology of child health and well-being, Earls and Carlson (2001) argued that child health and well-being should be understood as concerning a broad set of conditions relating to "one's sense of dignity, security and mastery" (p. 144) which "encompasses the elements of valued functionings, required resources and opportunities in the exercise of agency" (p. 144). Their definition identified the appropriateness of the use of the social ecological approach in this kind of research which indicates why it is being used increasingly in health promotion and well-being research with children and young people.

Heft and Chawla (2006) also discussed the appropriateness of a social ecological model for studying children's experience in environments and argued for its appropriateness because "it focuses on children's agency; it provides a rich description of the environmental context for action and development; and it places children and the environment together in a common realm" (p. 201). They argued that a social ecological

model offers the opportunity to consider the individual in context and embraces the complexity of the interplay that will exist between all components of the environment and children. It offers the basis of a holistic understanding of children's health and well-being.

### **Child Well-Being and Related Research**

Child well-being has been the subject of research in many disciplines. Measurement of child well-being has always been of prime concern. This research has mirrored the current approach to child health and well-being. Historically the field was dominated by research which focused on disorders, problems and disabilities (Pollard & Lee, 2003). More recently, in response to the change to health promotion, positive indicators for child well-being have been included in well-being measures. However, at this stage there are still many fewer positive indicators of child well-being (Bornstein et al., 2003; Pollard & Davidson, 2001; Pollard & Lee, 2003).

Pollard and Lee (2003) completed a systematic review of the literature published in the 1990s in the western world on child well-being. They were concerned with identifying how child well-being was defined, what the domains of child well-being were, and what were the indicators used to assess these. They reviewed 1658 studies and found that there was little consensus in the definition of what constitutes child well-being as most research did not define it directly. Instead the definition was inferred by the indicators used which also varied enormously. They were, however, able to define five domains consistently used in child well-being research, including the physical health, psychological, cognitive, social and economic domains of children's lives. The majority of the indicators used were negative or deficit measures rather than positive measures such as measures of happiness or satisfaction. Pollard and Lee's (2003) review led them to conclude that there was a need for a core set of positive indicators to be developed, and for research that explores and defines the complex construct that is child well-being.

In earlier work, Pollard and Davidson (2001) had advanced an initial definition of well-being as a multi-dimensional construct incorporating mental/psychological, physical and social dimensions.

Well-being is a state of successful performance throughout the life-course integrating physical, cognitive and social-emotional function that results in

productive activities deemed significant by one's cultural community, fulfilling social relationships and the ability to transcend moderate psychosocial and environmental problems. Well-being also has a subjective dimension in the sense of satisfaction associated with fulfilling one's potential (p. 8).

This is a comprehensive definition that resonates with the work of other contemporary commentators in well-being research (Bornstein et al., 2003; Earls & Carlson, 2001; Schor, 1995; Weisner, 1998). This definition reflects a positive approach that is oriented towards identifying the strengths and abilities that can be promoted in children and adolescents to assist them in attaining well-being. It also identifies the role of individual perception and satisfaction with all the other parameters as being part of the ultimate experience of well-being. This leads to a particular body of well-being research of interest to this study, known as the study of *subjective well-being*.

**Subjective well-being research.** Veenhoven (1984) described subjective well-being as how well the person likes the life he or she leads. Subjective well-being has both an element of cognitive evaluation and emotional response (Diener, 1984, 1994; Veenhoven, 1984). Diener (1984, 1994) suggests that there are three hallmarks to the area of subjective well-being research. Firstly, it is subjective and resides within the experience of the individual. Secondly, it assesses both the absence of negative outcomes as well as the presence of positive outcomes. Thirdly, it includes a global assessment of an individual's life rather than a narrow assessment of a single life domain.

According to Ash and Huebner (1998) subjective well-being researchers theorise that individuals use information from both their inner (self) and outer (environmental) worlds to construct their appraisals of global life satisfaction. Individuals make a comparison between their perceived life circumstances and their self-imposed standards and the extent to which these things coincide determines their overall life satisfaction (Pavot & Diener, 1993).

The interest in this area of well-being research lies in the introduction of the role of individual assessment and perception in an individual's well-being. This branch of well-being research depicts individual well-being as a subjective, negotiated and fluctuating

state, which an individual can influence and manage. In this conceptualisation of individual well-being, well-being is not simply a state of being that is comprised of a series of objective components, which need to be present in an individual's life. In subjective well-being research, an assessment of individual well-being involves the individual's perception of their own circumstances as well as the circumstances themselves.

At this stage, there is very little subjective well-being research completed with children and young people. In the small body of existing research, researchers have tried to address the multidimensionality of life satisfaction, reflecting an ecological approach (Ash & Huebner, 1998; Bracken, 1996; Crain & Bracken, 1994; Huebner, 1994).

**Coping.** Coping and the ability to cope are implicated in an individual's well-being in any situation. Similarly to subjective well-being, coping is understood as children and young people's self-evaluation and perception of their own ability to manage difficult situational demands (Folkman & Lazarus, 1986; Griffith, Dubow & Ippolito, 2000; Lazarus & Folkman, 1984; Wolchik & Sandler, 1997). Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141).

There are several conceptualisations of coping. One conceptualisation promoted by Lazarus and Folkman (1984) includes *problem-focused coping*, which equates to direct efforts to change the situation, and *emotion-focused coping*, which equates to altering emotional responses to stressors. A second conceptualisation promoted by Moos (1984) involves *approach strategies*, which involve direct efforts to alter stressful situations, and *avoidance strategies*, which are characterised by a lack of attempt to change the situation. A third conceptualisation discussed by Band and Weisz (1988) is a *primary–secondary control model*. Primary control equates to "coping aimed at influencing objective conditions or events" (p. 247) and secondary control equates to "coping aimed at maximizing one's goodness of fit with conditions as they are" (p. 247).

The principal variation between these conceptualisations is in their focus. The focus may be on the ways children choose to cope as in the case of Lazarus and Folkman's

(1984) conceptualisation, or it could be on the goals behind the strategies employed as in the conceptualisations of both Band and Weisz (1988) and Moos (1984). However, in all three conceptualisations there is consistency in relation to there being two types of strategies regularly employed in coping. These include a direct approach versus an indirect approach.

In research with children and young people some findings are consistent. As children age, a wider range of coping strategies are employed which translates into a higher self-rating of coping effectiveness (Causey & Dubow, 1992; Griffith et al., 2000). Children and young people also consistently show that coping is situational, and that coping strategies employed varied in response to each type of stressor and situation (Band & Weisz, 1988; Griffith et al., 2000).

Band and Weisz's (1988) study with children aged 6, 9, and 12 years into their response to everyday stress included medical stress. They found that in this situation children most often described secondary control approaches "aimed at controlling the psychological impact of stressful events without changing the events as such -for example, thinking happy thoughts to distract oneself from the pain of getting a shot" (p. 251). Distraction was a principal strategy employed.

The obvious question in relation to these findings is what motivates children and young people's selection of coping strategy in each situation? Lazarus and Folkman (1984) and Moos (1984) offer the explanation that it is a question of children's perception of personal control over the stressor or situation. If children and young people perceive that the objective characteristics of the situation are not alterable, and therefore a direct approach response will not change anything, they then adopt an indirect strategy to mediate the effects or impact of the situation. However, Griffith et al. (2000) suggest that this might be an oversimplification. "Perceptions of control appear to predict the relative use of approach and avoidance coping rather than the absolute level of use of each strategy" (p. 200).

Band and Weisz (1988) also suggest that familiarity with the type of situation may play a role in the variation between situations and the ways that children and young people cope. Another interesting finding from their study is that the children in their sample

showed a strong inclination to cope (96.5% of all responses) and that overall, children and young people's strategies to cope were effective in all but 7.7% of cases. This finding implies that children and young people are likely to try and cope with what happens to them by implementing coping strategies.

The literature indicates that children's coping strategies, their emotional regulation and self management strategies include a preference for having contact with nature. Natural environments are shown to be preferred environments in young people's experience for their restorative effects and capacity to help with emotional self-regulation (Korpela, 2002; Korpela, Kyttä & Hartig, 2002; Korpela & Hartig, 1996).

### **Nature and Restoration**

There is a growing body of contemporary evidence that supports the view that passive or active interaction or contact with nature has a wide range of social and health benefits (Gesler, 1992; Kaplan, 1992; Morris, 2003; Ulrich & Parsons, 1992).

Hartig, Johansson and Kylin (2003) offered this description of restoration: "restoration involves the recovery of functional resources or capabilities diminished in efforts to meet demands" (p. 614). Recent studies with children and young people have suggested that emotional and cognitive self-regulation, place attachment, privacy regulation and restorative effects of environments are interrelated in young people's experiences (Korpela, 2002; Korpela, Kyttä & Hartig, 2002; Korpela & Hartig, 1996; Thurber & Malinowski, 1999). Natural settings in particular have been identified as having more emotional significance for children and young people than could be expected in relation to the actual time spent in these kinds of settings (Hart, 1979; Korpela, 1992; Moore, 1986).

Research with adults has shown that exposing adults to natural views or settings following negative, stressful experiences produces larger physiological changes towards relaxation and higher levels of restoration than exposure to built environments (Kaplan & Kaplan, 1989; Ulrich et al., 1991). At present there is very little of this research with children and young people (Bagot, 2004).

There are two main theories of restoration. The Kaplans' (1989) theory of attention restoration is a cognitive process in which the individual is active and purposive in the restoration process. This theory revolves around the restoration of directed attention (Hartig, 1993; Kaplan & Kaplan, 1989). This is not as useful a conceptualisation for the current study as the second approach which is Ulrich's (1983) stress reduction or recovery framework. This theory is focused on short-term recovery from psychophysiological stress.

Ulrich et al. (1991) define stress as the result of an individual's perception that the situational demands exceed their own capabilities. In this approach, prolonged affective response to the environmental aesthetics of natural settings has the capacity to bring about restoration (Hartig, 1993; Ulrich et al., 1991). In Ulrich's (1983) framework, the factors involved in an individual's affective aesthetic response are also involved in restoration. A momentary aesthetic response to a natural scene may have some rejuvenating value, and a prolonged response may contribute to a wider range of measurable psychological and physiological outcomes for someone who is stressed (Hartig, 1993; Ulrich, 1983). These assumptions are based on the belief that human beings are predisposed to live in natural environments and because of this, natural environments have the capacity to counteract the stress of artificial environments.

Ulrich (1984, 1999) has studied patients' response to nature and natural settings, using physiological measurements to determine the restorative impact of contact with nature via views and video material. From this, he has advanced his theory on the restorative components of healing gardens. These include four attributes: a sense of control and access to privacy; social support; physical movement and exercise; and access to nature and other positive distractions. In combination, Ulrich (1999) argued, these characteristics offer stress reduction and buffering or enhanced coping, which in turn improves patients' health outcomes.

**Emotional self-regulation and the environment.** A final body of literature that will be discussed here includes children's response to, and use of, the environment as a coping mechanism in emotional self-regulation. Research with children and young people has shown that strong emotions are attached to places, particularly natural places (Cooper Marcus, 1978; Hart, 1979; Moore, 1986; Sobel, 1990, 1993). Silbereisen and Noack

(1988) were one of the earliest groups to consider place selection in light of emotional self-regulation.

More recently, there have been a growing number of studies on children's favourite places and their relationship to self-regulation, particularly the work of Korpela and his colleagues (Korpela, 1989, 1992; Korpela, Kytta & Hartig, 2002; Korpela, Hartig, Kaiser & Fuhrer, 2001). The concept of environmental regulation holds that "the physical environment itself can become an essential part of the process of regulating the experience of self and emotions" (Korpela, 2002, p. 367). The results from this body of work indicate that favourite places are used by children and young people to regulate their experience of self and their emotions (Korpela, 1992, 2002). Results also indicate that natural settings are often preferred places for emotional self-regulation (Korpela, 1989, 1992; Korpela et al., 2001; Owens, 1988).

Thurber and Malinowski (1999) studied the environmental correlates of negative emotions in children. They were concerned with the power of emotions to change young boys' perceptions of the environment, and the way that the boys responded to their emotions in a "structured, novel, natural setting" (p. 506). These boys were participants in a summer camp, which they were obviously obliged to attend. Thurber and Malinowski found that negative emotions in boys were associated with negative attitudes towards their environment; that boys experiencing greater degrees of depression and unhappiness explored the environment *more*; and that "an unhappy boy [is] one who prefers environmental solitude but is also actively seeking something better" (p. 508).

Thurber and Malinowski's (1999) findings have several interesting implications for understanding emotional self-regulation and the environment in relation to the current study. Firstly, there is a parallel between the obligatory attendance at summer camp and the involuntary admission to hospital. Both these environments are likely to present structured and novel settings for most children; and a hospital is also likely to be a setting where children and young people experience unhappiness and emotional distress. Thurber and Malinowski's findings create the expectation that young people may not have the capacity to separate their impression of their own personal situation from their impression of the environment under difficult circumstances. Secondly, they

also create the expectation that young people in similar circumstances may use the environment to try to actively manage the situation and reduce their level of stress – in their case by exploring more of the environment, and seeking a better person-environment fit (Thurber & Malinowski, 1999). This suggests that the environment may present one of the vehicles for emotional self-regulation and direct approach coping strategies for children and young people in difficult circumstances.

This chapter has summarised literature that provides the theoretical and conceptual framework for the study. It encompasses literature on conceptualisations of individual health, well-being, self management, coping, and restoration. This provides a conceptual framework within which to understand children's capacity to achieve a feeling of well-being within their experience of hospitalisation. The following chapter will review healthcare and healthcare design literature in order to establish a more detailed and concrete level of significant concepts and considerations within children's experience of hospitalisation which will be relevant to the current study.

## CHAPTER 3

### HEALTHCARE DESIGN AND HOSPITALISATION RESEARCH

#### An Overview of Healthcare Design Research

There is little doubt that the role of the environment in health and healing processes is of increasing concern to healthcare providers, architects, planners, and researchers (Devlin & Arneill, 2003). Between 1998 and 2006, there have been a number of major reviews of healthcare design research which reveal that the volume of research in the area has increased tenfold in that time (Devlin & Arneill, 2003; Phiri, 2006; Rubin et al., 1998; Sherman, Shepley & Varni, 2005a; Ulrich & Zimring, 2004).

There is also an increasing body of research that shows changes made to the social and physical environments for patients, benefit medical outcomes and this has fuelled interest in the relationship between environment and health outcomes (Lawson, Phiri & Wells-Thorpe, 2003; Stichler, 2001; Ulrich, 1992a; Ulrich et al., 1991).

The evolution of hospital design across the 20<sup>th</sup> Century reflects a shift in healthcare philosophy from what Verderber and Fine (2000) describe as a *system empowerment paradigm* to a *patient empowerment paradigm*. Hospitals have changed from being large institutional structures dominated by function and medical process, to being environments oriented around patients' needs and well-being (Verderber & Fine, 2000). Changes in the approach to hospital design have consistently reflected changes in models of care and medical technology (Shumaker & Pequegnat, 1989).

Increasingly, an emphasis has been placed on the experience of hospitalisation from the patient's perspective, resulting in an emphasis on the attractiveness of buildings, on creating an uplifting environment, on reincorporating nature as a therapeutic element, and on recognising a patient's right to privacy and control. The scale of hospital buildings has become smaller and spaces more intimate, with a greater variety of spaces. The interior décor has become more sensitive to making patients feel more at home with greater colour and textural variation and the use of everyday furniture and fabrics (Malkin, 1992; Verderber & Fine, 2000).

These changes have reflected changes in models of care that have become more patient-centred. Models such as the Planetree Model, (Lindheim, Glaser & Coffin, 1972; Martin, Hunt & Conrad, 1990; Martin et al., 1998) which operate on principles of respect, comfort and support, and seek to provide coordinated and integrated care for patients (Beatrice, Thomas & Biles, 1998), have become the dominant healthcare models. Patients have reported a greater degree of satisfaction with hospitalisation when they have been cared for under these conditions (Martin et al., 1998). In these models of care, patient comfort, empowerment and control are understood as central to patients' well-being.

An emphasis on creating a holistic healing environment became the focus during the 1990s, in response to shifts in the sensibility surrounding patient's experience of hospitalisation (Malkin, 1992). Definitions of what these environments consist of are still largely unsupported empirically for many patient populations, including children and young people. Drawing from several reviews of the literature, however, it is possible to identify some of the main considerations from the patient's perspective.

The major considerations include aspects of the social, organisational and the physical environment. The influence of these considerations is discussed either in relation to their impact on patients' stress, or for their impact on patients' overall satisfaction with hospitalisation and the hospital environment. More research exists which is concerned with identifying and minimising stressors in the hospital environment, than research that is concerned with making recommendations for supportive measures for patient well-being. At this stage, there has been very little of either type carried out with populations of children and young people.

Key aspects of the social environment include having access to, and control over social contact with friends, family and other patients; having control over and access to privacy; and having access to support (Lawson et al., 2003; Rubin et al., 1998; Shumaker & Pequegnat, 1989; Ulrich, 1995, 1999; Ulrich et al., 1991; Ulrich & Zimring, 2004).

Key aspects of the organisational environment include having access to supportive facilities and amenities; attention to cleanliness, maintenance and tidiness; and access to

information (Bruster et al., 1994; de Vos, 2006; Harris et al., 2002; Lawson et al., 2003).

Key aspects of the physical environment are often categorised. Several commentators have offered frameworks of categories (de Vos, 2006; Dijkstra, 2006; Harris et al., 2002; Ulrich & Zimring, 2004). Harris et al. (2002) offer a particularly comprehensive and useful set of categories. In their study into patient satisfaction in a hospital environment they found that environmental satisfaction was a significant predictor of overall satisfaction. As part of their study, they conceptualise three levels of considerations within the physical environment. These include the *ambient environment*, *architectural features* and *interior design features*.

The *ambient environment* includes features such as the lighting, noise levels, temperature and odours in the environment. Patients report that having control over these environmental attributes is linked to satisfaction (Fottler, Ford, Roberts & Ford, 2000; Harris et al., 2002) and likewise not having control over these attributes is reported as causing stress (Baker, 1984; Topf, 1994, 2000; Ulrich, 1992b, Ulrich et al., 1991; Ulrich & Zimring, 2004).

The *architectural features* include relatively permanent characteristics such as the spatial layout, design configuration (e.g. shared versus single rooms), the scale of the hospital, room size and window placement, number and kinds of facilities and amenities, and having access to views, nature and outdoor areas (Cooper Marcus & Barnes, 1999; Lawson & Phiri, 2003; Ulrich, 1984, 1999).

The *interior design features* include less permanent characteristics such as the furniture, colour, texture, artwork, plants, aesthetic qualities of the hospital, and the legibility of the building through signage and maps (Carpman & Grant, 1993; Fottler et al., 2000; Shumaker & Reizenstein, 1982). Harris et al. (2002) note that there has been little research focusing on the interior design of hospitals but note that it is a belief held by many design and healthcare professionals that aesthetically pleasing environments enhance patient satisfaction and experience of hospitalisation (Behrman, 1997; Cooper Marcus & Barnes, 1999; Fottler et al., 2000; Friedrich, 1999; Malkin, 1992; Ulrich, 1992a, 1999).

**Ulrich's theory of supportive design.** A central body of work in healthcare design research is from Ulrich (1991a, 1991b, 1992b, 2000, 2001). Ulrich is focused on identifying the direct and indirect relationships between the designed environment of healthcare facilities and clinical outcomes for patients. Ulrich's (1991b) theory of supportive design in healthcare settings encompasses the assumption that "supportive surroundings facilitate patient's coping with the major stress accompanying illness. The effects of supportive design are complementary to the healing effects of drugs and other medical technology, and foster the process of recovery" (p. 97).

The starting point for Ulrich's (1991b) theory is that most patients experience considerable stress in healthcare settings in response to two things primarily: their illness and its repercussions, and the nature of the physical environment. He argues that patient stress has a variety of negative psychological, physiological and behavioural impacts on patient wellness (Ulrich, 1991a, 1991b, 1992b, 2000, 2001). Ulrich's main argument is that minimising environmental stress equates directly to supporting patient wellness.

Ulrich's (1991b) theory of supportive design suggests that patient well-being is linked to situational control, access to social support, and positive distractions within the environment. He argues that the importance of a patient's sense of control over their physical and social surroundings in influencing stress and wellness is well documented in research. Patient control spans two particular domains: control over the effects of illness, and control over the features in the sociophysical environment that patients do not like and cannot alter.

Access to social support is significant in Ulrich's research also (Ulrich, 1991b, 1992b, 2000; Ulrich & Zimring, 2004). Patients who have access to frequent support from family and friends experience less stress and higher levels of wellness.

Access to positive distractions is a more complex notion than the concepts of situational control and social support. It concerns providing patients with adequate amounts of positive sensory stimulation and addresses in what forms that stimulation may be beneficial or detrimental. In particular, Ulrich (1991b, 1992b, 2000, 2001) discusses the

positive effect of patients' exposure to nature, natural views (Ulrich, 1981, 1984, 1999), artwork and entertainment on patients' experience of stress (Ulrich, 1992b).

### **Healthcare Design Research in Paediatric Settings**

Research with children and young people in hospital settings is much more limited than it is with adults. However, the research available indicates that many of the same aspects of a hospital environment influence children and young people's satisfaction with the hospital and hospitalisation. Characteristics of the social, organisational and physical environments continue to be influential in patients' response to the hospital setting.

Personal control continues to be a central consideration. In a long-term study conducted in a psychiatric hospital, Rivlin and Wolfe (1985) identified young people's need for personal control, including control over privacy, confidentiality, time management and activity choice.

Olds (1991) also identified personal control as one of the four criteria that should be addressed in children's hospital design. She identified control over such things as social contact, privacy and personal space as essential to individual well-being. She also identified the need for children to experience competence regularly whilst in a hospital, move independently throughout an environment, and feel comfortable, by receiving optimal levels of stimulation to keep actively and positively engaged.

Lindheim, Glaser and Coffin's (1972) work also made many recommendations for paediatric design along similar arguments based on holistic human needs. They made a series of developmental age-related recommendations that encompass the need to provide adequate cognitive stimulation, access to recreational and learning activities, opportunities for social contact and self-care management, opportunities for personal space, privacy and confidentiality and individual control.

In relation to the physical environment specifically, research has recommended that new considerations are introduced in paediatric environments that differ from adult hospitals. These include the need for age-appropriate activities and spaces (Hutton, 2002, 2003; Tivorsak et al., 2004), the need to accommodate families and their needs, so that they

can fulfil their role in supporting their children (Hall, 1990; Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2005; Sheldon, 1997), and the need to provide for peer social interaction, particularly amongst adolescents (Blumberg & Devlin, 2006).

Recent research with adolescent and child patients has identified the following key environmental attributes within the hospital environment that support patient experience. For children and young people:

- The need for age-appropriate activities, spaces and interiors, especially for adolescents (Blumberg & Devlin, 2006; Carney et al., 2003; Hutton, 2002, 2003, 2005; Kari, Donovan, Li & Taylor, 1999; Tivorsak et al., 2004)
- Importance of having access to school (Kari et al., 1999; Liabo, Curtis, Jenkins, Roberts et al., 2002)
- Importance of having personal possessions and being able to personalise their bed area (Blumberg & Devlin, 2006; Shepley, Fournier, & McDougal, 1998)
- Preference for colour and artwork in the environment (Sharma & Finlay, 2003)
- Preference for medical equipment and paraphernalia to be hidden as much as possible (Tivorsak et al., 2004)
- Importance of having access to gardens to escape, and for something to do (Sherman et al. 2005a; Sherman, Varni, Ulrich, & Malcarne, 2005b; Whitehouse et al., 2001).
- Importance of good provision for families and their needs (Hall, 1990; Hopia et al., 2005; Liabo et al., 2002).
- Preference for 'home-like' qualities in the environment (Runeson et al., 2002; Tivorsak et al., 2004)

For adolescents (in particular):

- A preference for their own ward (Blumberg & Devlin, 2006; Hutton, 2003; Kari et al., 1999; Sharma & Finlay, 2003)
- A preference for adolescent wards to be located near children's wards rather than near adult wards (Sharma & Finlay, 2003)
- A preference for bright colours, without emblems of childhood such as cartoon characters (Blumberg & Devlin, 2006)

- The need for social spaces specifically for their own age group (Blumberg & Devlin, 2006; Hutton, 2005)
- The need for both single and shared rooms in adolescent wards (Blumberg & Devlin, 2006; Hutton, 2002; Miller, Friedman & Coupey, 1998)
- The need for control over privacy (Blumberg & Devlin, 2006; Hutton, 2002, 2003; Kari et al., 1999; Sharma & Finlay, 2003)
- The importance of access to television, music and a telephone (Blumberg & Devlin, 2006; Hutton, 2003, 2005)
- A preference for access to additional activities such as games rooms, gyms and kitchens within the hospital environment (Blumberg & Devlin, 2006; Hutton, 2003, 2005).

### **Children's Experience of Hospitalisation**

Very little of the recent research listed above focused exclusively on environmental considerations. Rather they usually emerged as part of a more comprehensive list of considerations within children and young people's experience of hospitalisation which will be explored in the next two sections of this chapter. These considerations helped to refine both the broad and the specific subject areas within children and young people's experience of hospitalisation that were addressed in the current study.

In their consultation with children and young people aged up to 18 years about their response to health services in the UK, Liabo et al. (2002) identified a range of considerations in addition to the environmental attributes already listed from this study.

These included:

- The importance of having family present
- The need for having enough to do
- The need for active support from staff
- The need for friendliness and respect and use of appropriate language from staff (this was used by participants to assess the quality of their communications with professionals)
- The need for information
- The need to maintain confidentiality

Runeson et al. (2002) in their study into boys' needs during hospitalisation, identified two different situations of need that occur in hospital including *threatening* and *non-threatening situations*. In threatening situations such as pain and discomfort, four categories of needs were identified: to feel in control of the situation, to have parents nearby, the familiar (that which reminds them of home), and the need for integrity (control over privacy). In non-threatening situations, six categories of need were identified: activity, new experiences, information, participation in their own healthcare, praise and recognition (for self-management), and needs related to physical resources (e.g. food and drink).

In a study conducted by young people themselves into children and young people's response to the quality of care in a hospital, the participants created a list of factors that, in combination, affected participants overall rating of the hospital as excellent (Moules, 2004). These included:

- The need for good technical skills displayed by staff to minimise pain and do things carefully
- The importance of friendly staff – who are willing to spend time and to talk with patients
- The need to give young people respect by listening to them and considering their need for privacy
- The need for good information and good explanation about what is happening

In addition to these studies which have produced overall recommendations, others have dwelt on specific aspects of children's and their family's experience. Children have identified that their family's experience whilst they are in hospital, is very important to them. Hopia et al. (2005) identified five ways to support the needs of parents and families in hospital which contribute to the family's experience. These included:

- Reinforcing parenthood (by clarifying their role)
- Looking after the child's welfare (by instilling confidence in the system of care and by showing an interest in the child)
- Sharing the emotional burden
- Supporting the everyday coping of families
- Creating a confidential care relationship with the whole family

Another key area identified in children's experience is the management of information, its type, volume and delivery, and the opportunities to participate in decisions affecting their own healthcare. Hallstrom and Elander (2003) state that "having a voice in decision making helps the child to develop a sense of himself as a person and gives the parents a feeling that they are part of a team giving their child optimal care during hospitalization" (p. 367). Smith and Callery (2005) found that patients aged 7 to 11 years could identify their own information needs and felt there was too little information provided ahead of their operation or admission.

Young, Dixon-Woods, Windridge and Heney (2003) found that children with chronic illness felt constrained by their parents' role in managing the information that they received. They reported feeling marginalised as a result. Ishibashi (2001) also found that children and young people had a clear interest in receiving information about their condition but that it was important that this information be age-appropriate.

In summary, the findings from this body of research reveal that the considerations for children in hospital include:

- Friendly, supportive and respectful contact with staff
- Competence from staff in their treatment of patients
- The need for sufficient, age-appropriate information and explanations of what is happening
- Appropriate inclusion and provision for families (respect for the need for continuity of care)
- The need for sufficient activities
- The need for control over privacy
- The need for patients to participate in their own healthcare management

### **Adolescents' Experience of Hospitalisation**

Special considerations, in addition to many of the needs listed for children are recommended for adolescents. There is clearly a need for a greater emphasis to be placed on age-appropriateness for this age group.

Research has indicated that adolescents were more sensitive to the treatment received from staff and whether it was age-appropriate, respectful or condescending (Moules, 2004). They were also aware of the age-appropriateness of available activities and spaces to carry them out (Hutton, 2003; Tivorsak et al., 2004). Adolescent participants wanted more lenient visiting hours policies to socialise with friends (Blumberg & Devlin, 2006). They required a greater range of activities and greater access to, and control over them (Hutton, 2003; Tivorsak et al., 2004), including a greater range of recreational facilities (Blumberg & Devlin, 2006). In Hutton's (2003) study, having age-appropriate activities was viewed as a coping strategy. Activities were used to prevent boredom and remain positively engaged in the experience of hospitalisation, which participants felt would lead to improved health.

Social interaction and having access to peers was more important for adolescents than having regular contact with family (Blumberg & Devlin, 2006). In Blumberg and Devlin's (2006) study, participants valued having a 24 hour visiting policy for families but it was not so important that parents stayed overnight. Carney et al. (2003) found that continuity of care was more important for younger children.

Access to, and control over, privacy was found to be more important for adolescents (Blumberg & Devlin, 2006; Hutton, 2002, 2005; Sharma & Finlay, 2003). Adolescents appeared to be divided in most studies as to whether they would like to share a room or have a private one. This preference was divided between some adolescents who felt a need for privacy and others who preferred to have company (Blumberg & Devlin, 2006; Miller et al., 1998).

Hutton (2002, 2005) outlined a conceptualisation of space for adolescents in hospital which included *private space* and *shared space*. Private spaces included their bedrooms, bathrooms, treatment areas and telephone. Shared spaces included social zones and places. The recommendation was that adolescents' needs for both should be respected.

Blumberg and Devlin (2006) also stated that personalisation of the bed area and being able to bring in personal belongings was very important for adolescents. This was linked to establishing their identity and their level of comfort in the environment. They

went as far as to say that being able to personalise the bed area was more important to their participants than the appearance of the ward room and its appropriateness for age.

Food and its quality, variation, and choice were also an important consideration for adolescents (Blumberg & Devlin, 2006). Carney et al. (2003), who also received feedback that the food, as well as the television and computer games was of importance, suggested that these considerations may be linked to adolescents trying to find some continuity with their home environment within the hospital.

The summary of the research in this chapter provides a basis for conceptualising the characteristics of hospital environments and hospital experience that are important to children and young people, and which can impact on their experience of hospitalisation. The following chapter will discuss literature on children's participation as a preferable approach to researching children's experience.

## CHAPTER 4

### **PARTICIPATORY RESEARCH WITH CHILDREN AND YOUNG PEOPLE**

This chapter will discuss the concept of children's participation and engaging children and young people in processes and decisions which affect their lives. This summary provides the rationale for choosing participatory methodologies in research with children and young people. This summary provides the background to the participatory methodology used in the current study.

#### **The Context of Participatory Research with Children and Young People**

The participation movement and participatory research have developed in response to an increased respect for children's competence and authority in their own lives, and in their ability to contribute meaningfully to adults' understanding about their lives. The interest in children's participation has developed in response to changes in the social status of children and childhood, and to changes in the understanding of children's rights as citizens to be consulted and heard on subjects which affect their lives.

In the last fifteen years in particular, there has been a wealth of change in many social science disciplines in attitudes to children and childhood, and to the approach to children's research (Christensen & James, 2000; Corsaro, 2005; Mayall, 2002; Qvortrup, Bardy, Sgritta & Wintersberger, 1994). The desire to depict or report *on* children and childhood in research, is now running in parallel with a desire to understand children and young people's lived experience (Pole, Mizen & Bolton, 1999). The aim of modern movements in children's research, such as the new sociology of childhood, is to contribute to changing the status of children and young people from being a socially marginalised group, whose perspectives are considered of limited value to social functioning and processes, to ensuring that children and young people are recognised as "competent social actors who actively contribute to and influence their own lives" (Barker & Weller, 2003, p. 34).

Historically in the western world, social attitudes towards the status of children and childhood have permeated research with children. The current interest in participatory research is part of the participation movement that is seeking to change children's traditionally powerless social state to a socially empowered position (Jones, 2001). The

development of the participation movement and participatory research mirrors the increasing visibility of the child rights movement. This culminated in the United Nations Convention on the Rights of the Child (UNCRC) in 1989, which sets out children's rights to provision, protection and participation. As discussed by Lansdown (1994) the provision articles outline the social rights of children to minimum standards of health, education, social security, physical care, family life, recreation and culture. The protection articles identify the rights of children to be safe from harm, discrimination, abuse, exploitation and conflict. The participation articles, articles 12 (the right to be listened to and to be taken seriously) and 13 (the right to freedom of expression) are concerned with giving children civil and political rights to be consulted and heard, rights to information, and rights to freedom of speech and to participate in decisions which affect their lives. Article 13 also states the need to provide support for children's participation (Lansdown, 1994, 2001).

In empowering the status of children and young people, the UNCRC does not seek to undermine the involvement of adults in children's lives. What this convention does for children and young people is identify the rights of children and young people independently of their relationship to adults. It accords them equal social status and recognises their competence to participate and to represent themselves and their own view points as social citizens in social processes.

The development of participatory research reflects a new respect for children's competence; an elevation in the status of childhood; and a recognition of the value to knowledge of children's insight into their own experience. These changes in the involvement of children in research represent the major shifts in attitudes, status, and respect accorded to children and childhood which reflect the influence of the child rights movement and of the increased recognition of the value of children's participation.

**Respect for children's competence.** Approaches to children's participation are linked to fundamental beliefs about children and childhood that are culturally engendered. It can be these beliefs that often restrict children's ability to participate effectively because they encompass views on competence, generations, power relations and status (Alderson, 2001; Mayall, 2002). In addition to these beliefs, approaches to participation

in research are also linked to the researcher's belief about whether research with children is the same as research with adults or is completely different. Inherent in these beliefs are positions on children's rights, competence, status and abilities (Punch, 2002). Within western societies there has been a long-standing classification of children as 'minors' who are not yet adult and therefore not yet competent, responsible and reliable (Casas, 1996). Researchers have been very cautious about carrying out research solely with child participants, questioning the reliability of children's data, the depth and quality of that data and the ultimate ability to be able to answer research questions based on that data alone (as discussed in Faux et al., 1988; and Miller, 2000). This concern largely revolves around the notion of children's competence (Casas, 1996; Coyne, 1998; Woodgate, 2001).

The traditional understanding of children's competence in research on children was largely influenced by the work of early psychologists such as Freud, Piaget and Erikson. Alderson (1994) discusses the tendency of these theorists to label children as incompetent "because they are thought to be incapable of 'cognitive complexity', to have unstable, transient values, no real concept of 'the good', of death, of their future, or their likely future values" (p. 51). Alderson (1994) argues that the danger in these assumptions is that they fail to recognise young children as having a sense of self, or a personal identity that needs respect. This leaves young children's rights and competencies vulnerable to being ignored, which is what has happened in traditional research with children and young people.

Participatory research assumes children's competence in being agents in their own lives. It also assumes that children and young people have unique insight into their own experience that adults cannot have. Indeed adults are seen as not competent to be able to give the insight that children can give. This major change in the accepted understanding of children's competence and agency heralds a new and positive expectation of the social input from children and young people which participatory research helps to reveal. Prout and James (1990) argue the social sciences are not neutral commentaries on childhood but are instead actively constructed. There is a need to give children and young people the opportunity to define themselves in research, rather than continually be defined by adults and their assumptions about childhood (Grover, 2004).

**An elevation in the status of childhood.** “Human beings rather than human becomings” (Qvortrup et al., 1994, p. 4). This phrase captures the shift in attitudes to children and childhood very well. In the past, in response to dominant developmental theories, childhood has been understood as part of a larger linear process of development in which the end goal is achieving the competence of an adult. In this framework, childhood consists of a series of developmental stages that an individual must pass through in order to acquire the skills to cope with adulthood (Corsaro, 2005). As such, childhood is valued in relation to adulthood and it can only be conceived of as a lesser state.

Contemporary commentators in sociology and psychology in particular acknowledge that the status of childhood has changed dramatically because of the changes to children’s rights and social status (Corsaro, 2005; Mayall, 2002; Qvortrup et al., 1994). Lloyd-Smith and Tarr (2000) offer a pertinent summary of the historical changes in constructions or conceptualisations of childhood. They describe a series of four constructions based on the work of Jenkins (1993), including children as *possessions*, as *subjects*, as *participants* and as *citizens*. All of these constructions embody a view of adult-child relations as well as a conceptualisation of childhood.

*Children as possessions* is a conceptualisation which considers the child as the property of parents or other adults and has no rights independent of them. Notions of biological dependency and immaturity legitimise this conceptualisation, which provides adults with complete and unquestionable power over children’s lives.

*Children as subjects* still conceives of children as in need of protection from adults but children hold basic rights to protection and the provision of basic welfare. However, in this conceptualisation, children are still largely disempowered in decisions that affect their own lives and are still conceived of as being dependent and incompetent in an adult world. Qvortrup (1997) states, whilst protection may be warranted it can also function as a form of exclusion, creating an opportunity for unwarranted dominance of adults in children’s lives.

*Children as participants* is a conceptualisation that has evolved in response to the child rights movement. In this construction, children are conceived of as participants in the

decision-making of adults, with the right to be consulted and heard in decisions that will affect their lives. The onus is on adults to facilitate children's participation in traditionally adult domains.

*Children as citizens* is the most recent conceptualisation and is a further development on from children as participants. This conceptualisation conceives of the child as an active autonomous social citizen, who has the competence and right to make decisions independently of adults (Lloyd-Smith & Tarr, 2000).

Aspects of these conceptualisations are the subject of debate, such as children's actual capacity for autonomy and agency in their own lives considering their generational position (Mayall, 2002). There is however, a clearly perceptible conceptual shift from the first construction of 'child with no rights or voice' to the fourth construction of 'child with rights and voice that is socially valued'. This reflects changes in the social status of childhood that are widely acknowledged (Christensen & Prout, 2001; Corsaro, 2004; Graue & Walsh, 1998; James & Christensen, 2000; Mayall, 2002; Qvortrup et al., 1994).

**The value of children's insight into their own experience.** The changes in the social status of children have been reflected in children's research. Children have only recently been given the opportunity to speak for themselves in research (Barker & Weller, 2003; James & Christensen, 2000). Traditional research *on* children reflected adult interests, agendas and assumptions, rather than the interests of children (Barker & Weller, 2003; Hood et al., 1996; Valentine, 1999). Qvortrup (1990) argued that "if we mean to improve the life conditions for children we must, as a minimum precondition, establish reporting systems in which they are heard themselves as well as reported on by others" (p. 94). Most of what we know about children in research comes from adults (Graue & Walsh, 1998).

In the introduction to their book, Graue and Walsh (1998) discuss why research with children is crucial. They offer several reasons. One includes the fact that as an adult researcher "one remains a very definite and readily identifiable other" (p. xiv). Adults can never be full participants in children's social worlds (Hill, 1997; Punch, 2002). This recognition alone indicates the value of children's insight into their own experience.

The second reason as discussed by Graue and Walsh (1998) is that research offers the opportunity to find things out rather than make them up, or in the case of children have them made up for you. Graue and Walsh (1998) argue that in the past, whole categories of children and of childhood experience have been made up by researchers which have limited basis in evidence. They cite theories such as Piaget's theory of development as an example. This theory was researched in de-contextualized, contrived conditions with limited numbers of children which he then espoused as a universal pattern of development, applicable to all children.

Graue and Walsh (1998) state that we need:

To find it out. And to keep finding it out, because if we do not find it out, someone will make it up...and what they make up affects children's lives; it affects how children are viewed and what decisions are made about them. Finding it out challenges dominant images. Making it up maintains them (p. xvi).

As Kellett (2005) describes it "the journey from research *on*, through research *with* to research *by* children is a natural progression accompanying the shifting changes in adult-child power and participation agendas" (p. 30). As discussed by Christensen and Prout (2001) children have been conceptualised in research in a number of ways. These all currently co-exist. This includes the child as *object* of research, the child as *subject* of research, the child as *autonomous social actor* and agent in their own experience, and most recently the child as participant and *co-researcher*. The final three of these conceptualisations of children and research are potentially participatory.

*The child as object* is described as a person that is "acted upon by others, rather than a subject acting in the world" (Christensen & Prout, 2001, p. 480). It is based on the assumption of children's dependency. This is a traditional, non-participatory view.

*The child as subject* challenges the first position by acknowledging children as people with subjectivity. This is the founding position for child-centred research. However, this research is still largely controlled by adults and adults' assumptions about children's competence and abilities.

*The child as autonomous social actor* is a relatively new approach and extends the view of children as subjects to children as social actors “with their own experiences and understandings” (Kellett, 2005, p. 480). In this view children are considered autonomous in their own lives and are considered to have the capacity to take part in the social and cultural spheres they live in and to act on them to create change (also discussed by Corsaro, 2005; Prout & James, 1990). This approach to research involves children and young people in the development of methods and methodology much more actively than the previous approaches.

The most recent view is of *children as co-researchers* (Alderson, 2001; Kellett, 2004, 2005). This has developed from the premise that children and young people have the capacity to carry out their own research on their own questions, providing they are given sufficient “scaffolding” by adults (Kellett, 2005, p. 19). Scaffolding in this instance is research training provided by adults. Children are taught the rules of research and then go on to apply them to their own questions (Alderson, 2001; Kellett, 2004, 2005). Implicit in all of these categories are assumptions about children’s participation which need further exploration.

### **A Summary of the Assumptions and Principles of Children’s Participation**

This summary represents a cross-disciplinary collation of assumptions and principles of children’s participation (Alderson, 1994, 2000, 2005; Christensen & James, 2000; Farrell, 2005; Graue, & Walsh, 1998; Greig & Taylor, 1999; Grodin & Glantz, 1994; Hart, 1997; Hill, Laybourn, & Borland, 1996; Kellett, 2004, 2005; Mauthner, 1997; Mayall, 2002; Morrow, 2001; Pole et al. 1999; Punch, 2002). This list is not a definitive list, it just identifies some of the main considerations shared by commentators. These principles encompass conceptual as well as methodological considerations for research. The methodological considerations will be discussed further in relation to the current study in Part B of the thesis.

**Fundamental underlying assumptions.** Three fundamental assumptions emerge from the literature in support of children’s participation. These include:

- Children and young people have the capacity to participate
- Children and young people have the right to participate
- Children and young people have critical and unique perspectives on their lives

**Main principles of participation.** Four principles emerge continuously in the literature in relation to children's participation in general. These include:

- *Participation should contribute to children's lives.* Children's participation should have the capacity to contribute to their lives individually and collectively. In relation to research this means that the research should have benefit for both children and young people who participate as well as for the project itself. Alderson (2005) states that the first question that should be asked is, is the research worth doing?
- *Participation should be voluntary.* Children's participation should be their own choice and not the result of coercion of any kind from surrounding adults. It should also be an informed choice, meaning that children and young people should be provided with sufficient information to be able to make their own choice.
- *Participation should bring no harm.* Care is needed to ensure that participation brings children no harm. This reflects the ethical principle of beneficence.
- *Participation should be supported.* Children's capacity to participate needs to be facilitated by surrounding adults who may need to provide them with sufficient 'scaffolding' (Kellett, 2004) in the form of training and information to enable them to participate. This may need to vary according to the group of children in focus. Children are not an homogenous group and the variation in children's perspectives based on age, gender, disability, cultural or religious background needs to be recognised so that their participation can be facilitated.

A further four principles emerge in relation to participatory research specifically. These include:

- *Develop a sound ethical strategy.* A sound ethical strategy needs to reflect the values of beneficence, justice and respect, and encompass formal ethical considerations such as obtaining access, consent, anonymity and confidentiality. The strategy needs to allow for the need for the flexibility to alter in response to changes in the project. Ethical issues should be revisited and renegotiated throughout the research project, particularly if studies involve the same group of children in a number of stages.

- *Redress power imbalances.* There can be many situations of potential power imbalance for children and young people participating in research managed by adults. The most obvious is the need to minimise generational power imbalances (Mayall, 2002). Methods for achieving this will be discussed in Part B of the thesis.
- *Seek to empower.* The research process should be designed in a way that genuinely empowers children and young people in research decisions. This may be achieved by developing their skills and knowledge, showing respect for their expert knowledge and continually re-engaging children and young people in successive steps of the research process when possible, including in data analysis and interpretation. The representation of children's views needs particular consideration.
- *Be continually reflexive.* Researchers should be mindful as to how their own beliefs and values, as well as broader social and cultural attitudes to children and childhood, are shaping their research. Researchers also need to reflect on the experience of the research as it progresses, allowing the conduct and intermediate results and experience to inform successive stages.

### **Participatory Research in Healthcare and Healthcare Design**

Since the early 1990s, there has been increasing interest in research on children and young people's experience of hospitalisation. This research has reflected the participatory philosophy for the most part with authors articulating the value of gaining children and young people's insight into their experience (Carney et al., 2003; Miller et al., 1998; Sandbæk, 1999; Sartain, Clarke & Heyman, 2000; Smith & Callery, 2005). There remains, however, very little participatory research on children and young people's experience of hospitalisation.

Participatory research began tentatively in medicine and health science disciplines. In early research into children's experience in healthcare contexts, children's voices were often obscured by the voices of surrounding adults (Eiser, 2000). However, more recent studies have used sample groups of children and young people as their only sample group (Miller et al., 1998; Morison, Moir & Kwansa, 2000; Hutton, 2002, 2005). This reflects a confidence in children's abilities and competence that has developed in response to research with children and young people (Mauthner, 1997).

From the body of participatory research with children and young people in a healthcare context that has been completed it is possible to identify the key considerations for conducting participatory research in a healthcare setting. These include:

- The need to negotiate a hierarchy of ‘gatekeepers’ to access children in hospitals and the difficulty of this (Stalker et al., 2004)
- Managing ethical considerations, power relations between researcher and participants and empowering children in the research process (Alderson, 1993, 1995; Bricher, 1999, 2000; Morison et al., 2004)
- The importance of the social and physical context of the interviews and the need for privacy (Coyne, 1998; Mauthner, 1997; Miller, 2000; Morison et al., 2004)
- The challenging nature of the research topic for participants and the perceived benefits and threats of the research (Morison et al., 2004)
- The influence of parents or ‘significant adults’ on children’s participation (Morison et al., 2004; Sandbæk, 1999)

At present children and young people’s experience of hospitalisation and hospital settings is underrepresented in research. There are only a small number of participatory studies into children and young people’s experience of hospitalisation, and an even smaller number into children and young people’s experience of hospital environments. The picture that is created by the research that exists is incomplete. There is a need for a more holistic picture of children and young people’s experience of hospitalisation and of hospital environments from their own perspectives.

### **Participatory Research in Environment-Behaviour Research**

In contrast to the small amount of participatory research with children in healthcare contexts, there is a large body of work of participatory research with children and young people in environment-behaviour research.

In this field, participatory research is used to enrich our understanding of children and young people’s experience, and it is used to advocate for children and young people’s involvement in design and planning processes (Francis & Lorenzo, 2002; Hart, 1997). Hart (1997) advocates that participatory processes in research and design and planning

give children and young people a hands-on understanding of the issues in environmental management which may be a more effective way of learning about them. They also give researchers, designers and planners the opportunity to gain insight into the needs from children's environments, from children themselves.

There are many examples of participatory research and design projects with children and young people in environment-behaviour research. Outdoor and neighbourhood settings are the environments most frequently in focus, in particular as part of place preferences studies (Korpela, 1992; Korpela et al., 2001; Korpela et al., 2002) and neighbourhood use studies (Burke, 2005; Chawla, 1991; Clarke & Uzzell, 2002; Hart, 1979; Malone, 1999; Moore, 1986; Rissotto & Tonucci, 2002). A more recent area of participatory research reflects the new emphasis on creating child-friendly cities and the change in attitudes towards children's participation. These changes have inspired an increase in studies into participatory planning with children and young people (Horelli, 1998; Horelli & Kaaja, 2002; Sutton & Kemp, 2002; Tonucci & Rissotto, 2001).

Participatory projects completed with children and young people in indoor environments however, are far fewer in number. School settings are a common environment for these projects (Baldassari, Lehman & Wolfe, 1987; Bernardi & Kowaltowski, 2006; Killeen, Evans & Danko, 2003; Moore & Wong, 1997). In relation to healthcare settings, there is only a small body of participatory research that is focused on children and young peoples' response to healthcare settings, which identifies the significant attributes of the physical environment for designers in this context (Blumberg & Devlin, 2006; de Vos, 2006; Rivlin & Wolfe, 1985; Sherman et al., 2005b; Whitehouse et al., 2001).

**Hart's ladder of children's participation.** One of the most well known models of participation is Hart's (1997) *ladder of children's participation*. It offers a typology of both non-participation and participation that may be embodied in projects with children. Each rung on the ladder reflects a dominant characteristic of either a participatory or a non-participatory approach with the 'degrees of participation' increasing as the ladder is climbed. The strength of this model is that it is an applicable and relevant tool for many different kinds of organisations to use as a base from which to conceptualise and

consider children's participation. It is used in many different types of contexts including research, policy development and design practice.

However, the use of the image of a ladder is problematic. It implies that the ultimate aim for a participatory project is to operate at the highest rung. The ladder implies that participation is a hierarchy of characteristics that moves toward an ultimate type of children's participation. It also implies that participation is a linear spectrum which can indicate whether a project is better or worse, or more or less participatory. All of these implications are problematic. Hart (1997) tries to undermine the implications of the ladder image by identifying that it should not be the ambition of every project to aim for participation as it is described for the highest rung. He states that it is quite possible for a sound participatory project to use different approaches to participation at different stages of the project, because it is appropriate.

The model itself is arguably not as useful as Hart's (1997) surrounding discussion in which he identifies some fundamental principles of participation. These include the importance of providing individual choice, the need to consider how to represent children's input, and the need for structures and processes that support children's capacity to participate. Understanding children's participation as a series of principles of practice which need to address issues of respect, agency, power, access, and information (Alderson, 2000, 2005; Kellett, 2004, 2005) is preferable to understanding participation as a hierarchical or linear spectrum of children's involvement.

The previous three chapters have identified the theoretical orientation, and the key conceptual and methodological considerations for the study. The following section will explore the methodology and methods used in the study in detail.

## **PART B: METHODS**

### **CHAPTER 5**

#### **OVERALL RESEARCH DESIGN AND METHODS**

In Chapter 5 the questions for the research are stated, and the methodology of the research is described. The specific considerations for completing qualitative research with children and young people, the Hospital context, and a summary of the study outline and rationale are also described and discussed.

#### **Research Questions**

**Question 1: What is the experience of children and young people of the sociophysical environment of a paediatric hospital?** In response to the literature reviewed in Part A, the voices of children and young people are largely missing in the evidence from healthcare or healthcare design research. At present, we have an incomplete notion of what is involved in children and young people's experience of a paediatric setting. The first research question has been developed in direct response to the need for a more holistic understanding of children and young people's experience of a paediatric hospital environment from the patients' perspective.

**Question 2: Is there a relationship between children and young people's feeling of well-being, and their interaction with the physical environment of the hospital?** This question seeks to address another gap identified in research. Most of the parameters for the physical environment that are understood to influence patients' feeling of well-being in hospital have been the result of research with adults. In answering the first question, it should become evident which domains in children's experience are influential in their feeling of well-being in this setting. Within this experience, the aim is to identify the role(s) of the physical environment in particular in children's experience.

#### **Overall Research Methodology**

The methodology that was used in this study was qualitative. Qualitative research has the capacity to tap into the richness of human experience, normally the province of individuals, and bring it into the public domain. Evidence from qualitative research

allows individual experience to contribute to knowledge in a way that exceeds the capacity of most individuals. This is particularly true for children and young people. Qualitative research offers children and young people a potentially sympathetic opportunity for them to contribute to the world in which they live.

One of the key strengths of qualitative research is its capacity to anticipate the complexity of peoples' lives and accept and acknowledge the multiple contextual influences that will be shaping their experience. This is no less the case for children and young people. There are strengths in using this methodology which make it particularly appropriate for research with children and young people and these are outlined below.

**Qualitative research with children and young people.** With the development of the participatory research movement, a new body of research has emerged which is mostly qualitative and focused on understanding the specificity of children's experience in particular contexts (Christensen & James, 2000; Fraser et al., 2004; Greene & Hogan, 2005; Lewis & Lindsay, 2000; Mayall, 1994; Qvortrup, 2000). Through the experience of this body of research, the strengths of using a qualitative approach in research with children and young people have been revealed. A few of these key characteristics include:

*Direct insight:* The advantage of qualitative methods and methodologies, in the words of Prout and James (1997), are that they allow children "a more direct voice and participation in the production of sociological data than is usually possible through experimental or survey styles of research" (p. 8). Qualitative research offers children and young people an opportunity for them to give direct accounts of their experience.

*Reveals competence:* As Alderson (2000) states, "most research measures children" (p. 82). In reports that reduce children's information to numbers, standardised questions and tests, children often look less competent than when researchers have the capacity to be more flexible and interact more naturally with children and young people (Alderson, 2000). She refers to Dunn's (1995) comment that young children's logical capacities in conversation are considerably greater than those reported in test situations. Qualitative techniques reveal the competence of children and young people as critics and commentators on their own lives.

*Flexibility and adaptability:* Using qualitative research techniques it is possible to explore individual circumstances in depth and pay attention to idiosyncrasies and diversity. Qualitative research techniques are flexible, adaptable and various, so the range of children's experience can be explored, accommodating the differences in interests and abilities that exist between children and young people (Alderson, 2000; Fraser et al., 2004; Lewis et al., 2004; Mayall, 1994, 2002).

*Reflexivity:* Whilst this is not only a qualitative technique, the capacity for reflexivity in qualitative research is a cornerstone in children's research. Both the researcher and the participants can respond directly to the data and the process of research as it proceeds, allowing it to influence subsequent steps within the research as it progresses (Christensen & James, 2000; Miles & Huberman, 1994; Yin, 2003). This ensures that the research is tailored to the needs and abilities of the participants as closely as possible.

*Grounded interpretation:* Traditional data collection, analysis and trustworthiness techniques used in qualitative research increase the chances of being able to offer an informed perspective on children's experience. This is not a claim to being able to present an insiders view of children's experience, as this is not possible as an adult researcher (Mayall, 1994, 2000, 2002). Instead, it reflects one of the key measures of authenticity in qualitative research, which is the researcher's ability to reveal an in-depth and sound understanding of the subject of the research and its context (Lincoln & Guba, 1985; Miles & Huberman, 1994; Stake, 1995; Yin, 2003).

**Selecting case study as a research design: Strengths, limitations and responses.**

Case study was used as the research design. Case study research is often discussed as "an exploration of a bounded system or a case" (Creswell, 1998, p. 61). Most commentators identify case study research as an appropriate choice when the case for study is distinct, and when the contextual considerations are pertinent to understanding the case. Yin (2003) argues that case study should be selected when the researcher is interested in "a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (p. 13). He argues that case study should be used when the researcher deliberately wants to address the contextual conditions believing that they might be highly pertinent to the

phenomenon of study. Stake (1995), discusses the case as a bounded system, consisting of working parts and definable boundaries. The focus of case study for Stake (1995) is in “learning all of the case out to its boundaries, tracking its issues, pursuing its patterns of complexity” (p. 2) for the purpose of establishing its uniqueness as well as its commonalities with other situations. Creswell (1998) describes a case as a bounded system, where the case is studied in its social, physical, economic or historical context, and bounded by time and place, because this is essential to understanding the case. Miles and Huberman (1994) describe a case as “a phenomenon of some sort occurring in a bounded context” (p. 25). For them it consists of a heart or focus and a “somewhat indeterminate boundary” (p. 25), which defines what will not be studied.

In relation to the current study, the bounded system of a single hospital environment is necessarily a distinct and definable case. It is bound by place, time, organisational, physical and social characteristics, the description of which is necessarily unique. Children’s experience of this healthcare environment will also be unique to that environment. In understanding this experience, it is not possible to separate children’s experience from the context of the hospital environment. A comprehensive understanding can only be achieved if attention is given to both. These characteristics identify case study as an appropriate choice for the research design.

A single case study can provide a rich collection of information that gives great insight into the particular situation being studied (Creswell, 1998). The key strengths of case study research include being able to focus on a single situation in detail, being able to be sensitive to the specific nature of that context and its particularities, and being able to explore the focus of the study in depth and in context.

In identifying the principal strengths, the main limitation is also revealed. The characteristics, which help to identify the case, make it difficult to generalise the findings from single case study research (Lincoln & Guba, 1985; Miles & Huberman, 1994; Yin, 2003). Invariably small samples are used in case study research, which negates the possibility of generalising findings across populations. However, it may be possible to generalise theoretical propositions to other contexts (Yin, 2003). In discussing this potential limitation, Stake (1995) states:

The real business of case study is particularization, not generalization. We take a particular case and come to know it well, not primarily as to how it is different from others but what it is, what it does. There is an emphasis on uniqueness, and that implies knowledge of others that the case is different from, but the first emphasis is on understanding the case itself. (p. 8)

This statement also suggests another potential weakness of case study research: that it may have no capacity to contribute to a larger debate. Findings may be completely unpredictable, they may have minimal obvious benefit, or the case may be so obscure that it can only reveal information about itself. Many of these situations can be avoided by the selection of the case to be studied, by clearly defining the case, and by using a well-considered, well-structured research design, which considers the potential of the research to contribute at the outset.

In this study, the research design was guided by Yin's (1994, 2003) approach. For Yin, case study research is a research strategy equally applicable to qualitative or quantitative research. Structure is emphasised for its role in eliminating potential points of breakdown or loss of methodological strength. Yin's (2003) structured approach to case study research enables researchers to understand how to develop a credible chain of evidence between the research questions and the conclusions. It is an all-encompassing method which includes the logic of design, data collection techniques and data analysis.

The real benefit of a structured research design in qualitative research is that it helps the researcher remain aware of the modifications he or she is introducing as the process progresses because it provides a framework that can be used to assess change.

**The typology of the case study.** Yin (1994, 2003) identifies five different applications of case study. Two are relevant for this study. The first relevant application is to describe a real-life situation, and the second, is to explore a situation in which more is revealed about the nature of this situation and the relationships within it.

Answering the first research question required developing a comprehensive description of children and young people's experience of the hospital environment. Answering the

second research question required exploring the role of the physical environment within patients' experience in particular.

In the final instance, the typology of this case study could be defined as a single, qualitative case study, which has both a descriptive and an exploratory application (Yin, 1994, 2003).

**The specific case for study.** In drawing on Miles and Huberman's (1994) terminology, the *focus* of this study is on understanding the experience of longer-term patients of a paediatric hospital environment. The context or *boundaries* of the case include time, and the physical, social and organisational characteristics of The Children's Hospital at Westmead<sup>2</sup>.

### **The Children's Hospital at Westmead: Setting and Population**

**The setting and its history.** The Children's Hospital at Westmead was selected as the site for this study because it represents a modern, purpose-built, paediatric hospital. It is designed to cater for the needs of sick children and their families. Children are admitted to this hospital from all over the state of NSW, other parts of Australia and from overseas. It is a 310-bed hospital and functions as a teaching and research hospital for the University of Sydney and the University of Western Sydney (The Children's Hospital at Westmead, 2003).

Originally, the hospital was established in Glebe, a suburb of Sydney, in 1880 as the Sydney Hospital for Sick Children. It became the Royal Alexandra Hospital for Children in 1904 and in 1906, it was moved to Camperdown (another suburb of Sydney) where it remained for the next 89 years (The Children's Hospital at Westmead, 2006).

The new hospital (the site for this study) was opened in 1995. It consists of a cluster of low-rise buildings situated on an 11.2 hectare site area with 78,500 square meters of

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<sup>2</sup> One examiner questioned why staff, parents and other key players were not interviewed in the research as part of the detailed description of the case. This is because 'the case' defined for this research is: understanding the experience of longer-term patients of the Children's Hospital at Westmead. It is not on the Hospital itself, nor does it encompass the understanding of patients' experience by the communities of people that surround children and young people in hospital.

building area and over 35 gardens and courtyards, 17 wards and more than 3750 rooms, housed within eight linked buildings (The Children’s Hospital at Westmead 2003, 2006). Figure 5.1 shows the front entrance of The Children’s Hospital at Westmead.

The design of the current hospital was overseen by the NSW Public Works Department. It involved NSW State Projects, in association with three architectural firms including: Lawrence Nield and Partners Australia (now called Bligh Voller Nield), McConnell, Smith & Johnson, and Woods Bagot. Each group designed different sections of the hospital. Figure 5.2 shows which sections of the hospital were designed by which architectural firms. Figures 5.3 to 5.6 depict floor plans of the four levels of the Hospital.



Figure 5.1. Front entrance of The Children’s Hospital at Westmead.<sup>3</sup>

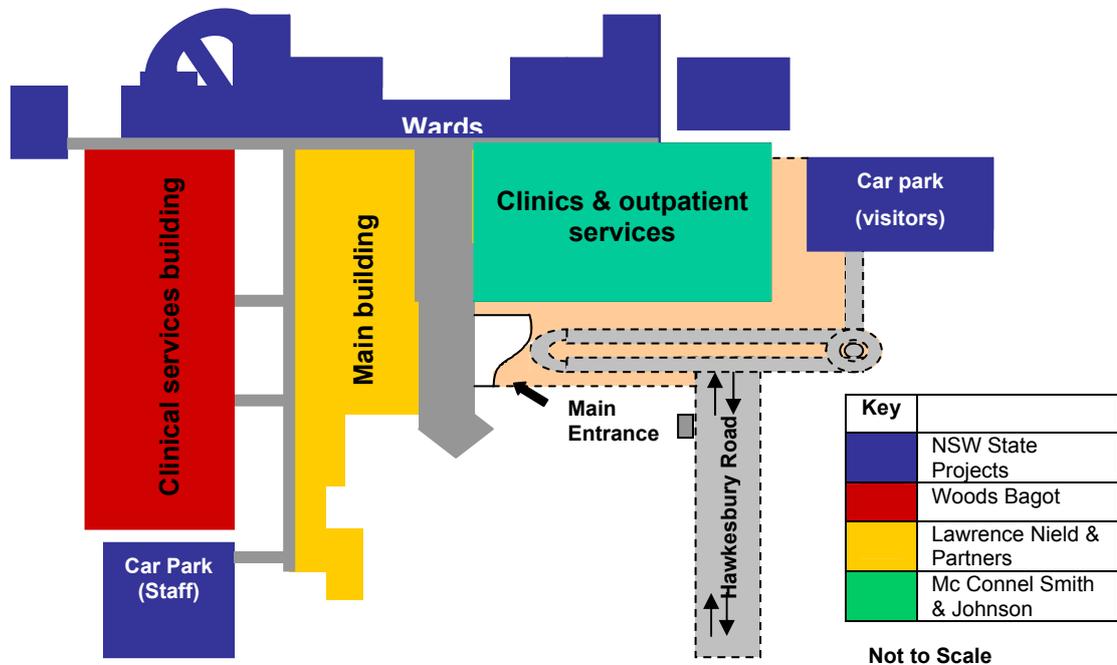


Figure 5.2. Plan of the sections of the Hospital completed by each group of architects.

<sup>3</sup> Photograph courtesy of The Children’s Hospital at Westmead.



Not to scale

Figure 5.3. Plan of Level 1, The Children's Hospital at Westmead.<sup>4</sup>

Figure 5.3 depicts Level 1, which is the building services level. It contains the maintenance areas and catering and food facilities for the hospital community, staff and patients. It also has ward areas for adolescents and babies, and provides access to the Children's Garden and the Chinese Garden. The Book Bunker and two of the schoolrooms are also on this level.

<sup>4</sup> Plans of the Children's Hospital at Westmead courtesy of the Maintenance Department at the Children's Hospital at Westmead

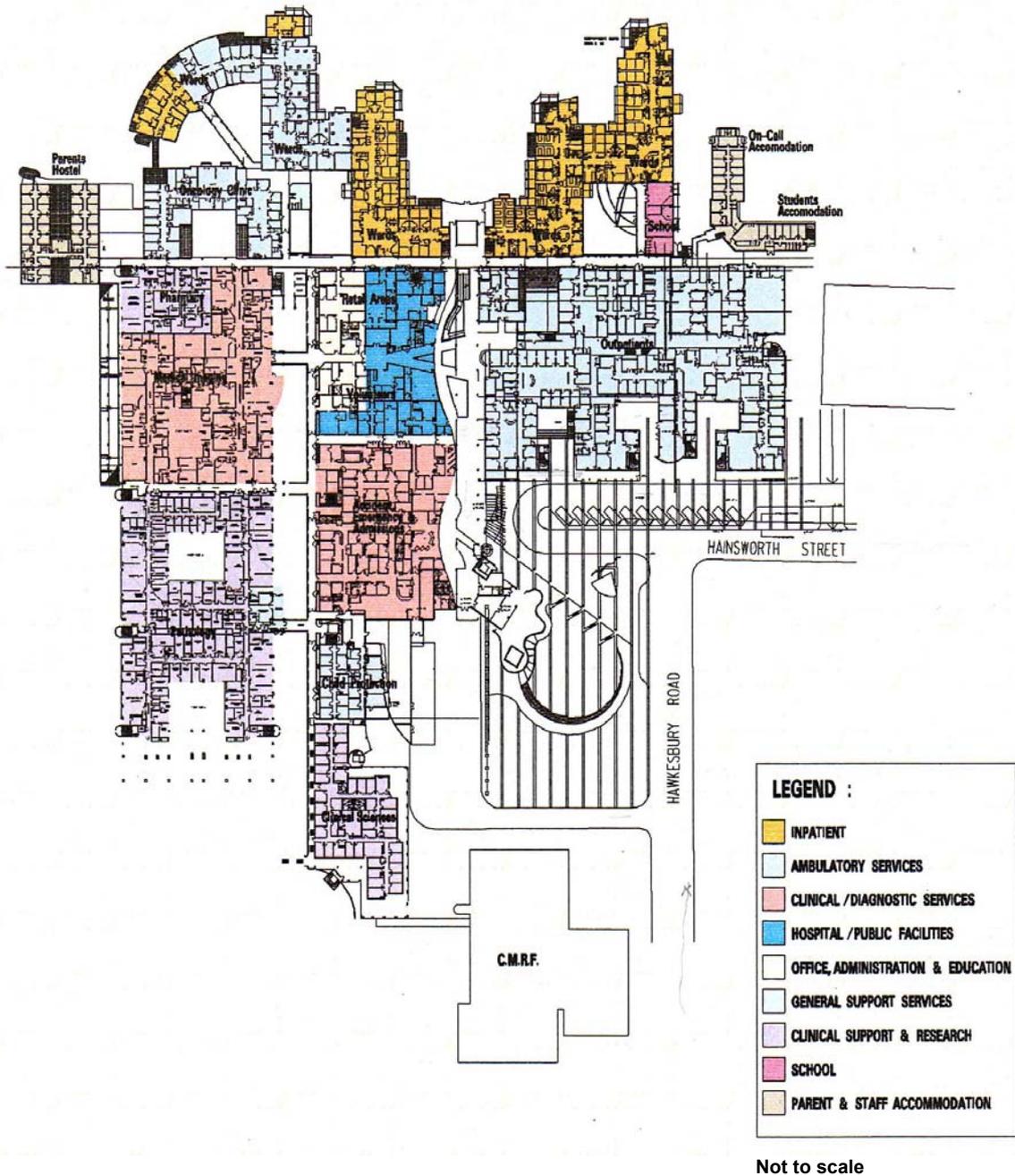
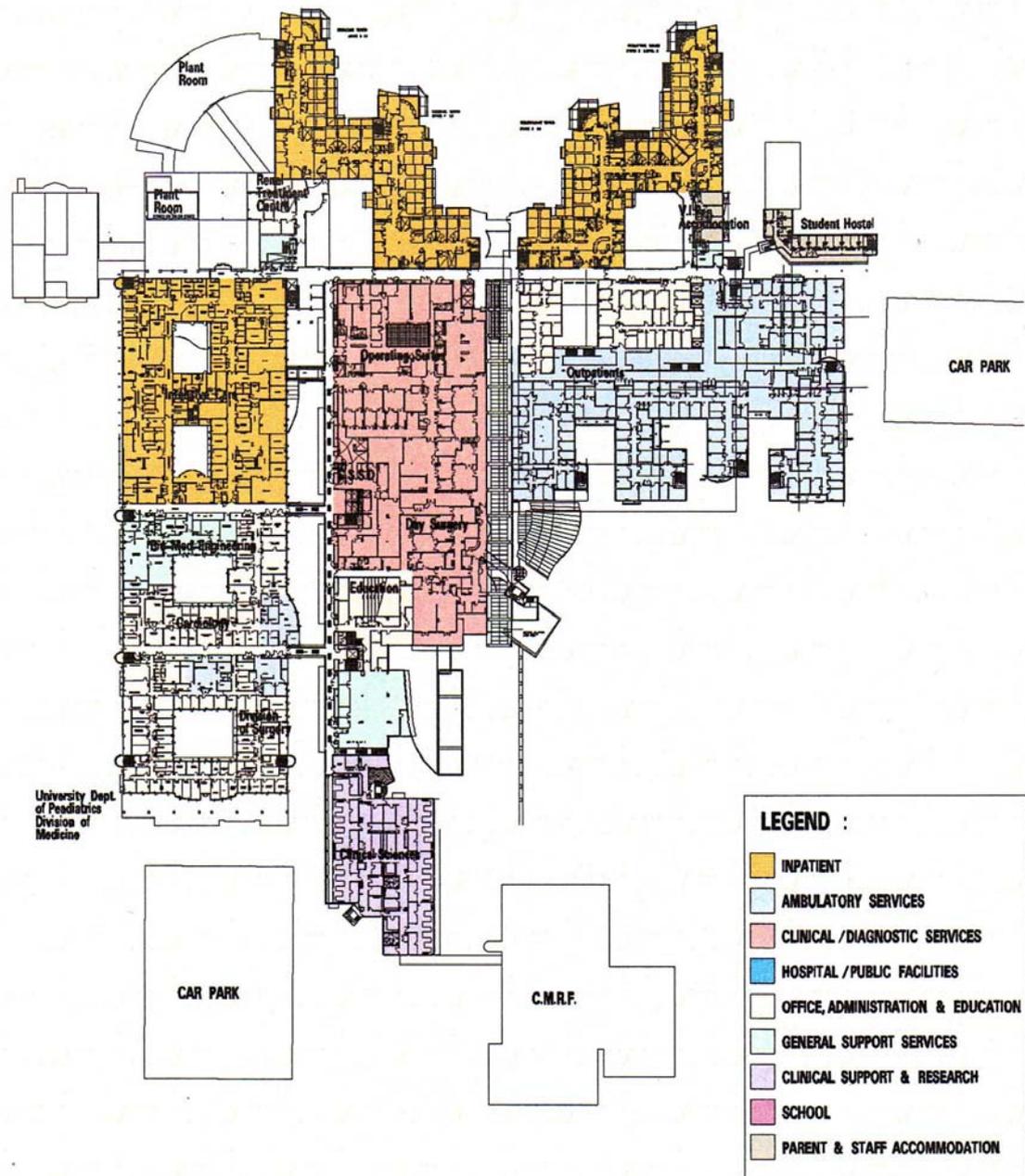


Figure 5.4. Plan of Level 2, The Children's Hospital at Westmead.

Figure 5.4 depicts Level 2, which is the entrance level. There is a single main entrance to the hospital, from Hawkesbury Road. This level contains the emergency department, the outpatients' clinics, other clinical and diagnostic services, general ward areas, shops, the Bear Café and the Starlight Express Room.



Not to Scale

Figure 5.5. Plan of Level 3, The Children's Hospital at Westmead.

Figure 5.5 depicts Level 3, which contains general ward areas and one of the three schoolrooms. On this level also are diagnostic and clinical services, research facilities, administration facilities, the hospital library, and parent and staff accommodation.

Figure 5.6 depicts Level 4, which is where most of the offices and administration and education facilities are located.

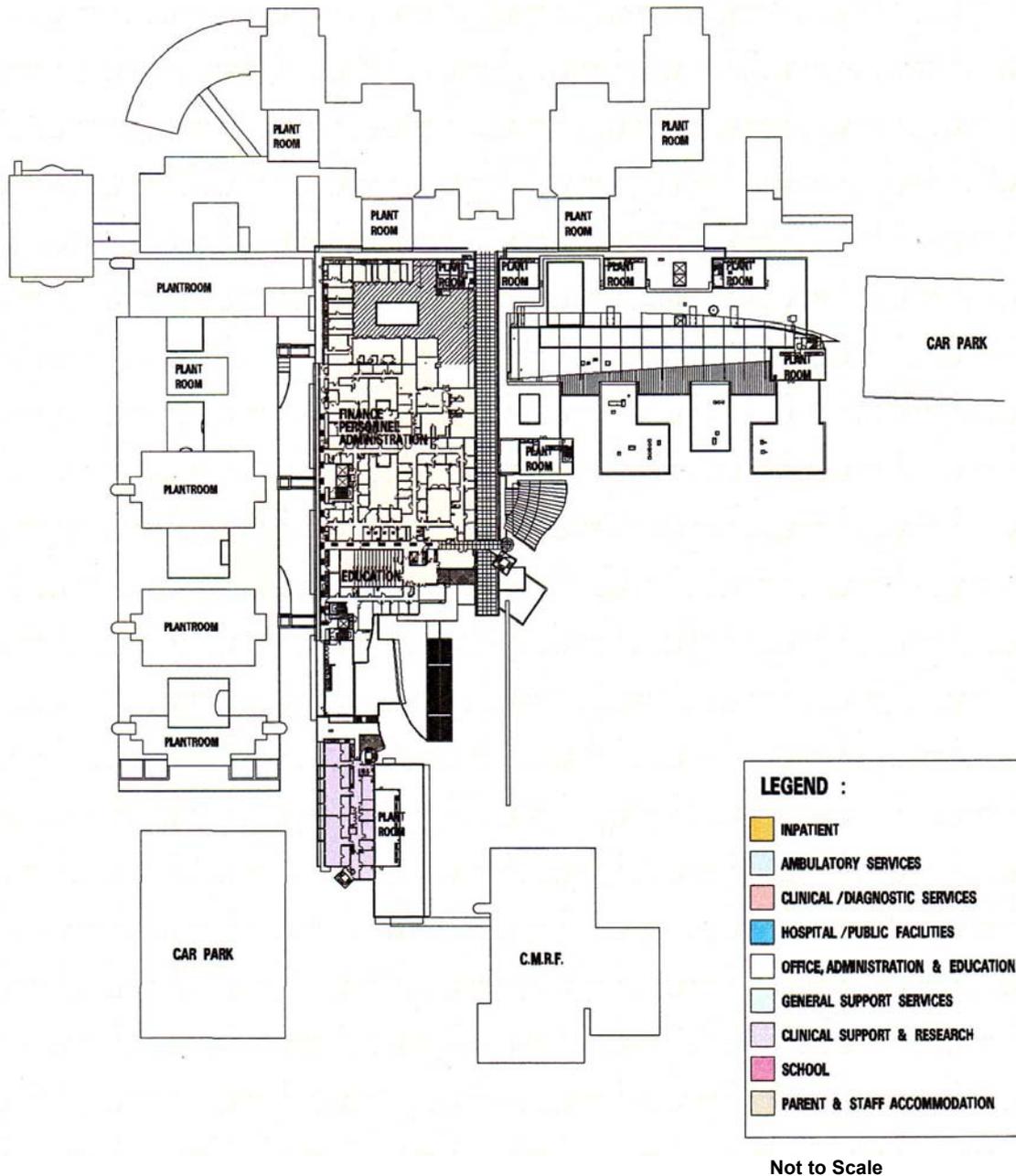


Figure 5.6. Plan of Level 4, Children's Hospital at Westmead.

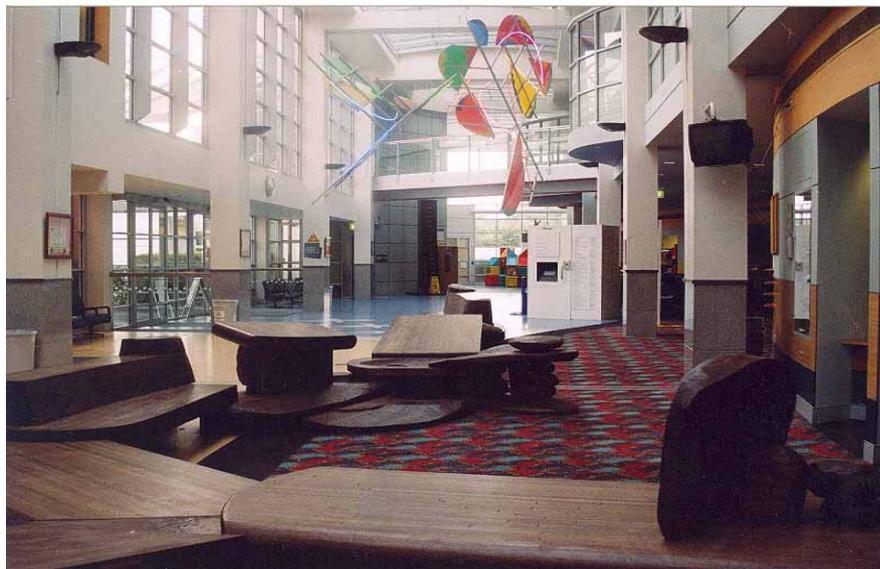
Figures 5.7 to 5.14 consist of photographs of the Hospital environment. They include the entrance areas, main recreational areas and a few examples of the types of areas most patients would experience. Additional photographs showing more detail of additional areas are included in chapter 7.

Figure 5.7 depicts the Hospital entrance. There is a single entrance on Level 2, through which most children arrive, except if they come to the Hospital by ambulance. Patients

appreciate the unconventional awning over the entrance and the sculptures in the forecourt.



*Figure 5.7.* The main entrance looking toward the Hospital from Hawkesbury Road.<sup>5</sup>



*Figure 5.8.* Front foyer area.<sup>6</sup>

Figure 5.8 shows the front foyer through which most children pass as they are admitted to hospital. This is a bustling area with a coffee cart, shops, emergency department, outpatient clinics, and large pieces of sculpture. Figure 5.9 shows the bank of shops and seating in the front foyer.

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<sup>5</sup> Photograph courtesy of The Children's Hospital at Westmead

<sup>6</sup> The Hospital stipulated that all photographs taken by the researcher in the Hospital environment as part of this study could not include people.



*Figure 5.9.* Shops and seating in the front foyer.



*Figure 5.10.* Wards overlooking the Children's Garden.

Figure 5.10 depicts the northern side of the Hospital that overlooks the Children's Garden. This section of the building contains many of the wards, all of which have big windows and outdoor views of the gardens. The Children's Garden is frequently used by patients and their friends and families.

Figure 5.11 shows a typical corridor in the ward area. Most of the corridors are lined with artwork and broken by shafts of light. Figure 5.12 shows a typical nurses' station.



*Figure 5.11. A typical ward area corridor.*



*Figure 5.12. A nurses' station.*

Figures 5.13 and 5.14 show the main hospital cafeteria (The Bear Bite Eatery). This is a facility on Level 1 of the Hospital, which is used by most patients and their families at some point during their visit.



Figure 5.13. Seating area of Bear Bite Eatery, photographed from above.

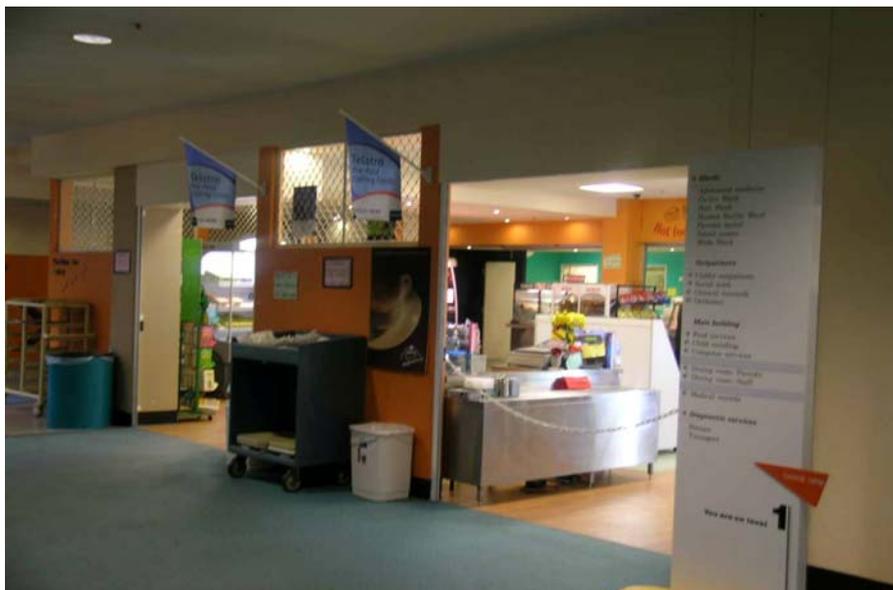


Figure 5.14. Bear Bite Eatery on Level 1.

**Population.** The children and young people admitted to The Children's Hospital at Westmead are predominantly aged between newborn and 17 years old. They come from a diverse range of cultural and socioeconomic backgrounds. Young people aged 18 and 19 years are also admitted to this hospital but usually only if they have a history of admissions before this age.

In 2005, 26,874 children were admitted to the Hospital. The average length of hospital stay in 2005 was three days.<sup>7</sup>

There are also approximately 3000 staff working at the Hospital including approximately 400 doctors and 600 nurses (The Children's Hospital at Westmead, 2006).

### The Overall Study Outline: Research Plan and Rationale

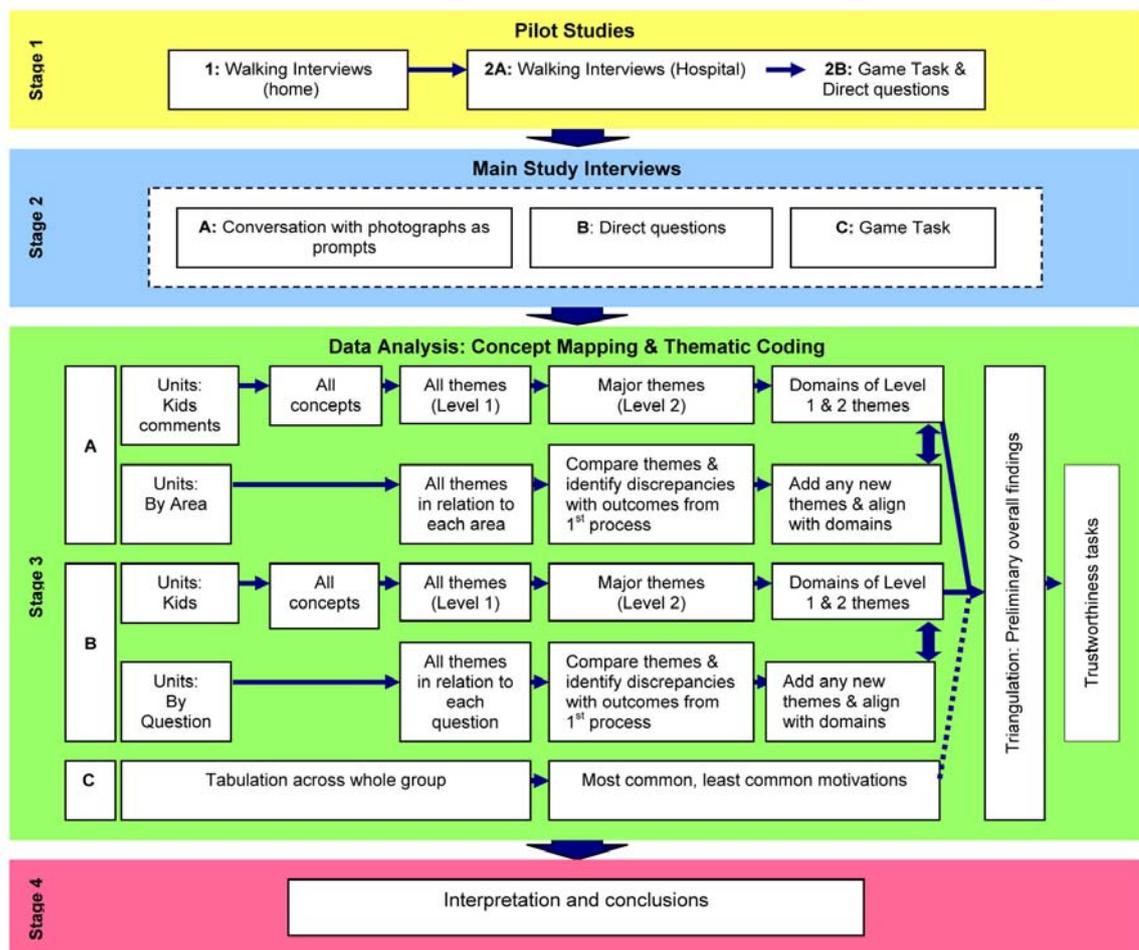


Figure 5.15. Overall plan for the research.

**Outline.** The research consisted of four stages. The first stage included two pilot studies designed to develop and refine the research tools and methods to be used in the main study. The second stage included the data collection phase of the main study. The third

<sup>7</sup> Statistics on admissions provided by the Management Support and Analysis Unit, The Children's Hospital at Westmead

stage involved data analysis of the main study data. Findings from this process were triangulated, preliminary findings were reached and a member-checking task was carried out. The final stage included finalising the interpretation and drawing conclusions. Figure 5.15 shows the overall plan for the research.

**Overview and rationale.** This study was designed to allow the experience of each stage to inform the following stages. The first stage involved two pilot studies, with the second pilot study consisting of two parts.

The pilot studies in this project were each designed to do some of the following:

- address specific areas of concern for the main study (such as the potential scope and depth of interviews)
- contribute to the development of particular research methods and tools
- identify appropriate concepts, complexity and approaches to the main subject areas of the study with the age-range of participants that may be involved

**Stage 1: Pilot Study 1.** The first pilot concerned the need to identify and use appropriate concepts, complexity and approaches to the main subject areas of the study with the age-range of participants that may be involved. Using age-appropriate and respectful language is acknowledged as being instrumental in eliciting quality data from children (Deatrick & Faux, 1991; Faux, Walsh & Deatrick, 1988; Guba & Lincoln, 1981; Mauthner, 1997). This is a consideration for all research with children and young people. In this instance, the particular focus was on understanding the most useful ways to approach talking about the physical environment, and to see whether the approach needed to vary with changes in age, and possibly gender.

Environment-behaviour research with children and young people has been very successful when talking with children and young people in a familiar environment (Hart, 1979; Korpela et al., 2002; Moore, 1990) This pilot study was conducted with children and young people in their home environments. In choosing participants' home environment, it was hoped that their comfort and familiarity with this environment, and the family relationships within it, would lead to more in-depth responses and more conceptual complexity than participants might give in an environment where they experienced little or no attachment to people or place.

Walking interviews were used where children and young people took the researcher on tours of their home environment, talking about what they did in each area and how they responded to each type of environment. This idea grew in part from Robin Moore's (1990) research in the UK in which he asked children to take him on field trips. Moore realised that an enormous amount of information concerning how children engage with their outdoor environments, use them, respond to them, and exist within them could be gained from observing the children in action. He gained additional insight and information from non-verbal language and behaviour that would not have been discovered through an interview. This was also true in this instance. Participants were able to give much greater insight into their activities and preferences by showing the researcher than would have been possible through explanation.

Furth's (1980) work provided the background for approaching the analysis of the conceptual content of participants' conversation in the first pilot study. He identified ways of understanding children's conversation and its meaning. He stated that to make sense of what children say is to interpret, and he offered two ways of "ensuring adequacy of interpretation" (p. 20). Firstly, to assume that what children say makes sense and, secondly, to be sensitive to what he described as children's mental framework. He suggested three frameworks that children may be using:

- Spontaneous expressions of previously articulated connections
- Elicited comments made in response to the interviewer's prompting in which children may reason things out for the first time but it is according to their habitual mode of thinking.
- Comments that he calls developmental experiences that occur during the course of an interview where children spontaneously consider things in a new light and in doing so go beyond their habitual mode of thinking.

Furth's (1980) work presented a way of remaining mindful of the conceptual components of the conversation in the analysis process. It was interpreted in this study as a way of assessing the degree of sophistication in participants' responses and as a way of illustrating their comprehension of the exercise.

**Stage 1: Pilot Study 2, part A.** The second pilot study consisted of two parts (2A and 2B). Both were completed at the Hospital. Part A of the pilot study consisted of walks

through the Hospital environment, which were used to identify the areas of the Hospital that should be included in the main study. These walks ensured that the areas used and valued by children in the Hospital were the basis for the discussions in the main study. This step removed the assumptions that the researcher would have to make about which sections of the environment were used or valued by children and young people.

On these environment walks, participants were also asked to take photographs that were used as the basis of a set used as prompts for conversation in the main study interview. The inspiration for this task came from Morrow's (2001) study on the use of neighbourhoods by Year 10 students. The students were given disposable cameras and asked to take about six pictures of "places that are important to them" (p. 258). In the current study, the participants were simply asked to photograph the areas that were visited on the walks. A risk of relying on this task to establish the physical environment for discussion was that every kind of area in the Hospital may not have been included.

**Stage 1: Pilot Study 2, part B.** Part B of the second pilot study was used to trial the set of direct questions that were to be used in the second task of the main study interview and to also to refine the third interview task, the game task. The detail of these research instruments was developed from the findings from Pilot Study 2A. During these walking interviews, participants identified the areas of the Hospital outside of their wards that they most regularly visited, and the most common motivations for visiting them. This information was used to form the basis of a game task, which was refined through Pilot Study 2B. The set of direct questions was guided by the literature initially and the findings from Pilot Study 2A. Pilot Study 2B was used to modify the detail of those questions, and their running order.

All research instruments used in the main study were generated in large part from the findings of the pilot studies and from the experience of working with children and young people during these. This process reflected the participatory nature of this research, and ensured that the research instruments were closely aligned with the interests and capabilities of participants, and that their content and tasks were meaningful to them. In both stages 1 and 2 of the study, 'the semi-structured interview' was the central technique used with participants to enable them to give information on a subject. As Partington (2001) argues the advantage of semi-structured interviews is that

they “enable us to gain explanations and information on material that is not directly accessible: perceptions, attitudes, and values, matters which are difficult to obtain by alternative methods” (p. 1). This technique also enables the interviewer to influence the information gained from participants but at the same time remain open to following new leads as they arise during the interview.

**Stage 2: Main study fieldwork.** Within the main study interviews, participants were asked to complete three tasks (tasks A, B, and C). Having a range of varied research tools and techniques with children and young people is regularly recommended in research (Graue & Walsh, 1998; James & Christensen, 2000; Lindsay & Lewis, 2000; Morrow, 2001). Using both directed and non-directed techniques allowed a greater scope for children to express themselves. It also ensured that there was sufficient data on children’s experience to enable a full discussion in relation to the research questions, and increased the potential for each task to contribute different information pertinent to the study.

Task A was an informal, non-directed discussion revolving around the set of photographs created in Pilot Study 2A. Using a visual image to prompt response in research with children and young people has been recommended in research with children of all ages (Backett & Alexander, 1991; Dockett & Perry, 2003; Fasoli, 2003; France, Bendelow & Williams, 2000; Morrow, 2001). This task was used as a rapport-building exercise to begin the interview in a relaxed way. The photographs represented a way of locating the discussion on the Hospital environment without restricting it to this and without predetermining how children and young people should respond. Task A allowed participants to sculpt the conversation and the themes, subjects and priorities within it more readily than the other tasks in the interview.

Task B involved answering a series of directed questions that spanned the domains of participants’ experience of the Hospital. Docherty and Sandelowski (1999) recommend that direct and structured questioning is the most useful way of acquiring information from children. The questions were originally developed from the literature. Stokols’ (1992) social ecological model for health promotion indicated the domains that may be involved in patient well-being. Healthcare design research and research into patients’ experience of hospitalisation provided the specific dimensions within those domains

that could be the subject of questions. These questions were then refined through Pilot Studies 2A and 2B.

Task C was another directed task, a game task. The third task was designed to be quick and fun to complete, as well as being able to provide data that was complementary to the first two tasks. It could also function as an internal consistency check within each interview. The task consisted of linking six places within the environment with nine possible reasons for visiting them.

**Stage 3: Main study data analysis.** Tasks A and B of the interview were analysed for content and theme using two different breakdowns. The first breakdown to be used in each instance is described in the study as the *Hybrid Process*. This process combined techniques from both concept mapping, which included identifying units of meaning or concepts within the data (Jackson & Trochim, 2002) and thematic analysis, which involved identifying the major and minor themes within the concepts (Lincoln & Guba, 1985; Miles & Huberman, 1994; Ryan & Bernard, 2003; Strauss & Corbin, 1990; Weller & Romney, 1988). The Hybrid Process represents a process of direct interpretation where single instances can be recognised in a process where data are pulled apart and put together again in ways that are more meaningful (Stake, 1995). The strengths of the Hybrid Process are that it does not impose a prior way of knowing on the data (a preconceived coding framework) and it does not rely on a researcher-driven classification scheme and allows the researcher to attend to all the data. The child-centered approach being used in this study made the researcher uncomfortable with imposing a researcher-driven coding framework on the data, and led to the development of the Hybrid Process.

Many commentators on thematic analysis advocate using a process of continuous systematic winnowing in which focal issues are identified early and pursued through selective analysis techniques (Creswell, 1998; Lincoln & Guba, 1985; Miles & Huberman, 1994; Stake, 1995). Part of what Ryan and Bernard (2003) call classic content analysis in most cases is the recommendation for developing a pre-conceived set of focal issues, codes, or a classification scheme. This consistent recommendation is motivated in large part by practical considerations. Case studies can produce massive amounts of data and as Stake (1995) says full analysis is not possible in most

timeframes, and there is no requirement that all data should be given equal attention in any case. In this study, it was quite possible to attend to all data and the researcher felt that in doing so it would improve the integrity of the findings and help to reduce the introduction of researcher bias<sup>8</sup>.

The second breakdown in both Tasks A and B of the interview was organised around the research instrument that had been used as the basis of each of the interview tasks. Again, this breakdown would involve all data, which would be analysed for theme. For Task A, the second breakdown would be organised around the areas in the photographs. For Task B, the second breakdown would be organised around the direct questions. The resulting units of data were much larger than those created in the Hybrid Process. This gave the researcher the opportunity to recognise additional themes.

The game task, Task C produced results, which could be tabulated. The hierarchy of the results identified the major themes for consideration from this task.

**Stage 4: Main study, conclusions and interpretations.** The major findings from each of the tasks of the interview were then triangulated (Lincoln & Guba, 1985; Yin, 2003). Within the literature, there is debate over whether triangulation is a worthwhile process. However, much of this debate revolves around assumptions about the aim of this process being to provide a more correct position, or, to provide a single truth, or to negate the effect of a defective method (Silverman, 2001). None of these need be the motivation or function of this process. Undergoing the process of methodological triangulation gives the researcher an opportunity to recognise both corroborating evidence and variation in evidence that may exist between different data sets, and to recognise the distortion being introduced by any or all of the research instruments

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<sup>8</sup> One examiner was clearly concerned with the potential of the researcher's personal and professional experience and interests to bias the interpretation of the data. In reality, the researcher's professional interests had the capacity to bias the whole research process. The consistently participatory methodology used enabled children and young people to influence and shape all aspects of the research including the research questions, methods and findings. This served to ground the research in children's experience and perceptions throughout the research process and to undermine the introduction of researcher bias. To minimise the introduction of researcher bias into the data analysis process, the researcher developed a method of analysis for this study (discussed in the thesis as the Hybrid Process) which ensured that all data were addressed and analysed to assist in overriding the potential of bias. Specifically this method did not require that the researcher impose a coding framework onto the data, a common methodological approach in qualitative thematic analysis (Miles & Huberman, 1994; Ryan & Bernard, 2003; Strauss & Corbin, 1990; Weller & Romney, 1988), as this would reflect a preconceived notion of what was important information within the data and would therefore be subject to the researcher's bias.

(Lincoln & Guba, 1985). In this study, it was viewed as part of sound methodological rigour and as an opportunity to increase the trustworthiness of the findings.

Lincoln and Guba (1985) suggested four types of triangulation: sources, methods, investigators and theories. They discount triangulation of theories as being “epistemologically unsound and empirically empty” (p. 307). However, the other three types they support as a way of corroborating findings and minimising distortions and biases. In this study, triangulation of methods was used. A single source of information (participant interviews) was used within which three different tasks were consistently used to create three distinct bodies of data, which were then triangulated to form a single set of findings. Yin (2003) calls this process convergent data triangulation. The preliminary findings that resulted from this process were then discussed with a representative group of patients in a member-checking task, before conclusions were reached.

This process of data triangulation was one of a number of trustworthiness tasks that were used in this study (Lincoln & Guba, 1985; Miles & Huberman, 1994). Trustworthiness in qualitative research includes discussions on truth, validation, reliability and authenticity amongst other powerful concepts (Lincoln & Guba, 1985; Patton, 1990; Silverman, 2001; Stake, 1995; Yin, 2003). In this study, trustworthiness is understood more simply as the capacity to support the researcher’s interpretation of children’s experience<sup>9</sup>.

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<sup>9</sup> One examiner questioned why the researcher was the only person involved in the analysis of the data. The idea of including another person in the data analysis process was discussed for the analysis of this research. The constraints in this instance included:

- The capacity of an outside researcher to be sufficiently immersed in the nature of the case to be able to make an interpretation of data that was comparable in depth to that of the primary researcher. It would be necessary for an outside researcher to have an in-depth understanding of a paediatric healthcare context.
- Involving a second researcher from within the hospital context was also considered. This was discussed with the research partner at the Hospital who felt it was not possible due to the number of hours that would be required to complete the analysis and the lack of funding available for a second researcher to be involved.
- The researcher did involve children and young people in the synthesis of the data in two member-checking tasks. Firstly, in approximately 30% of cases, the researcher returned a summary of the major ideas of participants’ interviews back to participants for further discussion, the day after their interviews. This would have been carried out with all participants but securing visits with participants a second time proved very difficult as their lives in hospital were very unpredictable. Secondly, at the point of preliminary findings, the researcher took the major findings that were emerging from the data to a new group of children for further discussion and clarification of concepts and to test the resonance of the emerging findings with a new group of children before final conclusions were reached. It was not possible to return the findings to the original group of participants as this did not have the Hospital’s approval.

A range of measures was chosen to provide the researcher with many opportunities to make contact with children and young people who represented the key stakeholder group. These included member checks, a reflexive journal, maintaining a consistent chain of evidence, prolonged engagement and persistent observation, and methodological triangulation (Lincoln & Guba, 1985; Yin, 2003). Final interpretations and conclusions were reached following the final member-checking exercise.

In combination, the steps chosen span three of Lincoln and Guba's (1985) four trustworthiness components. These include credibility, dependability and confirmability. Transferability of findings is the fourth. As a single case study, the accepted limitation is that there is almost no likelihood of transferable findings to other populations. There is however, the chance of transferring findings at a conceptual level.

### **Participatory Research with Children and Young People in a Hospital Setting**

**Ethical considerations.** Tisdale (2004) recognises ethical considerations in relation to research at two key points: ahead of the study, which she calls *a priori vulnerability*, and during the study, which is called *posteriori vulnerability*. This presents a useful framework for considering ethics in research with children and young people.

Recognising *a priori vulnerability* amounts to respecting participants' diminished autonomy in any circumstance in advance of the research exercise and estimating what will be the burden of research for participants. It also includes being sensitive to issues of empowerment and representation. Ethical strategies for observing the needs of *a priori vulnerability* with children and young people involve:

- Obtaining informed consent from children and young people as well as their parents
- Maintaining confidentiality
- Choosing physical contexts to conduct research where participants will be comfortable
- Excluding authority figures from interviews
- Not reporting information that would allow a participant to be identified yet being truthful to the account given by the participant

All of these things were anticipated in this study. Informed consent was sought from both participants and their parents. Participants were interviewed without adults present in places of their choosing mostly, depending on availability, and the contents of the interview were kept confidential. All interview transcripts were de-identified and a pseudonym was used which reflected the participant's gender. As findings were developed, they were taken back to participants or representative groups through member-checking tasks for their comments and feedback.

Maintaining confidentiality has to be balanced against researchers' duty of care to respond to situations of harm or abuse that children and young people may report during an interview. At the beginning of each interview, a discussion took place with each participant in which the researcher indicated that if participants talked about an incident where someone had hurt them, or they were in danger of hurting themselves, that it would be necessary to talk with them about getting help. This covered the eventuality of children reporting abuse that they may have experienced which the researcher would be ethically bound to report. In support of this, the researcher participated in child protection training at the Hospital prior to conducting the data collection.

The researcher was also briefed by medical staff as to how to handle a medical emergency should it occur. The counselling unit was notified about this research in the event that participants became traumatised by the interview and needed additional support. The counselling unit also offered support for the researcher.

Posteriori vulnerability considerations are those that occur during the study. In this research, ethical considerations or ethically sensitive situations occurred everyday in the field. These often occurred at points of contact between the researcher and the staff, and with participants and their parents. They often involved issues of priorities and timing. It was important for the researcher to accept from the outset that in all cases everyone else's priorities in this context were more important than the needs of the research. Sensitive situations included:

- Choosing when to enter wards at times when staff were likely to be more receptive and not caught up in their regular routines which obviously had priority

- Choosing when to introduce the study to parents and participants so that it did not add any further pressure or stress to their situation
- Discussing the study so that both parents and participants felt equally empowered in the decision to participate and neither group was alienated, yet making it clear to the participants that it was their choice as to whether they participated or not. (Parents consent was compulsory for all patients at the Hospital so this effectively gave parents the ultimate right of veto over their child's participation which could have been problematic but this was not tested throughout the study)
- Family members 'encouraging' younger children to participate because they thought it was a good study
- Minimising potential conflicts between participants and their parents when parents visited the hospital unexpectedly and participants wanted to continue to do the interview. This particular situation usually occurred with adolescent participants
- Stepping into participants' lives and asking probing questions at a time when they were feeling unwell and vulnerable
- Responding to children who became emotionally distressed during an interview

Each of these situations was negotiated as they occurred. Invariably the challenge lay in ensuring that participants remained empowered in the decisions they wanted to make and that families were not alienated by this. It was also important that the medical staff were not affronted by the research in any way either.

**Obtaining access.** Obtaining access to children and young people in a hospital context has been acknowledged as being difficult (Blumberg & Devlin, 2006; Coyne, 1998). This study was no exception.

In this study, obtaining access to the setting and to participants was a process that began in earnest a year in advance of the submission for ethics approval. It involved establishing partnerships with key people in the hospital who would be involved in the research and finding a research partner from within the hospital staff. Having completed these initial meetings and made these initial contacts, a student agreement was drawn up and signed by both members of the University, the Hospital community and the

researcher. As the study protocol was developed throughout the following eight months, several meetings were held with relevant staff groups to seek advice on the research methods and strategies being selected for the study and their appropriateness. This culminated in an ethics submission, firstly to the Scientific and Ethics Committee of the Children's Hospital at Westmead and then to the Human Ethics Committee of the University of Sydney.

Obtaining access to participants in the Hospital environment was an arduous task. It involved seven layers of permission. The first five of these were only negotiated once. The final two were negotiated constantly throughout the data collection phases in the hospital. In summary, these layers included:

1. Ethics clearance from the Hospital
2. Ethics clearance from the University
3. Permission from the heads of all the medical and surgical departments whose patients were likely to fit the profile of the study. To give this permission, they in-turn had to seek approval from all the consultants involved in each team individually (12 units participated).
4. Security clearance for the researcher by the Hospital. To achieve this the researcher had to provide: written permission from departmental heads giving permission for this research to be conducted with their patients; a written letter of recommendation from the main supervising research department; passport; certified copies of educational qualifications; written evidence of ethics approval from both the University and the Hospital ethics committees; and a completed criminal record check.
5. Contacting all the Nursing Unit Managers on relevant wards and briefing many groups of nursing staff
6. Weekly ward rounds and consultations with nursing Team Leaders seeking patients who fit the study profile and then daily returns based on the availability of patients
7. Introducing the study to parents, children and young people following an introduction by a member of the nursing staff

In the final count approximately 10 gatekeepers had been approached in levels six and seven alone for each interview completed. The ethical guidelines of both the University and the Hospital were adhered to in this study.

**Conducting interviews.** According to the literature, a successful qualitative interview with children and young people is dependent on the following:

- A conducive physical context (Burgess, 1988)
- Empowering the perspective of the interviewee – through empathy, respect, rapport-building and non-judgemental listening (Partington, 2001)
- Accepting multiple realities and perspectives (Fine, 1994)
- Minimising the impact of the interviewer on the interview by minimising interruptions, talking too much, avoiding tangential changes in direction within interviews that may be interpreted as the interviewer not listening to the participant, and ensuring participants adequate opportunity to contemplate an answer. Keats (1993) argues that saying little can lead to ‘choice morsels’ of information from participants.
- Practising attentive listening – where questions build on the answers of the previous ones (Partington, 2001)
- Practising restatement, which demonstrates that the interviewer has listened to the answer (Partington, 2001)
- Gentle persistence- finding ways to persevere with a path of questioning without alienating the participant (Partington, 2001)

The researcher was mindful of these guidelines throughout the study. Many of these considerations needed to be anticipated ahead of the interviews and in the format of the interview as it was planned. Others became significant at the point of interview (such as where the interview could be conducted), and others involved the personal techniques used by the researcher which improved with practice.

The extract below from the researcher’s journal is the first in a series used to illustrate some of the methodological and conceptual considerations as they emerged during the course of the study.

**Interviewing**

Whilst question type and subject area are playing a role in the success of my interviews, rapport with the kids is playing a much greater part. I think the key ingredient in a successful interview is simply engaging successfully with the personality of the participant. This is the task that is more fundamental to the success of the interviews than anything else. The challenge for the interviewer is managing this without becoming too much of a presence in the interview.

Journal: (30 November 2004, Bk 5)

**Managing power and generational difference.** Mayall (1994, 2000) argues that power and generational difference are always issues in research with children conducted by adults. Children are used to adults structuring their daily lives and making assumptions about how their lives should be lived. They are used to according adults authority in their lives and this can influence the experience of children's participation in research. The considerations for this research include:

- Recognising children's competence to consent
- Empowering participants in the planning and process of the study
- Managing and minimising the impact of the researcher during interviews
- Understanding the researcher's position as being outside the experience being studied
- Employing strategies that will minimise the researcher's interpretation of events

Some of these considerations regarding how consent, interview procedure, ethical considerations and data interpretation were managed in this study have already been discussed.

The influence of the context itself on all the power relationships experienced is not often discussed. In this case, the participants as patients in a hospital were already in a situation they are unlikely to choose voluntarily. Already their power to influence their situation or to control it was limited and unlike a school context which so far could be described similarly, there was a regular component of fear involved for many participants. The fear of what was going to happen next, of what doctors might tell them, or of the outcomes of their diagnosis, were all induced by the context.

The researcher was not a healthcare professional but was sensitive to the implicit (and explicit) messages of the environment that the healing processes and medical business

of the environment were the most important considerations. She was constantly aware that she had no ability to contribute to this, which also undermined her capacity to feel confident in the context. Clearly, it was not within the power of the researcher or the research process to reduce any of these imbalances in reality. The aim was simply to ensure that the research did not contribute further to children and young people's experience of disempowerment in this context.

## CHAPTER 6

### PILOT STUDIES

In Chapter 6 the methodology of each of the pilot studies is described in detail, including the processes of data analysis. The findings from each study and their relevance to the main study are also discussed.

#### **Pilot Study 1: Walking Interviews - Home Environment**

**Aims and objectives.** The main aim of the first pilot was to expose the researcher to the way children and young people talked about the physical environment.

The specific objectives of Pilot Study 1 included:

- Discovering the variation in conceptual complexity and in subject interest that may exist due to age
- Discovering children and young people's ability to distinguish between and talk about different kinds of environments
- Identifying the kinds of observations about the physical environment that children and young people might make and the level of detail they might notice

**Research design.** Pilot Study 1 was designed as a small qualitative study in which a number of semi-structured interviews were conducted whilst walking with children and young people in and around their home environments.

These interviews were recorded, transcribed and analysed for theme and content (Lincoln & Guba, 1985; Miles & Huberman, 1994), and for the complexity of concepts and the success or failure of questions (Furth, 1980). The findings from this analysis were then assessed for any methodological implications relevant to the main study.

**Research settings.** An outlying suburb of Sydney was chosen, where participants had access to large backyards and large neighbourhoods. It was hoped that this would ensure participants had an extensive response to both indoor and outdoor environments, because they were able to use both regularly.

**Sample.** Fourteen children and young people participated including six girls and eight boys. The aim was to conduct similar numbers of interviews with boys and girls in each of two age groups: 7-12 years and 13-18 years. The age groups reflected those that would be used in the main study. Table 6.1 shows the breakdown by age and gender. Participants were located through a colleague who lived in the area and had contacts with families who had children in the relevant age groups. It was considered essential for this task that the participants speak English fluently, and that they had lived in their current home for a period greater than six months to increase the chance that they had had the opportunity to explore their environment and develop considered responses to it. All participants came from English speaking backgrounds and had lived in their current home for at least a year. Interviews were discontinued when the researcher had sufficient data to address the aims and objectives of the pilot study.

Table 6.1

*Summary of Participants in Pilot Study 1*

	7-12 years	13-18 years	Total
<b>Girls</b>	3	3	6
<b>Boys</b>	4	4	8
<b>Overall total</b>	7	7	14

**Research instruments.** A semi-structured interview was used (Deatrick & Faux, 1989; Faux et al., 1988; Partington, 2001). The questions developed were designed to cover a broad range of areas including: participants' use of their physical environment, their response to it, descriptions of it, how much they considered it, who they used it with and for what purposes, and how they saw themselves in relation to it. Table 6.2 lists the questions developed as a guide for the interviews and the areas that they were notionally covering. A strict schedule of questions was not used in the interviews in this pilot study because both the topic areas and the questions were being developed and refined. Both topic areas and questions were subject to variation based on the experience of the pilot as it progressed.

**Data collection procedure.** Participants and their families were introduced to the study at the same time and given opportunities to ask the researcher questions before each

signed their consent. Consent forms and information sheets were developed for both participants and their parents/guardians (see Appendix A).

The walking interviews were completed across a period of a month in August 2004. The walks lasted between 20-40 minutes. Participants led the researcher around their houses, their gardens, and their immediate neighbourhood areas. An Olympus DS-2200 digital voice recorder was used and a small microphone was clipped to the front of participants' clothing to record his or her commentary.

Table 6.2

*Potential Questions and Topic Areas for Pilot Study 1*

<b>Potential Questions</b>	<b>Areas of Interest to the study, covered by the questions</b>
<p><b>Indoor environment (Home)</b></p> <ul style="list-style-type: none"> <li>• Do you like your house?</li> <li>• Why?</li> <li>• Do you have favourite places?</li> <li>• Where do you spend most of your time?</li> <li>• What do you do there?</li> <li>• How would you describe this place to someone who couldn't see it?</li> <li>• When you come into a new room what things do you notice?</li> </ul>	<ul style="list-style-type: none"> <li>• Preferences for and within environments</li> <li>• Sense of place</li> <li>• Emotional response</li> <li>• Activities /actions carried out</li> <li>• Place descriptions</li> <li>• Attributes of the environment being noticed / environmental perception</li> </ul>
<p><b>Outdoor environment (backyards)</b></p> <ul style="list-style-type: none"> <li>• Why do you come out here?</li> <li>• Where do you go?</li> <li>• What do you do?</li> <li>• What do you like about this place?</li> <li>• How does this place make you feel?</li> <li>• How would you describe it?</li> <li>• Do you have places where you like to go by yourself and others where you like to take friends?</li> <li>• When you come out here what do you notice?</li> </ul>	<ul style="list-style-type: none"> <li>• Motivations for being in environment</li> <li>• Environmental use</li> <li>• Activities/actions</li> <li>• Preferences</li> <li>• Emotional response</li> <li>• Place descriptions</li> <li>• Sense of place/ self regulation / environmental use</li> <li>• Attributes of the environment being noticed / environmental perception.</li> </ul>
<p><b>General</b></p> <ul style="list-style-type: none"> <li>• Do you ever think about the environment around you?</li> <li>• Do you ever think about your place in it?</li> <li>• Do you feel better in some places than in others? Why?</li> <li>• Do you feel like you belong in some places more than others?</li> <li>• How long have you lived here?</li> <li>• Do you like it?</li> <li>• How would you describe your suburb?</li> </ul>	<ul style="list-style-type: none"> <li>• Environmental perception/response</li> <li>• Sense of place, sense of self</li> <li>• Emotional response</li> <li>• Sense of place</li> <li>• Consciousness of time</li> <li>• Preferences</li> <li>• A perspective question/ environmental experience</li> </ul>

**Field work**

Interviews with children in their home environments completed. I have been amazed at the welcome from children of all ages, and their generous, open and insightful responses. I have enjoyed the frankness they bring to the conversations and their tolerance for the exercise as a whole. I have also found them so willing to participate and to help. It makes me feel self-conscious that there is not really enough in it for them in return. How does their participation in my research benefit them? Needs more thought for future stages in the study.

Journal: (2nd October 2004: Bk 5)

**Methods of analysis.** A coding framework was developed which consisted of six areas, each with a simple set of governing characteristics (Furth, 1980; Miles & Huberman, 1994). These categories reflected the need to assess theme, content, conceptual complexity, and the success of question type. The characteristics for each area are in parentheses. These included:

Theme and content:

- Key themes and subjects within interviews (defined by: longest stream of language, subjects most frequently referred to, evidence for habitual modes of thinking, evidence for previously articulated connections)
- Participants focused on physical environment (indicated by: participants capacity to single out and discuss the physical environment as distinct from the social environment, and observations made specifically about the physical environment)

Question type:

- Evidence for comprehension of exercise (indicated by a consistent response to similar questions)
- Most successful approach and most successful question type (such as open, closed, direct, indirect, single or multiple subjects)
- Cross-over questions (questions that resulted in answers that spanned multiple aspects of the individual's experience including the physical and social environment and their personal situation)
- Subject areas that were a struggle or caused confusion (questions that produced short stilted answers, questions which participants struggled to articulate a response, showed poor understanding of, were clearly confused by, or questions which showed evidence that the subject was being considered for the first time)

**Data analysis: Key subjects in interviews.** The key subjects in all interviews were personal stories and experiences, personal likes and dislikes and stories about socialising with friends and family.

**Key themes in interviews.** The key themes in these interviews spanned a range of subjects including: having a strong sense of belonging and attachment to place, comfort in the environment linked to the social relationships participants experienced there, comfort in environment linked to familiarity with surroundings, appreciating qualities of natural surroundings, appreciating potential in environment for having things to do.

**Participants focused on the physical environment.** All participants were able to focus on, and talk about the physical environment, often in detail. In the extended example below, the participant recounts from memory the detail of his grandmother's house and its neighbourhood context.

Participant: My Grandma's place was right on the beach, or wasn't, a minute or two's walk from the beach, um, it was just a small property it was in [suburb name], but I don't mind areas where there's sort of like, I don't mind the suburban area like – oh well I don't know what suburban is sort of like, I don't know but I don't mind, not like the city but I don't mind the – like [suburb name] not too populated, I don't mind it like that. You could smell the salt in the air and you could walk to [suburb name] beach and swim in the beach, and like you had all these strange but wonderful plants like big trees. I think it was a big Macadamia tree like that one, and um the - what do you call them, she had a big – one of those trees with those flowers? Those white and yellow flowers?

*Researcher: Frangipani?*

Participant: Frangipani, yeah she had one of them and we picked flowers off and it was like an old style house. They bought it years and years ago and then grandma passed away and we sold the house.

*Researcher: So how would you describe the house? What do you remember about the house itself?*

Participant: The house? Little house it wasn't too big, it was small, wasn't too small, it had sort of like a um a sort of well when they bought it was just one floor but they built their bedroom upstairs and they had an ensui...ensui...ensuite up there and - downstairs basically, the backdoor which were basically running this way [demonstrates with hands] – the driveway was sort of just, just it only just allowed the little mini to get in, no it just allowed the Pajero to get in, and um you'd sort of drive up to the garage and there was a little carport in front of the garage, and to the right was the back door and you'd walk into this little entrance way and the laundry and the little toilet just there and you'd come out into the kitchen, which Grandma did up, like got it refurnished and stuff about two or three years ago, and um – then you'd walk out into this old style lounge room which had, which was a nice big room and had an old fire place. She had some nice old couches and to the left was like glass opening doors which led out into a, I think an extension which wasn't part of the original house, it was sort of like the lounge room, like the TV room, to the, you sort of go to the right - was where the bedrooms were and the bathroom and then you sort of went straight ahead up the stairs to the upstairs area, that was just about it. (Aden, 12)

**Evidence of comprehension of exercise.** Participants responded consistently to similar questions. The excerpts below are taken from an interview with one of the youngest

participants. These questions occurred throughout the interview and are not identical but they are striving for similar information from the participant. The answers given by the participant are consistent and indicate that she comprehends what is being asked of her.

**Question 1:**

*Researcher: How would you describe this space to someone else who hasn't seen it?*

Participant: Um - I'd say that it isn't too big like I don't have too much space but I have enough space to be with and - it has got a hat and bag stand where we keep our gowns and our bags and our hats and - a hammock for all our toys and - I've got a desk and there's two beds for Sam and me.

**Question 2:**

*Researcher: So how would you describe this place to someone?*

Participant: Um well it is a good space to be in and - it is a good place to be at when you like want to be alone. And....probably it is a good eating space

**Question 3:**

*Researcher: Ok, if the person you're talking to can't see it what else might you tell them about this space?*

Participant: Um - it is really nice and that we have worked a long time on it and - sometimes it looks really colourful, like in spring when we've got all flowers everywhere it looks really nice, really colourful.

**Question 4:**

*Researcher: Ok, so how would you describe this space?*

Participant: Um it is a very big space and it is a very playful space that you could play cricket or soccer or things like that ...you just play around. (Alicia, 8)

**Most successful question type.** Direct questions with a specific subject focus were handled most comfortably; especially those that could lead to a discussion about what participants liked to do in the space. The example below consists of a typical set of direct questions and their answers.

*Researcher: Do you like this place that we're standing in?*

Participant: Yeah very much

*Researcher: What do you like about it?*

Participant: Well I like the colours of the flowers and stuff 'cause they're very colourful and um there's lots of space so you could like ride your bike around here and pretend you're like in the Olympics and stuff, 'cause there's so much space. (Stephanie, 9)

Open-ended questions with more abstract subjects, which were subject to individual interpretation, and were clearly more difficult to answer, often produced the most in-depth answers. In the excerpt below the participant is asked to think about the concepts of belonging and comfort.

*Researcher: Are there spaces that make you feel...are there spaces you feel you belong in more than others? That you're more comfortable in?*

Participant: Um - no, no - not really - I mean like - I wouldn't feel comfortable, I'd feel more comfortable being um down there than behind the office

*Researcher: Yeah? Why would that be?*

Participant: Um - because here there's a lot more to do and it has more to do and it's more safe 'cause like behind the office there's a sewerage tank that is about to fall, cave in, there's um the big heavy wood stack. (Nick, 10)

**Cross-over questions.** Questions which asked participants for their emotional response to being in the environment, to describe the environment, to say what they noticed within it, to describe why a place is special, all produced answers that covered a multitude of concepts which spanned social, personal and physical considerations. In the quote below the description of the place encompasses what she thinks of the spaces, links to the people who use it, and a description of what they use it for.

*Researcher: How would you describe this place to someone?*

Participant: This place is um...very spacious and um it's good because we have Dad's studio and it's also got a room in the back where people can come and stay, so that's very, very good. We have um lots of space upstairs, we've got ah 4 rooms because Mum and Dad sleep together, me and Sally sleep together, Mandy and Jake have their separate rooms and we have a toilet upstairs and so it's very good. Um lots of space and our rooms are big so that's very good 'cause we can do anything in our rooms except for when it's messy which is right now. (Mirabel, 10)

**Subject areas with which participants' struggled.** All participants struggled with large abstract concepts such as considering their place in the world. Children under 11 years also struggled with nebulous concepts such as 'how did a place make them feel?' Or 'were there places that they felt they belonged more than others?' Or 'what makes a place special to them?' In these instances, the struggle rarely indicated poor comprehension. They often clearly understood the question but struggled to articulate their response. The excerpt below gives an example of the struggle that many participants had with these questions and the comprehensive answers that often resulted. It is also an example of what Furth (1980) calls a developmental experience where it is clear that the participant is considering things in a new light.

*Researcher: So is the space where you feel you belong?*

Participant: Yep

*Researcher: And what defines that? What makes you feel like you belong?*

Participant: Umm...well...all...

*Researcher: What's that feeling made up of?*

Participant: .....I don't know

*Researcher: It's ok, it's a tough question I just asked it in case you have thoughts on it.*

Participant: I s'pose its because - it's - an area that my family live in, its got the belongings of my family, its got some of the belongings of mine, and just maybe it's, because I have been here for awhile? Like when I move into a new house I sort of feel I'm not meant to be here but after awhile you just get used to it and come to think of it as your own

*Researcher: And what do you think changes between that feeling of 'I'm not meant to be here' and coming to feel you're...*

Participant: Just getting used to it, getting used to the area. (Aden, 12)

Younger participants also struggled with compound questions (questions with several parts that each needed answering). Simple questions with a single subject were more successful.

**Interpretation of findings.** Overall, the analysis of this study showed that children and young people were able to focus on, and talk freely about the physical environment. Participants were able to distinguish between different kinds of environments and were frequently very observant of the detail and nature of their surroundings. However, there was substantial variation in the volume of discussion on the physical environment amongst the group of participants. This was linked to individual interest in the physical environment.

Within these interviews, it was possible to identify key ways that children and young people assessed the physical environment. These included assessing the environment for its beauty, for the potential of things to do, for the capacity to support the things that they wanted to do, and for the friendliness of the neighbourhood context. Many of these themes are in evidence in the excerpts included above.

The questions that children and young people were most comfortable with were direct questions that contained a single concept that they had considered before. Asking participants what they did or what they liked to do was particularly successful. These questions worked well in gaining factual information from participants about their own lives.

However, it was the open-ended questions, or the questions in which the subject was less well defined or more nebulous in nature, with which participants consistently struggled, but which consistently produced the most comprehensive, complex and in-depth answers. These types of questions were the most useful in gaining insight into how participants responded to something, or how they felt about it and why. The quotes above provide examples of the answers to questions about how participants would describe the environment or how they felt in it. The answers given in these excerpts are illustrative of both participants' struggle with these kinds of questions where the subject is not as prescribed, and the comprehensive answers given to them.

Concepts and conceptual complexity needed to be discussed using simpler language for younger participants but the concepts in focus did not need to change. In most cases, the younger participants comprehended difficult concepts but struggled to articulate their response to them.

**Methodological implications for the main study.** The results from this pilot study directly influenced the research in the following ways:

- Helping to identify key considerations within the social and physical environments for children and young people
- Clarifying what questions and topics are likely to produce answers which directly focus on the physical environment and which questions will likely produce answers on the social environment
- Clarifying which types of questions reliably produce answers that span the physical and social environments
- Grounding the researchers' expectations of the outcome of questions and the types of interpretations children and young people might make
- Clarifying the conceptual complexity that could be managed by children and young people in these subject areas, and indicating how this may vary with age

### **Pilot Study 2A: Walking Interviews - Hospital Environment**

**Aims and objectives.** The aim of Pilot Study 2A was to use the Hospital environment to continue to research conceptual complexity, topic interest, comprehension, and the kinds of observations that children and young people might make about their environment. This would enable comparisons between the two pilot studies, to see if the major considerations or themes had changed in the hospital context, and to provide site specific information for the main study.

In addition to this aim, Pilot study 2A was also used to establish which areas in the Hospital environment should be included in the discussions in the main study, and to develop a collection of photographs of these. Pilot Study 2, Parts A and B also offered an opportunity to begin to develop insight into patients' experience.

The specific objectives of Pilot Study 2A included: establishing which areas of the hospital environment children used and why, taking photographs of the areas of the environment visited on the walks, identifying the key themes and subjects of the walking interviews, establishing children and young people's interest in, and ability to focus on, the physical environment in this situation.

**Research design.** Pilot Study 2A was designed as a small qualitative study in which a number of semi-structured interviews were conducted whilst walking with children and young people around the hospital environment. Participants were asked to take the researcher around the hospital to the areas that they used had been to.

These interviews were recorded in the same manner as the interviews in Pilot Study 1. They were transcribed by the researcher and analysed for theme and content (Lincoln & Guba, 1985; Miles & Huberman, 1994). The findings were then assessed for their methodological implications for the main study.

**Research settings.** The setting for these interviews included any area of the hospital environment that participants chose to visit. These usually included the public and communal areas of the hospital such as the gardens, front foyer and shops, the Starlight Room, schoolrooms, the Book Bunker (patient library), as well as their wards and ward areas such as common rooms.

**Sample.** Five girls between the ages of 11-16 years participated, including two girls aged 11 and 12 years and 3 girls between the ages of 14 -16 years. Participants were eligible to be involved if they were aged between 7-18 years, well enough to walk around the hospital for half an hour, comfortable with English, had been in the Hospital for at least a week, and were from medical and surgical units that had given permission for their patients to be approached. These eligibility criteria was the same as the criteria used in the main study.

The initial aim was to complete equal numbers of interviews with boys and girls spanning the full age group. However, the boys who were approached, declined to participate. It is not clear why this happened but it may simply be because the study did not interest them. There were also no possible participants younger than 11 years, who fit the profile required in the Hospital during the time of recruiting for this study.

The absence of any boys or participants younger than 11 years in the sample meant that areas and activities within the hospital may not have been included. It also meant that key issues for these groups may not have been recognised in the schedule of questions to be used in the main study interview. However, it was felt that even if this was the

case, the format of the interview that would be used in the main study, was sufficiently flexible to accommodate variations of this nature if they occurred. The experience and findings from the pilot studies was only used to help define the areas of the hospital and the topic areas of interest for interviews that the main study should include.

Although the five interviews completed did not reflect the diversity of perspectives in relation to age and gender that were initially desired, there had been an almost complete overlap in the five walking tours completed, and sufficient data had been gathered to address the aims and objectives of this pilot study, to discontinue the interviews.

**Research instruments.** As in Pilot Study 1, a semi-structured interview was used. The question areas were designed to cover a broad range of patient experience in relation to the Hospital environment. These included: participants' use of the Hospital environment, their response to it, descriptions of it, how much they considered it, who they used it with and for what purposes, and how they saw themselves in relation to it. Table 6.3 lists the questions developed as a guide for the interviews and indicates the areas that they were notionally covering. As in Pilot Study 1, a strict schedule of questions was not used in the interviews in this pilot study.

Disposable cameras were given to participants on these walks to enable them to take photographs of their choosing, of the Hospital environment as the walking interviews progressed.

**Data collection procedure.** Potentially eligible patients were identified on wards with the help of the nursing staff Team Leader. Then the nurse looking after the patient was approached and he or she introduced the researcher to the patient and their family when available. The researcher would complete the recruitment by explaining the purpose of the study and what was involved for participants. Informed consent was obtained from both parents and participants, and an interview time was arranged. Information and consent forms were developed for both participants and their parents. (For all consent and information forms associated with this pilot study see Appendix B).

Walking interviews were completed individually across a period of a month in October 2004. The interviews lasted between 20-40 minutes. Similarly to Pilot Study 1, an

Olympus DS-2200 recording device was used with each participant to record her commentary.

Table 6.3

*Potential Questions and Topic Areas for Pilot Study 2A*

<b>Potential questions</b>	<b>Areas of interest to the study covered by the questions</b>
<p><b>Indoor environment</b></p> <ul style="list-style-type: none"> <li>• Tell me about your ward</li> <li>• Do you like it? Why/Why not?</li> <li>• How would you improve it?</li> <li>• When you go for a walk where do you go to? Why?</li> <li>• What do you like to do best here?</li> <li>• What are the things you like here?</li> <li>• What are the things you don't like here?</li> <li>• What would you change to make this place better for you?</li> <li>• How would you describe the Hospital to a friend?</li> <li>• What do you think you notice as you walk around the Hospital?</li> </ul>	<ul style="list-style-type: none"> <li>• Descriptions of place</li> <li>• Preferences</li> <li>• Consciousness of environment</li> <li>• Use of environment</li> <li>• Preferences for things to do</li> <li>• Emotional response</li> <li>• Consciousness of self and needs from environment</li> <li>• Place descriptions</li> <li>• Attributes of the environment being noticed / environmental perception</li> </ul>
<p><b>Outdoor environment</b></p> <ul style="list-style-type: none"> <li>• Why do you come out here?</li> <li>• Where do you go?</li> <li>• What do you do?</li> <li>• What do you like about this place?</li> <li>• How does this place make you feel?</li> <li>• How would you describe it?</li> <li>• Do you have places where you like to go by yourself and others where you like to take friends?</li> <li>• When you come out here what do you notice?</li> </ul>	<ul style="list-style-type: none"> <li>• Motivations for being in environment</li> <li>• Environmental use</li> <li>• Activities/actions</li> <li>• Preferences</li> <li>• Emotional response</li> <li>• Place descriptions</li> <li>• Sense of place/ self regulation / environmental perception and use</li> <li>• Attributes of the environment being noticed / environmental perception.</li> </ul>
<p><b>General</b></p> <ul style="list-style-type: none"> <li>• Do you think of this as a 'kids' hospital? What makes it that?</li> <li>• What did you think it was going to be like going to hospital? Was it like that?</li> <li>• Questions about participants' response and contact with people</li> <li>• Questions about their response to their own situation</li> </ul>	<ul style="list-style-type: none"> <li>• A sense of age-appropriateness in environment</li> <li>• Preconceptions of a hospital environment</li> <li>• Response to social environment</li> <li>• Response to personal situation</li> </ul>

**Outsider**

Feeling awkward in the Hospital environment and a complete outsider at this point. I lack knowledge of the Hospital routine and therefore how best to connect with it in each ward. I lack understanding of the terminology that the staff is using. The speed of the wards is very intimidating. Everyone moving with an acute sense of purpose. Entering a ward is like jumping into a double skipping rope, it seems to be all about timing. I feel a lot like a bull in a china shop, clumsy and unknowing. The staff members are very welcoming and helpful. It would be too tough if they weren't.

It occurs to me that what I am actually doing with these interviews is seeking a connection with this environment through the kids' experiences and to speed up the removal of this feeling of complete outsider. It is interesting really. There is probably a need to make a connection in every environment in which we dwell, even temporarily. This may be the fundamental thing underpinning our feeling of well-being in any environment – perhaps it rests in our ability to find something in an environment with which we can connect.

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**Methods of analysis.** The same coding framework, theme and content analysis was used in Pilot Study 2A as was used in Pilot Study 1. This enabled a comparison between the two groups, to see if major considerations or themes had changed in the Hospital context.

The interviews were also analysed to identify all of the areas that had been visited during the interviews so that the final selection of areas to be discussed in the main study interview could be identified.

The photographs taken on the hospital walks were developed so that the example of each area that was the clearest and most descriptive, could be selected.

**Findings.** The areas visited on the walks overlapped almost completely across all interviews. This consistency meant that all areas visited on the walks were included in the final list for discussion in the main study.

The findings in relation to the photographs were that many of these were of poor quality, with images of some indoor areas not being useable at all. This led to the researcher having to re-photograph some areas of the indoor environment for the main study.

In reporting the findings from the theme and content analysis, Pilot Study 2A reaffirmed the findings from Pilot Study 1 in relation to conceptual complexity and key question types and so these findings will not be reported again here. However, there were

differences in the key subject areas in these interviews that were introduced by the influence of the participants' illness.

**Key subjects in interviews.** In the interviews in Pilot Study 2A, the influence of patients' illness featured consistently for its influence on their responses. The three excerpts are examples of the dominance of this side of their experience in participants' response to hospitalisation and the Hospital environment.

**Example 1:**

*Researcher: So how does this place make you feel?*

Participant: If you're feeling really sick and you have just had enough, you hate being here and you just want to go home. (Debbie, 14)

**Example 2:**

Participant: Um this is like my little bed and as you can see, I've decorated it quite a lot

*Researcher: Beautifully, you all have.*

Participant: Yeah 'cause it just gets a bit lonely sometimes so you just got to try and decorate it and make it like home and everything

*Researcher: So how does the decoration help?*

Participant: Um well – I like the things that say like happiness and stay happy and everything - just reminds me to kind of stay positive and everything 'cause like it gets really sad sometimes and the photos and just the cards yeah they're from my friends so I just put them up. (Vicki, 11)

**Example 3:**

*Researcher: So where do you like to go?*

Participant: Um it all depends on how you feel. 'Cause if you don't feel good then you don't want to go anywhere, but um, I like to go out to the gardens 'cause it's just fresh air and a nice place to go to. (Eliza, 12)

The new themes in these interviews revolved around patients' efforts to cope with their time in hospital and with the effects of their illness. They included:

- The importance of peer support
- Using outdoors as a place of escape
- The importance of making friends whilst in hospital
- Family as a key presence in the experience of hospitalisation
- The influence of the ambience and atmosphere of the Hospital on patient's feeling of welcome
- Patients' appreciation of artwork, colour and light
- The importance of keeping busy
- The importance of friendliness from staff
- The consciousness of age-appropriateness
- The dislike of boredom
- The importance of being able to decorate or personalise their bed area

**Interpretation of findings.** Patient illness introduced a dynamic between the participants and the Hospital environment that was not present in Pilot Study 1. In these interviews, there was an inherent tension between participants' personal situation, and what they seek and need from the Hospital environment. This is illustrated in the excerpts above. There is also evidence in the quotes above that these participants seek to actively manage this experience for themselves as they can, by taking control over aspects of it.

Many of the new themes indicate patients' interest in finding effective coping strategies and ways to alleviate the effect of time in the environment. From the interviews it was also clear that patients use as much of the environment as they know about or have access to. Variations occur with the type of diagnosis, and with the restrictions of treatment programs.

**Methodological implications for main study.** The results from Pilot Study 2A directly influenced the research in the following ways:

- Identifying key themes in patient experience
- Identifying questions for inclusion in the main study that may not be solely linked to any particular domain of well-being or experience but which may lead to rich answers which span several domains including:
  - asking participants to describe the environment
  - asking them if they think it's a good hospital for kids
  - asking them to suggest changes
  - asking them about what they notice in the environment
- Identifying the areas of the Hospital environment that should be included in the main study interview discussions. These areas are listed in Table 6.4.
- Creating the set of photographs that formed the basis for the set used in the first task of the main study interview. Three examples of photographs taken by participants that were included in the main study selection are shown in Figure 6.1. The full set will be shown later in chapter 7.



Figure 6.1. Examples of photographs taken by participants in Pilot Study 2, Part A

Table 6.4

*List of Areas in the Hospital for Discussion in the Main Study*

Areas of the Children's Hospital at Westmead			
1	Main Entrance	13	Red Pagoda: Chinese Gardens
2	Front Foyer	14	Fish Pond: Chinese Gardens
3	Volunteers' Shop	15	Seats: Chinese Gardens
4	Chemist	16	School Room 1: Level 1
5	Level 2 Café: Bear Café	17	School Room 2: Level 1
6	Starlight Express Room	18	School Room 3: Level 2
7	Book Bunker	19	A children's ward play room
8	Level 1 Cafeteria: Bear Bite Eatery	20	A children's ward room
9	Main Fountain: Children's Garden	21	An Adolescent ward room
10	Small Fountain: Children's Garden	22	Wade Ward Common room
11	Courtyard: Children's Garden	23	Bed rest area (Wade Ward)
12	Aviary: Children's Garden		

**Pilot Study 2B: Refining Direct Questions and Game Task**

**Aims and Objectives.** The aims of Pilot Study 2B were to pilot the second and third research instruments proposed for the main study interview. These included the series of direct questions and the final game task.

In Pilot Study 2B, the set of direct questions was piloted for the first time. The aim was to alter and refine the questions, eliminating material that did not make sense to respondents, and to refine the order so that they flowed as comfortably for participants as possible.

The game task was developed by identifying from the interviews in Part A, the areas most commonly visited in the Hospital outside the wards, and the motivations for

visiting them. In Part B, the main objectives were to see how the game task was received by participants, how they interpreted the exercise, and how they responded to it, to understand if and how it should be modified.

**Sample.** The criteria used to select these participants was the same as used in Part A. Four patients between the ages of 10 and 16 years participated, including three girls between the ages of 10 and 15 years and one boy aged 16 years. Locating the participants, the recruitment and consent procedures were the same as in Pilot Study 2A. The consent and information forms developed for Pilot Study 2A are representative of the forms used in Pilot Study 2B, see Appendix B. Four interviews provided sufficient data to address the aims and objectives of this study.

**Research instruments.** As previously discussed the direct questions were developed initially from the literature. The social ecological concept of well-being consisting of a series of interconnected domains was used as an organising framework. The domains used, and the specific considerations within them, were suggested by the healthcare research literature. The domains included personal experience, social experience, physical environment, organisational considerations and time. This initial list of considerations had largely been the result of research with adults. The indications from the literature were then combined with the findings and the experience of the interviews with children and young people in Pilot Studies 1 and 2A to create a set of approximately 30 direct questions. For a full listing of the initial list of questions used in this pilot study, see Appendix C.

The game task was also developed from the findings in Pilot Study 2A. From these interviews, the six most frequently visited areas were identified, along with the most common reasons for visiting them. This information formed the basis of the game task. Figure 6.2 shows an uncompleted game task form, version 1, which was used in this pilot study.

**For each place, choose as many reasons as you want for why you might like to go there and join the reasons to each picture with a line**

	<b>To hang out with friends</b>	
	<b>Just for a walk</b>	
	<b>Something to do</b>	
	<b>Because I like it</b>	
	<b>Because it's a nice place</b>	
	<b>People to talk to</b>	
	<b>It's bright and colourful</b>	
	<b>Spending time with friends or family</b>	
	<b>To get away</b>	
	<b>Other reasons?</b>	

Figure 6.2. Game task, version 1, Pilot Study 2B.

**Data collection procedure.** Participants completed the interviews in a place of their choosing which was invariably either on their beds or in the little interview rooms on their wards.

A different order of questions was used with each participant. It was explained to participants that they were part of the process developing these questions. They were asked to say if they were struggling at any point and to say what aspect they were struggling with. They were also asked to add any additional subject area that they felt should be on the list of questions about their experience.

Following the direct questions, participants were given the trial game task form and asked to complete it. They were then asked to comment on what it was like to do and whether it made sense to them. Pilot Study 2B was carried out across a period of a month in November, 2004.

**Findings: Direct questions.** The experience of trialling the direct questions and their order revealed topic areas that participants were consistently comfortable with, which included questions about the social environment, the physical environment and organisational considerations. It also revealed the topic areas that participants might struggle with or even find uncomfortable which included personal questions, and questions about the effect of time in the environment.

Questions concerning social support and social contact were the most easily answered and the questions that participants were most comfortable with.

**Example 1:**

*Researcher: So do you make friends with other patients in here?*

Participant: Yep

*Researcher: And does that help?*

Participant: It helps a lot 'cause I don't feel alone and I don't feel like I'm by myself in this illness. Makes me feel like there's someone like supporting me 'cause my friends support me, like we support each other so it makes me feel like I'm welcome and like I fit in, so it's important. (Elena, 12)

**Example 2:**

*Researcher: Now your family, how often do they come in?*

Participant: Um well they come in like twice a week probably? Sometimes, once, it depends when they can come here 'cause both my parents work, so it's hard for them to come from (place name) to Westmead yeah since my Mum doesn't have a car now that makes it even harder so

*Researcher: So is that another important thing?*

Participant: Yeah it's really important for my family to come and visit me. At first like in the first week I was having trouble to fit into the Hospital, just 'cause like I felt homesick a bit and I wanted my parents to take me out but they didn't 'cause they thought it was for the better good and I got a bit upset and told them not to come anymore but I regret that and I felt guilty after so, it's really important for like family to be there to support you through this. (Roxanne, 15)

Questions concerning the physical environment posed a greater challenge, consistent with the experience in earlier pilot studies, many of the participants had not considered these aspects of their experience consciously before. These questions did not, however, cause discomfort or confusion. They often produced detailed answers as to participants' preferences for areas and environmental attributes, and their preferred patterns of environmental use.

**Example 1:**

*Researcher: Ok now you've said you noticed the pictures and sculptures around the Hospital*

Participant: Yep

*Researcher: Do you think they make a difference?*

Participant: Yep a lot um

*Researcher: What's the effect of them?*

Participant: Well um...it's just like it doesn't make you feel like you're in a gaol or something, or closed in to a place and you're not allowed out or it just kind of gives you I

don't know some kind of feeling like you can always like um... get like a feeling or um... you know and idea from a painting or sculpture, and it makes you react to it and it's just something that adds a little touch to the Hospital. It's good. (Roxanne, 15)

**Example 2:**

*Researcher: How would you describe the hospital environment to some one – to a friend who is not here?*

Participant: Mmm clean, sometimes

*Researcher: What do you think you notice as you travel around the Hospital?*

Participant: Not much really, just enjoyable like, it's just like having a stroll on the beach or something. It's nice, I wouldn't say it's terrible.

*Researcher: Ok, what makes it nice?*

Participant: The gardens, and the birds and being able to talk to friends and the nursing staff and yeah

*Researcher: How about the building itself? How would you describe it?*

Participant: Colourful, be better out the front if it was more colourful but, 'cause its full like all white, be nice if its like different colours and like, you know even if there was like a pink girl on the front or a blue boy on the front or a car or a diary or something I don't know, something for the kids to look at and go "oh wow! I love coming here!" (Elena, 12)

Questions on organisational considerations produced a mixed response, depending on whether participants were happy with these aspects of their experience or not. These questions did not cause confusion but they could cause discomfort if participants wanted to talk about difficult incidents they had had with medical staff, or if they wanted to make a complaint about some aspect of the hospital organisation.

*Researcher: What would you like more control over?*

Participant: Everything! Just the program I'm on makes it really controlling like um I don't know, I have a problem with control I think, in here like I don't get enough for myself and stuff like that like um we have to go to school and we have to go to Group like we don't really have a choice in going. I don't know why that is but it's just the program I'm on and we're forced to eat everything and um just stay on schedule and stuff like that. Not allowed too much time on our own like we're not allowed a door on our room 'cause they have to keep an eye on us and stuff. Yep it's pretty controlling. I tend to get um pretty depressed sometimes. (Eva, 14)

These questions also revealed how much knowledge patients had about what opportunities were available in the Hospital for them and how well informed they were about them.

*Researcher: Do you think they have enough activities and entertainment for kids your age here?*

Participant: I have no idea what activities they have. I don't really care.

*Researcher: Ok you don't seek them?*

Participant: No, I mean I've had people come in and they say um to like craft or something and also like a library and that's good since they're telling children what they can do but I'm fine just in the room with my stuff.

*Researcher: Yep so would you change anything on that front? Would you introduce anything that was more age-appropriate for you?*

Participant: Not really because I mean they say they've got computers at the library so really I can't think of anything. Actually I mean they've got books to read they've got computers, they've got game consoles to use, TV, they say they can play videos and DVDs and they've got the arts thing, they've even got school if someone is stupid

enough to want to go there. I can't think of anything else, I can't think of anything that I would want. (Joshua, 16)

Questions about personal experience definitely caused discomfort for some participants. Questions about the impact of participants' medical experience, their emotional response to hospitalisation, their efforts at emotional self-regulation and their ability to find privacy, touched on their difficulties. Answers to these questions were often short and dismissive.

**Example 1:**

*Researcher: Alright when things start to get too much for you?*

Participant: Mmm

*Researcher: How do you manage that?*

Participant: Um I tend to get um pretty depressed sometimes and I either just like lie on my bed and I don't know, cry and stuff. (Roxanne, 15)

**Example 2:**

*Researcher: Alright um what do you do when things get too much for you?*

Participant: Well, I just, 'cause sometimes the doctors have bad news sometimes and I just lie on my bed and cry.

*Researcher: Do you seek help or support?*

Participant: No not really

*Researcher: You sort it out for yourself?*

Participant: Mmm. (Eva, 14)

Questions on participants' response to spending time in hospital were also more difficult for participants to answer comfortably as they could lead to discussions about homesickness and boredom, both of which participants clearly struggled to cope with.

**Example 1:**

*Researcher: Ok you've been in here for awhile, how does it make you feel being in here for a long time? How does time affect things?*

Participant: Um it just makes you miss home more. It makes you wish you weren't here and um like the thing that distresses me the most is that I haven't seen my friends for so long, they're so important to me and yeah I think it's really stupid how we're not allowed to see them 'cause it's not going to do anything just to have company every now and then. (Eva, 14)

**Example 2:**

*Researcher: When you're in here for a long time, does that change the way you feel about being in hospital?*

Participant: Yes

*Researcher: In what way does it change? What happens?*

Participant: Um oh well I don't know if it changes in a good way or not? I know it changes um... 'cause normally I think when I have to come in here I'll settle for the days that I have to be in here and say "look just get past those days and you'll be out of here". Um but as when you're in here for a long period, you don't know how long you're going to be in here for, then you tend to just sort of change and just want to get out of here more.

*Researcher: So you get more restless as the time goes on rather than easier with it?*

Participant: Yep, yes. (Elena, 12)

The experience of this task in Pilot Study 2B indicated that the five domains chosen were useful as a framework for encompassing patient experience, and the schedule of questions developed were relevant to children’s experience and were mostly well comprehended by participants. Alterations to the questions were made based on the experience of this pilot study.

**Findings: Game task.** The experience with the game task made it clear that the initial instruction was not clear enough. One of the proposed uses for this task was that it might function as an internal consistency check within each interview. For this to be possible, patients needed to complete the task in relation to areas that they had in fact visited. In the example shown in Figure 6.3, the participant had not been to all the areas she included as she had responded to the “might like to go” part of the instruction.



Figure 6.3. A completed game task form, version 1, Pilot Study 2B.

It was also clear that the participants responded directly to the photographs used. Participants did not consider a photograph of one section of a much larger garden for example, to be representative of the whole garden. They responded to the image itself.

It was also suggested that the photograph of the Book Bunker should be replaced by a photograph of the Bear Bite Eatery, because this group of participants said that they visited the café on Level 1 (Bear Bite Eatery) much more than they visited the Book Bunker.

The nine reasons used for visiting an area were clearly recognisable by the participants and resonated well with them. However, trying to analyse the findings from these sheets revealed that they were too ambiguous and open-ended to be able to ultimately allocate them to any particular domain of children's experience. This group of reasons required too many assumptions to be made about what each reason was referring to and whether it had implications for social, personal, organisational or physical domains.

**Methodological implications for main study.** The results from Pilot Study 2B directly influenced the development of this research instrument in the following ways:

- Helping to refine the direct questions and the order that they should be asked
- Illustrating the need to clarify the initial instruction and the central task in the game task
- Illustrating the need for less ambiguous reasons on the game task
- Identifying the need to use images which were as representative of each of the areas as a whole should be used.
- Identifying the need to replace the Book Bunker image with an image of the Bear Bite Eatery

All three pilot studies greatly contributed to the development of the research instruments and their detail. Pilot Studies 2A and 2B also contributed greatly to the researchers' understanding of working in the context of the Hospital, and the particular considerations that would be inherent in completing the main study in this context.

## **CHAPTER 7**

### **MAIN STUDY**

Chapter 7 encompasses the specific research methods, fieldwork procedures, and analysis techniques used in the main study. It also encompasses a discussion of the trustworthiness exercises and measures used within the main study.

#### **Aims and Objectives**

There were three specific aims for this study. The first was to arrive at a description of the experience of hospitalisation, and what constitutes a supportive environment, through the experience of children and young people themselves. The second aim was to increase our understanding of the involvement of the physical environment in patients' feeling of well-being in a paediatric setting. The third aim was to highlight the capacity of participatory research with children and young people to inform paediatric design.

The objectives were to identify the key considerations within the domains involved in children's experience of hospitalisation, and in their feeling of well-being in this context, and to explore the role of the physical environment, in patients' experience.

#### **Research Design**

The main study consisted of a major phase of data collection in which participants completed a single interview. Within the interview, participants were asked to complete three tasks including: in an informal conversation centred on a set of photographs of the hospital environment, a series of direct questions spanning the domains of their experience of hospitalisation, and a game task sheet. These interviews were carried out with children and young people individually and were conducted at their bedsides or in places of their choosing within the Hospital.

Each section of the interview was analysed separately and the results were triangulated to form preliminary findings. A member-checking task was then completed with a different but representative group of patients and conclusions reached. Figure 7.1 shows the outline for the main study.

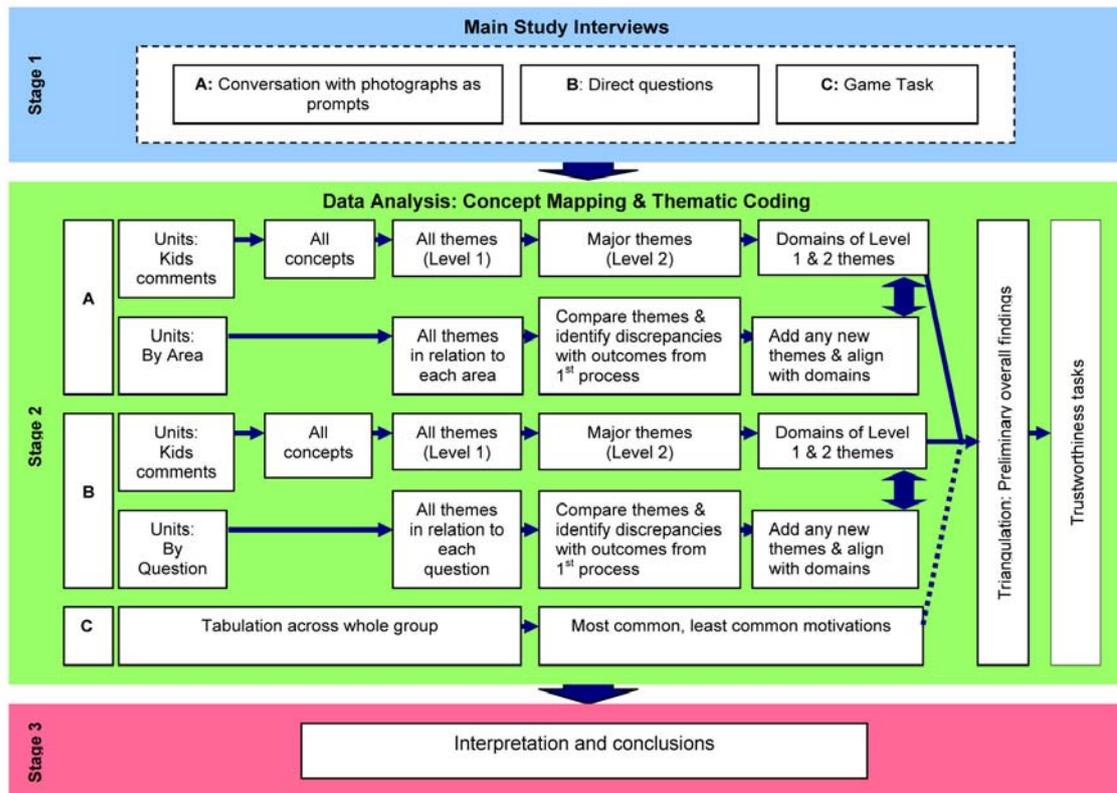


Figure 7.1. Study outline for the main study.

## Research Settings and Population

**Research settings.** The final list of areas included the public, communal and entertainment areas of the Hospital, including: the main entrance, the front foyer (or main foyer), the Starlight Room, the Book Bunker, the gardens, including the Children’s Garden, the Chinese Garden, the ward areas, including ward playrooms and common rooms, and the three schoolrooms.

These areas were established as an outcome of Pilot Study 2, Part A. Figure 7.2 consists of a map of the areas that were discussed by all participants. None of the clinical areas was included. However, participants in the main study were not prevented from talking about any area of the Hospital they chose. In the end, several clinical areas had been discussed including: the physiotherapy gymnasium, the X-Ray department waiting area, the pathology department, and the oncology clinic.

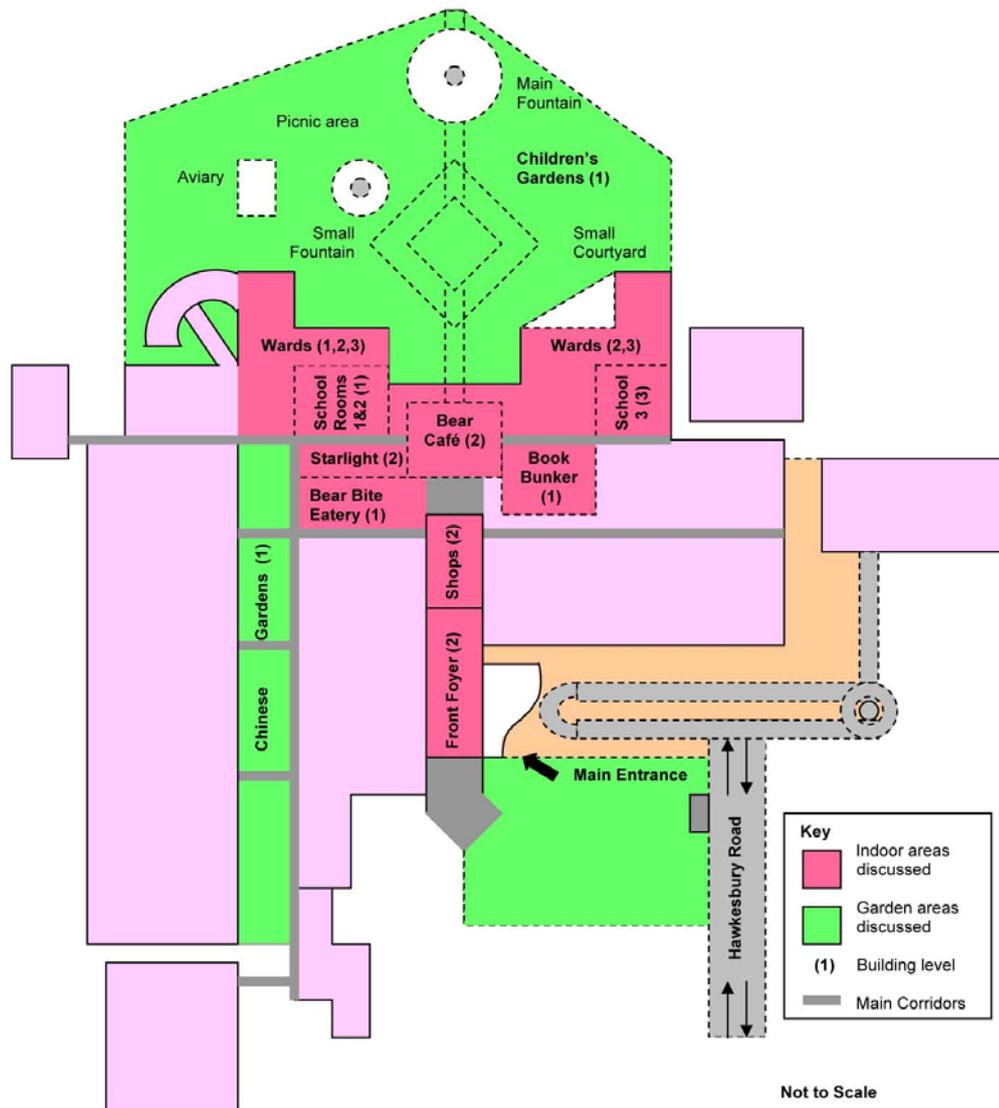


Figure 7.2. Plan of areas discussed by all participants in the main study.

**Population.** The Hospital admission records for 2005, show 1185 children and young people between the ages of 7-18 years were admitted for seven days or more. Four hundred and eighty two of these patients were between the ages of 7-12 years; 703 patients were between the ages of 13 -18 years.<sup>10</sup> This represents the total population of children and young people from which the sample population could be drawn during the data collection period.

<sup>10</sup> Statistics for admissions provided by the Management Support & Analysis Unit, The Children's Hospital at Westmead

**Sample**

The initial aim was to speak with similar numbers of boys and girls between the ages of 7-18 years, who met four selection criteria. These included being a patient in the hospital for at least seven days at the time of the interview, being able to speak English, and being well enough to cope with a 30-minute interview. They also had to come from the medical and surgical units who had given permission for their patients to be approached.

Variation in the characteristics of the sample was expected based on the type of illness, cultural background, wardroom and ward type, number of visits to a hospital, and length of time in hospital. This variation was welcome as it increased the range of different experiences explored.

Interviews were conducted between mid December 2004 and mid December 2005. The final group of participants consisted of 25 children and young people between the ages of 9 -17 years who had been in the Hospital for between seven days and seven weeks. The sample consisted of five girls and five boys between the ages of 7-12 years, six boys between the ages of 13-18 years, and nine girls between the ages of 13-18 years. Twenty-three out of the 25 participants were between the ages of 11-17 years.

Younger children consistently declined to participate in the study. It is possible to speculate why this might have been the case. It may have been because they were in an environment where things outside of their control happen to them all the time, and the study was something optional that they could choose not to do. It may have been because it was not immediately apparent whether this task would be fun or not, and it may have been because the task did not interest them.

Having completed 25 interviews, the sample group reflected a diverse range of children's perspectives, based on the initial selection criteria for participants, and based on illness, cultural background and hospital experience. Sufficient data had been gathered to address the questions for research and the aims of the study, so data collection was discontinued. Table 7.1 shows a breakdown of the characteristics of the 25 participants.

Table 7.1

*Summary Information for Participants in the Main Study*

Main Study	Age & Gender	Ward	Time in Hosp. as at interview	No. of visits to a hospital	Diagnostic group
1	14 G	Wade	10 days	Multiple	Respiratory
2	14 G	Wade	5 weeks	1st	Eating Disorders
3	14 G	Wade	4 weeks	1st	Eating Disorders
4	15 G	Wade	5 weeks	1st	Eating Disorders
5	17 B	Wade	3.5 weeks	1st	Gastroenterology
6	11 G	Camperdown	1 week	Multiple	Oncology
7	12 B	Camperdown	3 weeks	Multiple	Oncology
8	15 G	Wade	5 weeks	1st	Eating Disorders
9	15 B	Surgical	11days	2nd	Surgical
10	9 B	Camperdown	10 days	Multiple	Oncology
11	12 B	Wade	1 week	Multiple	Respiratory
12	17 B	Wade	10 days	Multiple	Respiratory
13	16 G	Wade	10 days	2nd	Respiratory
14	13 G	Clancy	7 weeks	2nd	Gastroenterology
15	12 B	Clancy	4.5 weeks	1st	Gastroenterology
16	12 G	Surgical	3.5 weeks	1st	Surgical
17	14 G	Camperdown	2 weeks	Multiple	Oncology
18	11 B	Camperdown	4 weeks	Multiple	Oncology
19	15 G	Wade	3.5 weeks	2nd	Eating Disorders
20	15 B	Surgical	1 week	1st	Surgical
21	11 G	Surgical	10 days	1st	Surgical
22	13 B	Wade	10 days	1st	Surgical
23	10 G	Clancy	2 weeks	3rd	Surgical
24	12 G	Wade	5 weeks	1st	Eating Disorders
25	14 B	Camperdown	3 weeks	Multiple	Oncology

The profile of the final sample population consisted of patients with a variety of different characteristics including variations in:

- Diagnoses (12 teams that had given permission for their patients to be approached but most participants came from six of the teams)
- Numbers of admissions to a hospital
- Types of mobility restriction (including patients who were confined to their beds, patients in isolation, patients on restricted movement programs, and patients with total freedom to move around the environment)
- The types of wards experienced (single or shared, adolescent or children's wards)

- Cultural backgrounds (nine of the participants came from non-English speaking backgrounds)
- Lengths of stay in the Hospital (ranging from seven days to seven weeks).

### Research Instruments and Tasks

**Photographs: Task A.** Task A consists of an informal discussion centred on a set of photographs of the Hospital environment. The set of photographs was developed through Pilot Study 2A. Photographs taken by these participants were supplemented by others taken by the researcher. This was necessary as it had been impossible to take photographs during the walking interviews, in all places, which met the Hospital requirement that they should have no people in them, and because the quality of some of the photographs taken by participants was too poor to use.

The final set contained photographs of all the key areas chosen by participants as well as generic photographs that aimed to be representative of many different examples of a particular room type. The generic photographs included an example of a children's wardroom, an adolescent wardroom, and examples of a common room and a ward playroom. There was no particular order to this set except that it deliberately began with the main entrance, front foyer and shops area as this was the beginning of most participants' contact with the Hospital. This offered a reasonable place to start the discussion. Figure 7.3 depicts the set of photographs used and their labels. (The actual photographs used were approximately 12cm x 15cm in size and each was labelled with the captions below).



Figure 7.3. The set of photographs used in the main study interview, Task A.



**Chemist**



**Bear Café (Level 2 café)**



**Starlight Room**



**Small Fountain:  
Children's Garden**



**Main Fountain:  
Children's Garden**



**Small Courtyard:  
Children's Garden**



**Aviary: Children's Garden**



**Bear Bite Eatery (Level 1 Café)**



**Book Bunker**



**Children's Ward Room**



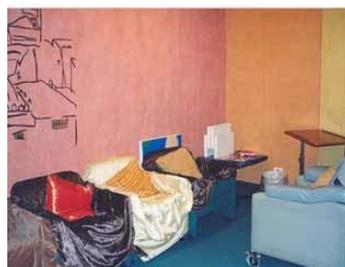
**Children's Ward Playroom**



**Adolescent Ward Room**



**Wade Ward Common Room**



**Bedrest area: Wade ward**



**School Room 1**

*Figure 7.3(continued).* The set of photographs used in the main study, Task A.



Figure 7.3(continued). The set of photographs used in the main study, Task A.

**Direct Questions: Task B.** Task B consisted of answering a series of direct questions spanning children's experience of hospitalisation. The aim of the direct questions was to ensure that participants had been asked to comment on many of the areas of their experience that may be part of their feeling of well-being in a hospital environment. This set of questions was not meant to represent a definitive list, but it was a comprehensive list of parameters and subject areas. As discussed previously, these were derived from the healthcare design research literature, the literature on children's experience of hospitalisation, and from the experience and findings of Pilot Study 1 and, more directly from Pilot Study 2, Parts A and B. In combination, these sources provided a solid starting point from which to understand what may be part of children's experience and feeling of well-being during hospitalisation.

Table 7.2 lists the domains, the subject area of each question, and the questions in the order that they were asked. The final set of questions span the domains of social experience, personal experience, organisational considerations, physical environment, and time. The final arrangement, blending and order of the questions were influenced by the experience of the Pilot Study 2B.

Table 7.2

*Set of Questions Used in the Main Study, Task B*

<b>Domains</b>	<b>Subject areas of questions</b>	<b>Corresponding questions for main study</b>
<b>Social Experience</b>	1. Availability of peer support (other in-patients) 2. Contact with friends 3. Contact with family 4. Contact with staff -of all kinds 5. Social support	1. How important is it making friends in the hospital? What kind of things do you do with them? 2. Do you have contact with your friends outside the hospital? Is this important to you? 3. When your family comes to see you, what kind of things do you like to do with them? 4. Do you talk with the hospital staff? Who do you normally talk to? 5. If you need support during a difficult time, who would you normally turn to?
<b>Physical Environment/ Organisational Considerations</b>	6. 'A good hospital for kids' 7. Sensitivity to the environment 8. Noticing things in the environment. 9. Presence of artwork 10. Presence of colour and 'brightness' 11. Like/dislike environment 12. Reduce noise 13. Spatial orientation 14. Needing a variety of spaces 15. Access to outdoor areas 16. Design configuration 17. Personalising bed space 18. A place to retreat to 19. Access to age-appropriate activities 20. Keeping busy	6. Do you think this is a good hospital for kids? Why? 7. How would you describe this Hospital environment to a friend? 8. What do you think you notice when you go around the Hospital? 9. Do you notice the pictures and sculptures around the Hospital? What do you think about having them? 10. Do you notice colour? Do you notice brightness? What makes a place bright? 11. Do you like the Hospital environment? What do you like/dislike about the hospital environment? 12. Is the Hospital noisy? Does noise bother you? 13. How do you find your way around? Do you find it difficult? 14. Do you think it is good to have different places to go to in the hospital? Why? (Do you have a preference for the sorts of places you like to go to when you leave the ward?) 15. Is being able to go out into the gardens important to you? 16. Would you rather share a room or be on your own? Why? 17. Is it important to be able to have your own things around your bed? Why? 18. When you want to be by yourself, where do you go? 19. Do you think there are enough activities & entertainment for kids your age here? What would you change? 20. Do you like to keep busy? Why? (So what do you normally do to keep yourself occupied?)
<b>Time</b>	21. The effect of time	21. When you're in here for a long time, does that change the way you feel about being in hospital?

Table 7.2 (continued).

*Set of Questions Used in the Main Study, Task B*

<b>Personal/ Organisational Considerations</b>	22. The effect of illness (and worry of treatments)	22. Do you have good days and bad days? What makes it a bad day? Does the way you feel change what you feel about the Hospital?
	23. Emotional self-regulation	23. When things get too much for you, how do you manage that?
	24. Personal privacy	24. Is your need for privacy respected here?
	25. Personal safety	25. Do you feel safe in the hospital?
	26. Reflection on experience	26. What do you find the hardest thing about being in hospital?
	27. Reflection on experience	27. What would be the thing that you would most like to change?
	28. Effect of rules and restrictions	28. Are there rules and restrictions that you have to follow here? How do you feel about those?
	29. Access to information	29. Do the doctors and nurses tell you what's going on? Is this important to you?
	30. Being consulted and heard	30. Do you feel the doctors and nurses listen to you when you want to tell them things?
	31. Personal control	31. Do you think you have enough freedom to do things as you want to here?

**Game Task: Task C.**

Figure 7.4 shows the final game task sheet which was used by participants.

**For each place you have been to, choose as many reasons as you want for why you go there and join the reasons to each picture with a line**





to be with my friends

to be outdoors instead of indoors

I like to get away from my ward

to spend time with my family

I sometimes feel bored so I walk around

because I like this place

because the place is bright and colourful

to find people to talk to

because the place has things for me to play with and use there

other reasons?





Figure 7.4. Final version of the game task form.

The final form of the game task sheet consisted of six photographs of the public areas most visited by the two groups of participants in both parts of Pilot Study 2. It also consisted of nine of the most common motivations for why patients may visit these areas as identified from the findings of both parts of Pilot Study 2. The list of reasons contained three personal, physical and social motivations for visiting areas within the hospital. The overall instruction was changed to make it clear that the exercise should be completed in relation to areas that the children had actually visited. Finally, a photograph of the cafeteria on Level 1 (Bear Bite Eatery) replaced the photograph of the Book Bunker.

### **Data Collection Procedure**

**Recruitment and consent.** Participants were identified in five wards as the result of a weekly ward round. On entering each ward, the nursing staff Team Leader would be located and would read the list of patients on the ward to identify who on the ward may fit the profile for participants in this study. The nurse looking after any patient identified was then located and he or she introduced the researcher to the patient and their family if they were present at the time, or he/she would often know when the family was likely to be available to talk to and a meeting would be organised for that time. The research was then discussed with the family and the participant and in most instances, a decision was reached at that point as to whether a patient would go on and participate, and an interview time was arranged.

Both the parents/guardians and the participants were given separate and different information forms and consent forms to sign. On returning to complete the scheduled interview these were talked through with each participant and their family to ensure that they all had the opportunity to ask further questions. The consent forms were signed and then witnessed by a member of the nursing staff (usually the staff member that was looking after the patient at that time). Copies of the signed consent forms were left on the patient's medical records, with the family, and with the researcher. For all information and consent forms used in the main study see Appendix D.

**The interviews.** Participants completed a single interview that ranged from 20-50 minutes in length. (Although the average running time for the interview was approximately 25 minutes, a few of the interviews were longer as the participants in

these interviews were interested in discussing some topics at length). Occasionally participants were well enough to choose areas away from their wards to carry out their interviews. Otherwise, interviews were conducted in the interview rooms attached to each ward because they offered privacy and reduced the risk of interruption. However, many of the interviews were also conducted at bedsides because children were not mobile. This was the most difficult interview circumstance, especially in shared rooms. It meant that these interviews were usually interrupted, sometimes a number of times.

The context of the interview has been acknowledged as being crucial to the data gained (Scott, 2000). It is possible that bedside interviews conducted in shared rooms affected the data that participants volunteered because of the risk that others could overhear. Interviewing participants in the interview rooms attached to the wards was also not ideal because these were associated with some participants' medical experience. Knowing this, participants were always given the option of choosing another place if they were uncomfortable. However, privacy on a hospital ward is very hard to find and these little rooms often offered the best option.

All interviews were recorded using an Olympus DS-2200 digital voice recorder. The interviews were then transcribed by the researcher.

**Reflecting on the data collection phase**

Data collection often feels like a marketing exercise. I often felt just like a salesman, conscientiously adopting a positive approach and a big smile. This begins with the initial contact with the ward nursing staff. The challenge is to represent the task succinctly and clearly and without falsifying it to any extent – in about three sentences, preferably short. These need to include info on: who you are, what you're doing, who you're looking for, their ages, gender, length of time in hospital, wellness and language, and the medical/surgical teams they need to come from – plus the actual task that is ahead for the patient if selected to be approached. Not easy.

In the end I did get more comfortable entering wards because I had a greater sense of purpose, and a greater understanding of the main game and the rules surrounding it. However, I never did get over the "what-am-I-doing-here" feeling entirely. I think this is largely because I had no real capacity to contribute to the healing process for children, nor the busy routines of the staff.

Overall, the interview worked well with participants. Some clearly reached the limits of their concentration toward the end of the direct questions. Bedside interviews were a challenge because of the need to maintain focus and momentum as many of these were broken up by visits from nursing staff needing to treat the participant. During these visits we would stop the conversation and try and resume it after the treatment was over. Actually I think I found this harder than the kids did.

Journal: (20 December 2005, Bk 6)

**Methods of Analysis**

**Tasks A and B: The Hybrid Process.** This process was long and involved and was completed manually. Having experimented with a software program (NVivo) in the analysis of the pilot studies, a manual process was chosen in response to the limitations of the size of the computer screen which prevented the researcher being able to see much of the data at any one time. As a manual process it was possible to lay out all the data at once, and to see it all at once, all the time. This was a particular consideration for this process as no pre-conceived coding framework was being used.

This process was developed from existing approaches to concept mapping (Jackson & Trochim, 2002) and existing approaches to thematic analysis (Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton, 2002; Ryan & Bernard, 2003; Strauss & Corbin, 1990; Weller & Romney, 1988). Concept mapping as defined by Jackson and Trochim (2002):

is a multistep hybrid method that uses original intact respondent statements as units of analysis, solicits the actual survey respondents or respondent proxies who use pile sorting to “code” the data aggregates quantitatively across individual conceptual schemes, and enables the data structure to emerge through use of multidimensional scaling and cluster analysis of the aggregated individual coding data (p. 309).

This process consists of a combination of qualitative and quantitative processes developed to analyse open-ended questions in surveys to produce statistical results that could be compared with results from the rest of the survey. Both words and codes are used as units of meaning or concepts. Units of meaning are defined and described to limit the variability in researcher interpretation. They are then pile-sorted by the respondents themselves and the results entered into a statistical analysis program which results in a visual representation of thematic clusters. In this instance it was the qualitative methodological component that was relevant to the current study. This process involved a system that enabled the researcher to attend to all data and required no pre-existing coding framework that could limit interpretation. The idea of having respondents carry out the pile sorting also appealed greatly but this was not possible in this instance.

Patton (2002) offered a useful set of definitions for pattern, theme and content analysis for this study. Content analysis is described as “any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (p. 453). Within this process, thematic analysis is described as the process of finding patterns of meaning which result in categorical themes. This process is usually systematised in some way. Lincoln and Guba (1985) argue that the rules surrounding the creation of patterns or themes need to be well defined, if not in advance then throughout the process with the final set of themes having been subjected to the final set of rules.

In combination, these approaches provided the basis of the Hybrid Process which was developed for this research. The Hybrid Process was an inductive process, consisting of five stages, which was completed manually. The first stage consisted of breaking down the whole of the transcripts into manageable, definable, and meaningful parts or units. These units were then clustered or sorted into concept piles. Patterns of meaning were recognised in the piles of concepts, which were then clustered to create Level 1 themes. Further patterns of connection were identified between Level 1 themes that were then clustered to create Level 2 themes. Finally, Level 2 themes were aligned with the domains of children’s experience with which they belonged, as indicated by the data aligned to them in early stages in the process.

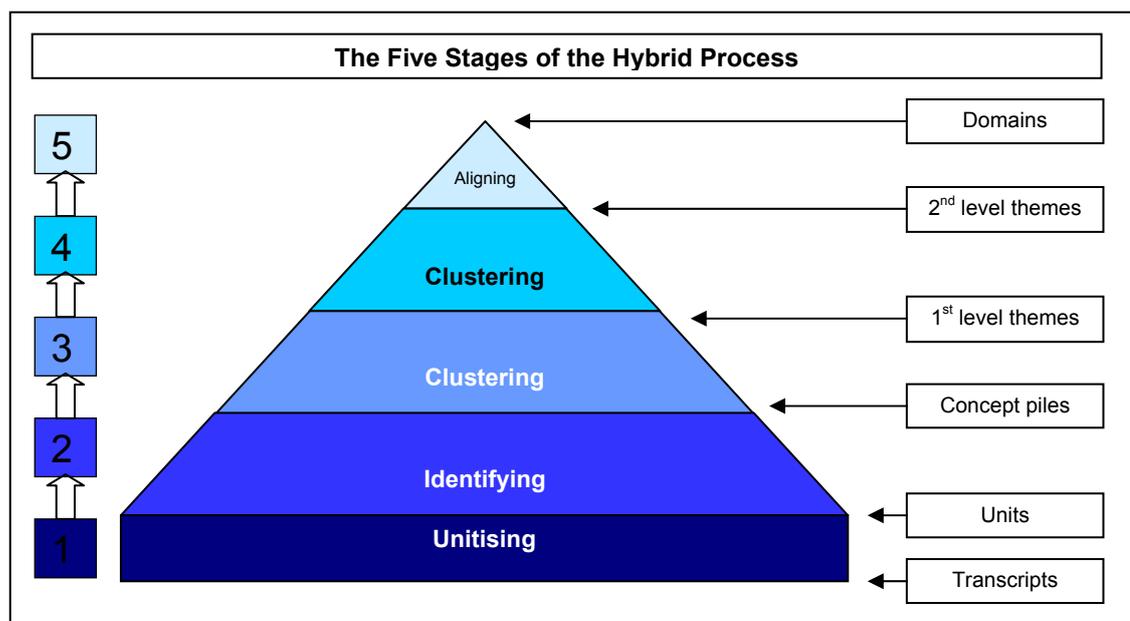


Figure 7.5. A diagram of the five-stage Hybrid Process used in the analysis of data from Tasks A and B.

As the data analysis process progressed, the upward movement between levels was determined by the recognition of the possibility for increased conceptual strength, breadth, and definition, if units, or concepts or themes were combined. This provided the organising principle for this process. Further definition of the characteristics of each level are discussed below. These governing characteristics were developed in response to recommendations from the literature identified in each instance. Figure 7.5 is a diagram of the five-stage process.

**Stage 1: Unitising the data.** Units consisted of statements of preference, statements of fact, illustrations of knowledge, emotional responses, acts and actions of themselves, and of others, and with others (Jackson & Trochim, 2002; Lincoln & Guba, 1985). Units had to be able to stand alone and they were created by isolating every comment, point made or concept implied in the data. They also had to include sufficient contextual information so that the context of the unit could be properly understood (this may range from an additional line, to an additional paragraph). Each unit would be given a tag line to identify the unit being isolated.

In the case of sentences with multiple units and concepts, these sentences or paragraphs would be kept as a whole to preserve their meaning but they may be copied so that they could be placed in a number of concept piles, ultimately ensuring that each unit could contribute to the development of the themes they each pertained to. Each copy would carry a different tag line to identify the unit being isolated.

Examples of single units by comment, point or concept:

This is for younger kids. (+ context)  
I really like the paintings. (+ context)  
I was on bed rest for 2 weeks and it really sucked (Concept: bed rest sucks)

Example of a sentence with multiple single units:

(We go there for walks) and (I really like the fresh air and sunlight) and (it's really pretty) but (I don't like how the water is always dirty.)

Example of a sentence with multiple concepts:

You know just the whole Starlight thing, you know as soon as you walk into the room it's all about you. 'Cause the people in Starlight are like 'Oh hey! Welcome how are you?' Everyone is so nice to you and nothing, you can almost like, like everything is for free you know, they're not trying to be nice to you because they're trying to get something out of it. There's no gain for them, it's all about the kids, it's great. You know, they really put smiles on people's faces. They've got crap jokes but they're funny as well. (Concepts: a place that says "kids first"; appreciating welcome and generous approach from staff; appreciating concept of Starlight)

**Stage 2: Sorting concepts.** Units were sorted into piles of concepts based on similarity of meaning where possible. Concept piles were made up of units which said almost the same thing about the same thing (Jackson & Trochim, 2002; Lincoln & Guba, 1985; Strauss & Corbin, 1990; Weller & Romney, 1988).

Examples of units with a similar meaning:

Bedrest area - I really like the picture on the wall  
Bedrest area - The design on the wall is great  
Bedrest area - I think the drawing on the wall is really cool

**Stage 3: Clustering concepts to Level 1 themes.** Creating Level 1 themes was the result of identifying patterns of meaning implicit in a single pile or in multiple piles of concepts. The basis of a Level 1 theme was subject, action/activity or actors, preference, response, type of incident. A Level 1 theme was created in response to repetition, similarities and differences, type of action, actor, group, or incident (Ryan & Bernard, 2003; Strauss & Corbin, 1990). Concept piles could contribute to the creation of more than one theme.

Example of how a Level 1 theme was created:

Concept pile:

I think it's more for little kids  
I think they're a bit too young for me (other patients in wardroom)  
I think it needs to look more "adolescenty"  
I think I'm a bit the wrong age  
They're a bit younger than me, I don't like to talk to them  
It's mostly for little kids (Starlight)  
It was unfair that I had to be in there with babies (ward room)

Level 1 theme: Consciousness of age

**Stage 4: Clustering Level 1 themes into Level 2 themes.** If patterns of meaning and further connection were recognised between Level 1 themes, they were clustered to create Level 2 themes. For a Level 2 theme to be created, the Level 1 themes had to pertain to a similar overarching concept or phenomenon (Strauss & Corbin, 1990). Level 2 themes were stand-alone subjects. They could be centred on a social group, an aspect of the physical environment, organisational considerations, or on an aspect of personal experience. They could also be overarching concepts that recognised an interconnection between all or some areas of children's experience. Themes at this level represent the major findings of the data and they are conceptually quite distinct, preventing any further possibility of conceptual clustering.

Example of how a Level 2 theme was created:

Level 1 theme: Consciousness of age  
Level 1 theme: Consciousness of age-appropriate spaces/places  
Level 1 theme: Consciousness of age appropriate activities

Level 2 theme: Age-Appropriateness

**Stage 5: Aligning Level 2 themes with domains.** Theoretically, Stokols' (1992) social ecological model of health promotion has guided the concept of individual well-being being used in this study. As discussed, his conceptualisation of well-being consists of a number of interconnected domains in an individuals' (or community's) experience. Until the point of data analysis, the idea of what those domains were, and what the key characteristics of them may be was notionally developed from the healthcare and healthcare design literature, as well as from the findings from pilot studies 2A and 2B. However, ultimately the domains selected had to be present in the data from the main study. This final stage of the Hybrid Process consists of identifying evidence for major domains from within the data aligned to each Level 2 theme.

The group of notional domains consisted of five domains: personal experience, social experience, physical environment, organisational considerations and time. Characteristics for each of these domains were developed again from the literature and from the pilot studies. Level 2 themes could be aligned with more than one domain if the data aligned to the theme contained evidence for a number of alignments. For a Level 2 theme to be aligned with a domain it must have data aligned to it with the characteristics identified for each domain:

1. Personal experience: The data must concern the individual, express an individual preference, or contain a response to a personal experience, or an account of a personal experience/story
2. Social experience: The data must concern a social process, behaviour or social group
3. Physical environment: The data must concern some aspect of, or use of, or response to, the physical environment
4. Organisational considerations: The data must concern some aspect of, or have implications for, an organisational strategy, policy, approach, or opportunity/facility/activity provided, that is within the control of the organisation.
5. Time: The data must concern some aspect of the effect of, or response to, time.

Example of a Level 2 theme with evidence for a number of alignments to domains:

Level 2 theme: Age-Appropriateness

Consists of:

Level 1 theme: Consciousness of age (Domain: Social)

Level 1 theme: Consciousness of age-appropriate spaces/places (Domains: Physical/Social)

Level 1 theme: Consciousness of age-appropriate activities (Domains: Organisational/  
Physical/Social)

This theme therefore is aligned with the domains of social experience, physical environment and organisational considerations.

**Tasks A and B: The second breakdown.** The second breakdown of the data in Tasks A and B was organised using the research instrument that had been used in the interviews in each task. For Task A, this meant grouping all the conversation that occurred in relation to each area shown in the photographs. For Task B this meant grouping all the conversation that occurred in answer to each question. These units of data were substantially larger than the first breakdown and allowed a further reading for themes. Themes identified in this process were equivalent to the Level 1 themes in the Hybrid Process.

The results from the first and second data analysis processes in each of both Tasks A and B were then combined to ensure the most comprehensive readings of possible themes in each of the tasks. This combined result constituted the overall findings for each task, to be used in the process of triangulation in the next stage of analysis.

**Task C: Game task.** The game task produced sheets that required tallying. Each line drawn by the participants linking a reason to an image was worth one count. Having tabulated the results, it was then possible to analyse which reasons and areas were selected most, and whether there was any pattern that could be identified.

**Triangulation.** Conducting convergent triangulation (Yin, 2003) is a challenging process. Convergent data triangulation involves analysing multiple sources of evidence that ultimately contribute to the one set of conclusions. The challenge is to be able to keep track of threads of information at both Levels 1 and 2 of the themes, in all tasks in the interview, so that the conceptual strength, accumulated through the repetition of an idea, is not lost.

The triangulation process was used to create ‘major’ and ‘minor’ themes. Whether a theme became a major or a minor theme depended on the *volume of evidence* present in the findings from the data analysis of the three tasks in the main study interview. The greater the amount of evidence, the greater the definition, breadth and depth on the subject in the data and therefore, the greater the presence of the theme in the data. This process was designed to recognise the themes with a major presence in the findings and those with a minor presence in the findings. These two groups of themes do not equate to a hierarchy of issues of importance in patient experience. At this level in the analysis process, a theme in either list is an issue of importance in children and young people’s experience. The characteristics used to define a major theme included:

- Recurred across Tasks A, B and C (but not necessarily all three, due to the limitations of Task C)
- Supported by a large volume of evidence in the data (volume being understood as the depth, breadth, conceptual strength and definition)
- Conceptually robust (likely to consist of multiple dimensions)
- Transcended the influence of any particular questioning or research instrument used
- Discussed by most of the participants

The characteristics used to define a minor theme included:

- May not have been a theme if the research instruments had not provided the prompts
- Important but not seminal in the experience for participants as revealed in the interviews
- Lacked the conceptual and evidentiary strength and robustness of a major theme
- May only be represented in the findings from one section of the interview (but may have been consistently discussed because it was introduced by the research instrument)

Creating major and minor themes by triangulating findings across all three tasks mapped out the breadth, depth, definition and description of each theme as revealed in the data. Beyond this, a further reading within each theme was still required to identify

variation influenced by characteristics of the sample such as age, gender, illness type, and length of time in the Hospital.

### **Establishing Trustworthiness**

**A reflexive journal.** From the outset of the study a reflexive journal as recommended by Lincoln and Guba, (1985) was kept by the researcher. Lincoln and Guba (1985) recommend this as it has the capacity to inform all aspects of their conceptualisation of trustworthiness including: credibility, dependability, confirmability and transferability. They recommend using the journal to record methodological, intellectual and logistical information and shifts throughout the research process. In this instance, the journal was used to record all of these shifts, as well as information learned and observed, and ideas as they developed on all these fronts. Entries were not regular but they were constant. The journal accompanied the researcher all the time.

At this end of the process, the journal is the only place where all the methodological, intellectual and logistical shifts are recorded, at least in part. It is also the only place where the reflexive approach used in the study is recorded. It is not only invaluable as a resource to the researcher for this, it also provided consistent practice in conceptualising what was going on, what decisions were being taken, and why. It is an invaluable tool in qualitative research because it has the capacity to record what would otherwise be footsteps in the sand; transitory thoughts in passing not otherwise remembered in the process. It is also a useful part of maintaining a consistent chain of evidence (Yin, 2003).

Excerpts from the journal are included in the thesis when appropriate. This reflects the recommendation by Lincoln and Guba (2002) that case study reports should contain reflections of the researcher's personal experience of fieldwork and examples of his or her conscious reflexivity because a case study is a construction. It is the product of the interaction between respondents, site and researcher, which is constructed by the researcher who has an obligation to be self-examining.

**Maintaining a consistent chain of evidence.** This is a step which Yin (2003) recommends for ensuring the reliability of a study. It is a procedure that allows an observer to follow the derivation of evidence from the research questions to the

conclusions. According to Yin (2003), it should minimise the loss of evidence and carelessness, and support construct validity within the study, increasing the overall quality of the case. For Lincoln and Guba (1985), this would be similar to maintaining an audit trail that has the capacity to support dependability and confirmability within the study.

Throughout the study, constant vigilance has been given to the need to supply all the methodological, intellectual and logistical stepping-stones between the research questions and the conclusions. Chapter 8 gives examples and insight into this process. The journal is also part of this record and is a substantial primary resource, which the researcher would like to make further use of and therefore does not want to make publicly available at this point.

**Prolonged engagement and persistent observation.** These are two credibility measures suggested by Lincoln and Guba (1985). In this study, they have been interpreted in relation to the context of the study. The whole process of the research has occurred in the context of the Hospital across 22 months. The initial data collection phase began in October 2004 with Pilot Study 2, Part A, and the final data collection phase was completed with the member-checking task in August 2006. This allowed for both prolonged engagement and persistent observation of the context in operation, and of the nature of the experience for patients, families and staff. It also made it possible to speak with many groups of professionals and patients and their families both formally and informally to supplement the researcher's knowledge and talk about emerging ideas and findings. Prolonged contact with the context has the capacity to inform the researcher's interpretation of actions, actors and events and increase the credibility of the findings as a result.

**Methodological triangulation.** This has been discussed previously. Triangulation addresses the issue of reliability and dependability of the findings. As a process in which multiple methods or sources of data are combined, it does have the capacity to provide a more complete picture and to reveal more clearly what are the areas of convergence and what are the areas of divergence which can be useful to the final interpretation made (Patton, 2002; Yin, 2003). However, this is not to be mistaken for a

claim to a more correct position as a result of this process, merely a more substantiated one.

**Member-checking.** The process of member-checking gives the researcher additional opportunities to be exposed to participants and key stakeholders in the context being studied. In creating these opportunities the researcher increases the chances of making a credible interpretation of the data, and ultimately, of children's experience. This is how this task was viewed in this study.

Lincoln and Guba (1985) discuss completing this process at two points: during the research and at the end of the data analysis. Although they viewed member-checking as part of a process of corroboration which is not how it was viewed in this instance, member-checking was carried out at both these stages in a limited capacity in this study.

In approximately 30% of cases, the main study interview was summarised in the following 48 hours and returned to the participant for further discussion. This was very productive but catching up with participants twice was very difficult as their lives in the Hospital were unpredictable and the process was discontinued.

The second set of member checks were conducted at the end of triangulation when preliminary findings were reached. Key insights from the findings were taken back to a group of patients who were representative of the same group of participants in the original group interviewed in the main study, for further discussion. (For information and consent forms see Appendix E).

This second group of participants was given a series of cards that contained strong statements in relation to aspects of each of the major and minor themes resulting from the triangulation process. These cards were used as prompts for discussion on the relevance of each statement to their experience (for prompt cards see Appendix F). The point of this exercise was to look for resonance or dissonance with the preliminary findings with a second group, and to challenge the developing understanding of the researcher at this point. These additional interviews were assessed for supplementary information in relation to all themes. These findings are reported separately in relation to each theme in chapter 10.

Across a period of four weeks, six participants completed the member-checking task. This group were selected using the same sample criteria used to select participants interviewed in the main study. In this task, participants were told that the prompt cards represented a summary of some of the main things learned from other kids in the hospital and that they were being asked to consider these things in relation to their own experience.

It was not possible to return the findings to the original group. Even if it had been possible, this is a doubtful methodological step. It is doubtful whether participants have the capacity to ‘validate’ the researcher’s interpretation or to corroborate the credibility of findings. Fielding and Fielding (1986) go as far as to say that individuals should not even be considered experts on their own actions let alone on the results of a complex process of analysis. The Fieldings (1986) argue that these tasks should be viewed as yet another source of data and insight rather than being part of a validation process. This is how this process was used in this study. Table 7.3 provides a breakdown of the sample in this exercise.

Table 7.3

*Profile of the Sample in the Final Member-Checking Task*

<b>Member-checking</b>	<b>Age &amp; Gender</b>	<b>Ward</b>	<b>Time in Hosp. as at interview</b>	<b>No. of visits to a hospital</b>	<b>Diagnostic group</b>
1	10 B	Surgical	2 weeks	1st	Surgical
2	12 G	Clancy	9 days	1st	Gastroenterology
3	16 G	Clancy	10 weeks	Multiple	Gas/Transplant
4	18 G	Camperdown	8 days	Multiple	Oncology
5	16 B	Wade	11 days	Multiple	Respiratory
6	14 G	Wade	4 weeks	1st	Eating Disorders

In chapter 7, the main methods used in the main study have been summarised. The methods of data analysis are complex and their application warrants further explanation. Chapter 8 provides further insight into the methods of data analysis and their use.

## CHAPTER 8

### DEVELOPING FINDINGS FROM THE MAIN STUDY

The aim of the chapter is to provide a window into the systematic handling of the data analysis, and into the development of connection and interconnection that exists within the data. It provides a more detailed description of many of the processes used in the analysis of the main study data, and the subsequent member-checking task carried out following triangulation. The aim is to make the process of interpretation as transparent as possible to provide a chain of evidence and ensure that the credibility and trustworthiness of the findings is supported (Lincoln & Guba, 1985). It also assists others following in the researcher’s footsteps in their ability to decide whether they would reasonably be able to arrive at similar conclusions if using the same methods on the same data (Patton, 2002)<sup>11</sup>.

Figure 8.1 provides a summary diagram of the data analysis processes used in the main study.

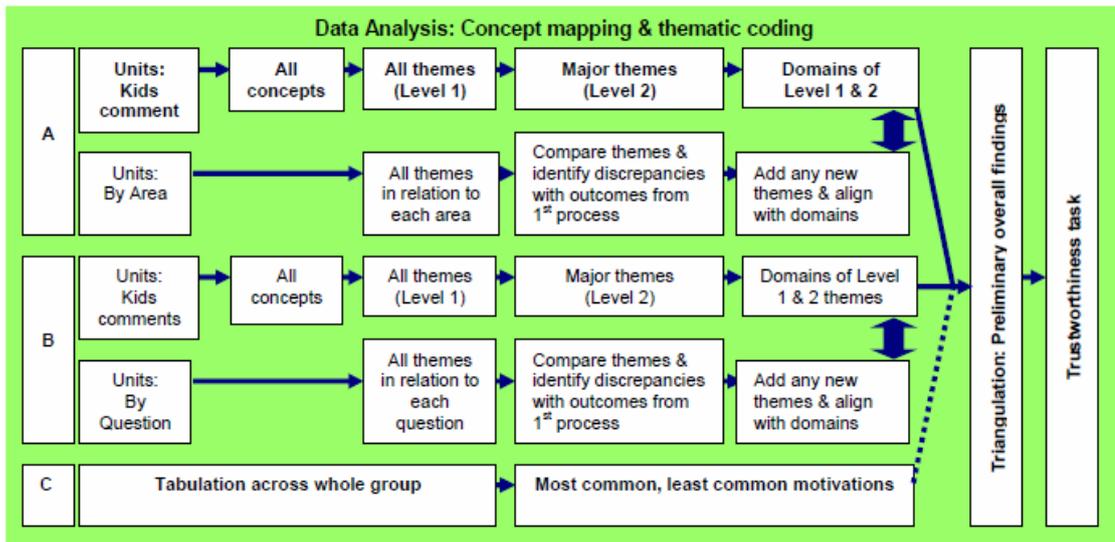


Figure 8.1. Plan of data analysis.

<sup>11</sup> One examiner made the comment that it is customary to demonstrate that “others” might reasonably draw the same conclusions as the primary researcher and cites Patton (2002). The researcher’s interpretation of Patton’s meaning was not literally that all qualitative researchers require external involvement in order to validate qualitative research. In many instances this would be problematic and unrealisable as it was in this study, due to practical constraints. Instead, the researcher interpreted Patton’s recommendation to mean that the researcher’s methods should be sufficiently exposed and explained to ensure the transparency of the process, enabling others to follow in the researcher’s footsteps and to understand how the researcher’s interpretation came into being.

The first process that will be discussed is the Hybrid Process. This process was used twice, on the data from both Tasks A and B. Here it will be discussed in relation to its use on the data from Task A only as the process used was exactly the same in Task B. The process involved in the second breakdown of the data in both Tasks A and B will then be described briefly. The data analysis for Task C will also be discussed here, as its analysis was quite different to the theme and concept analysis processes used in Tasks A and B. The process of triangulation will be described also. This too is a complex process which needed systematic handling and this discussion will give insight into how it was managed. Finally, the member-checking task that was carried out following the development of preliminary findings is also discussed further.

### **Tasks A and B: The Hybrid Process**

As described in chapter 7, the data from Task A, in 25 interviews were broken down into units, based on the criteria outlined. There were approximately 1500 of these in this section. Units were then grouped into concept piles based on the similar nature of the subject of the units. As described in chapter 7, in the case of sentences where there were multiple units which needed to remain together to provide the context and meaning of each other, this sentence would be duplicated until all the units within it were recognised and identified so that they could contribute to the development of the concepts that they were related to. In the end there were approximately 300 concept piles.

Concept piles were then clustered further into Level 1 themes, recognising the similarity that existed between concept piles and their ability to pertain to the same phenomenon (Strauss & Corbin, 1990). Some piles of concepts related to more than one theme. At this point they were not duplicated in hard copy as had been the case in the previous level. They were allocated to one theme, but a note was made that they also belonged in another theme as well, so that these connections could be accurately maintained in the electronic record. In the end there were approximately 90 Level 1 themes in the data from Task A.

At the end of creating Level 1 themes, it was clear that a further level of clustering and abstraction was possible. Between Level 1 themes there were still connections which could enable further groupings to be made. However, at this level of clustering, these

groupings would be made at the expense of other possibilities. Up until this point in the process the clustering of units to concept piles, and concept piles to Level 1 themes had been quite direct. At these levels there had been no elimination of possibilities. Any possible connection had been recognised and recorded so that the connection remained. However the movement from Level 1 to Level 2 themes meant that major decisions were made as to which were indeed the central themes of the data.

Whether a Level 2 theme was created depended on the volume of evidence for it at the previous levels of the process. Most Level 2 themes were well supported by data and were readily identifiable. A few were not as strongly supported and so various groupings were developed to finally isolate the strongest grouping within the data. The variation usually only concerned one or two themes and the question was usually whether they were indeed well enough supported by data to warrant Level 2 theme status. In the end there were 19 Level 2 themes created through this process in Task A.

Finally, each Level 2 theme, and the data that was aligned to it, were assessed for evidence for domains in children's experience of hospitalisation. In this interview task there was evidence for five domains including, personal experience, social experience, physical environment, organisational considerations, and time.

Figure 8.2 shows the record for one of the Level 2 themes from Task A as an example. Each of the levels is identified, including the units, concept piles, Level 1 themes, the Level 2 theme and finally, the domains for which there is evidence in the data. The coloured squares in the corner of the unit boxes indicate the domains that the unit provides evidence for. This is then reflected in the coloured boxes in the corner of the themes at both levels. This theme has evidence within the data for four domains. This process was carried out in a similar way for all Level 2 themes.

To give an indication of the overall findings from the hybrid analysis process of Task A data, Table 8.1 lists the final group of 19 Level 2 themes resulting from the Hybrid Process for Task A, and the Level 1 themes that were aligned to each of them. The Level 2 themes are in no particular order. To a limited extent this table shows the interconnectedness between Level 2 themes through the Level 1 themes aligned to them. The Level 1 themes in this table are listed beside all the Level 2 themes with

which they have a connection. Unfortunately it is not possible to show the units aligned to each Level 1 theme in this table due to the constraints of the page.

The domains which are involved, (as evident in the units aligned to each Level 1 theme), have also been indicated by coloured squares. When there are multiple domain colours attached to a Level 1 theme, it reflects the evidence in the units aligned to that theme as in the example in Figure 8.2. The domains associated with Level 1 themes are then reflected in Level 2 themes. Each colour is associated with a particular domain (as indicated by the key).

In effect these colour indicators show the interconnection between Level 2 themes and between domains. For example: both Level 2 themes *Influence of diagnosis on experience* and *Personalisation of bed space* have connections to all five domains via the units that are individually aligned to them. They also have connections to each other via the Level 1 themes aligned to them as some of these are shared between these two themes.

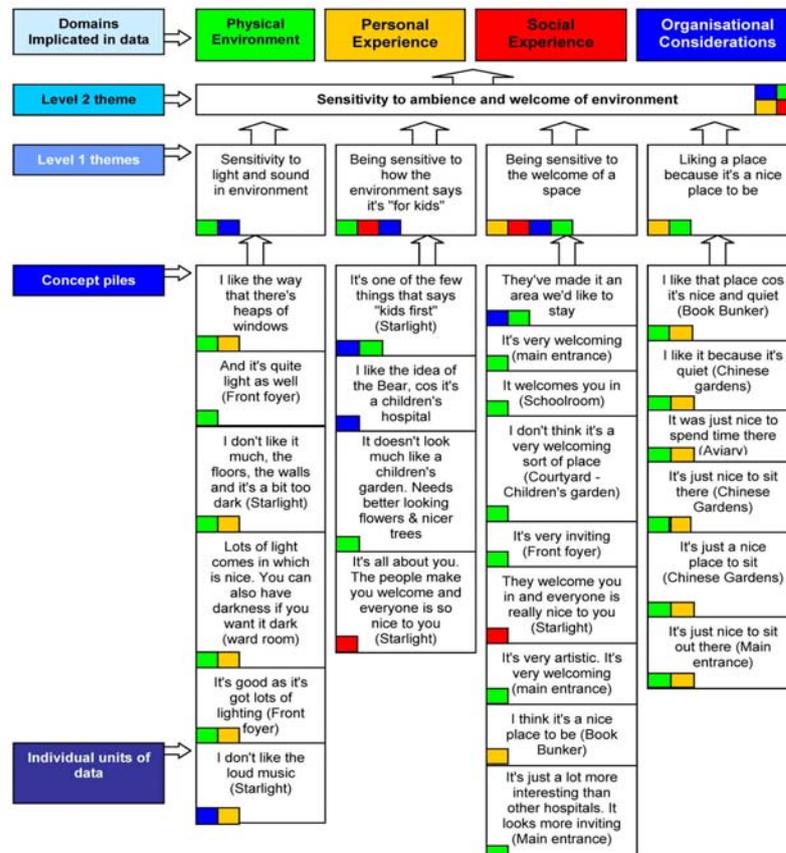


Figure 8.2. An illustration of the stages of the Hybrid Process in relation to the Level 2 theme: *Sensitivity to ambience and welcome of environment*, Task A, Main Study.

Table 8.1

*Final List of Level 2 Themes, and the Level 1 Themes Aligned to Them; Resulting from the Hybrid Process, Task A, Main Study.*

	Level 2 theme	Level 1 theme	Domains involved
1	<b>Influence of diagnosis on experience</b>  	Influence of diagnosis or illness on experience	
		The effect of being in hospital before	
		Appreciating support from staff	
		Family as key presence in the experience	
		Liking being able to personalise own bed space	
		Getting bored	
		Influence of treatment program on experience	
2	<b>Personalisation of bed space</b>  	Feeling more at home brings comfort	
		Liking being able to personalise own bed space	
		Liking things that remind them of home	
		Family as key presence in the experience	
		Influence of own condition or illness on experience	
		Influence of treatment program on experience	
3	<b>Other patients</b>  	Not appreciating how other kids leave facilities (messed up or broken)	
		About friends (other patients)	
		Moving around to socialise with friends	
		Knowledge of other kids experience	
		Roommates - companionship vs. privacy	
		Socialising with friends	
		Using places to socialise with other patients	
		Not using a social place because no one else does	
4	<b>Staff (includes anyone employed at hospital)</b>  	Being sensitive to the behaviour of staff	
		Appreciating support from staff	
		Socialising with staff	
		Using a place to socialise with staff	
5	<b>Age-appropriateness</b>  	Consciousness of age	
		Consciousness of age-appropriate activities	
		Consciousness of age-appropriate spaces/places	
		Appreciating variety of activities available	
		Appreciating facilities available	
6	<b>Family (immediate and extended)</b>  	Family as key presence in the experience	
		Socialising with family	
		Needing to get away from hospital and the feeling of being in hospital	
		Using places to socialise with family	

Table 8.1 (continued).

*Final List of Level 2 Themes, and the Level 1 Themes Aligned to Them; Resulting from the Hybrid Process, Task A, Main Study.*

	Level 2 theme	Level 1 theme	Domains involved
7	<b>Noticing architectural features</b>	Noticing architectural features	
		Not noticing physical environment	
		Appreciating variation and difference in environment	
		The look of an area being artistic	
		Not using a place because you don't like the way it looks	
		It looks boring	
		Appreciating how areas are laid out or set up	
8	<b>Variety and difference</b>	Appreciating variation in routine	
		Getting bored	
		Appreciating variation and difference in environment	
		Noticing architectural features	
		Needing to get away from hospital and the feeling of being in hospital	
		Noticing and appreciating the artwork in environment	
		Noticing the décor	
		Appreciating colour in environment	
		Appreciating variety of activities available	
		Appreciating facilities available	
		Appreciating artwork	
9	<b>Awareness of environment as "a hospital"</b>	Needing to get away from hospital and the feeling of being in hospital	
		This hospital looks different to other hospitals	
		Noticing architectural features	
		Appreciating variation and difference in environment	
		Noticing and appreciating the artwork in environment	
		Appreciating colour in environment	
10	<b>Appreciating aesthetics</b>	Noticing and appreciating the artwork in environment	
		Noticing the décor	
		Liking the wooden "seats" (Front foyer)	
		Appreciating colour in environment	
		Appreciating prettiness/beauty	
		Not using a place because you don't like the way it looks	
		The look of an area being artistic	
		Appreciating the artistry of the Red pagoda (Chinese gardens)	
		Appreciating artwork	
		Appreciating variation and difference in environment	

Table 8.1 (continued).

*Final List of Level 2 Themes, and the Level 1 Themes Aligned to Them; Resulting from the Hybrid Process, Task A, Main Study.*

	Level 2 theme	Level 1 theme	Domains involved
11	<b>Functionality and serviceability</b>	Not appreciating lack of control over noise and light in ward rooms	
		Being sensitive to the physical comfort of spaces	
		Appreciating how areas are laid out or set up	
		Appreciating functionality of features of physical environment	
		Noticing disrepair	
		Noticing uncleanliness	
		Considering the space in light of its use or purpose	
		Appreciating facilities available	
		Noticing how a hospital system operates	
		Appreciating products available to buy	
		Considering the functionality of the space	
		Not appreciating how other kids leave facilities (messed up or broken)	
12	<b>Using places to socialise</b>	Using places to socialise with friends (from outside the hospital)	
		Using places to socialise with family	
		Not using a social place because no one else does	
		Using places to socialise with other patients	
		Using a place to socialise with staff	
		Visiting a place for the activities & entertainment available there	
13	<b>Contact with nature and outdoors</b>	Appreciating having a view of the outdoors	
		Appreciating having access to outdoors (to escape, socialise, for variety/change)	
		Appreciating natural qualities and features in outdoor areas	
		Liking the animals in the environment	
		Not appreciating contact with nature	
		Not liking an outdoor area because of the sensory quality	
		Using places to socialise with family	
		Using places to socialise with friends (from outside the hospital)	
		Appreciating prettiness/beauty	
		Appreciating variety of activities available	
		Appreciating variation and difference in environment	
		Needing to get away from hospital and the feeling of being in hospital	

Table 8.1 (continued).

*Final List of Level 2 Themes, and the Level 1 Themes Aligned to Them; Resulting from the Hybrid Process, Task A, Main Study.*

	Level 2 theme	Level 1 theme	Domains involved
14	<b>Improvements &amp; Recommendations</b>	Improving hospital in general	
		Improving Cafeteria	
		Improving Children's Garden	
		Improvements to Wade Ward Common Room	
		Improving Starlight Room	
		Improving Main Entrance	
		Improving Chinese Gardens	
		Improving the Moroccan area	
		Dislike of ward beds	
		Improving the Ward Rooms	
		Improving the School Rooms	
		Improving the Chemist	
		Not appreciating lack of control over noise and light in ward rooms	
			
15	<b>Sensitivity to the ambience and welcome</b>	Sensitivity to light and sound in environment (ambience, welcome & spatial quality)	
		Being sensitive to how the environment says it's "for kids"	
		Being sensitive to the welcome of a space	
		Liking a place because it's a nice place to be	
		Appreciating colour in environment	
		Appreciating artwork	
			
16	<b>Activities and keeping occupied</b>	Using places for what you can do there	
		Going to school	
		Liking mobile & interactive activities that visit ward rooms	
		Visiting a place for the activities & entertainment available there	
		Not visiting a place because the activities available don't interest	
		Going to a place to buy things	
		Pastimes- (wandering on own, with friends or family; people watching; talking on phone)	
		Appreciating variety of activities available	
		Getting bored	
			
17	<b>Value for money</b>	Cost of things to buy or rent too expensive	
		Getting free stuff is good	
		Things being of good value	
		Going to a place to buy things	
		Dislike of food (Lvl 1Cafeteria)	
		Good food (Bear café)	
			

Table 8.1 (continued).

*Final List of Level 2 Themes, and the Level 1 Themes Aligned to Them; Resulting from the Hybrid Process, Task A, Main Study.*

	Level 2 theme	Level 1 theme	Domains involved
18	<b>Food</b>	Dislike of food (Lvl 1 Cafeteria)	■
		Good food (Bear café)	■
		Getting bored	■ ■
		Appreciation variation in routine	■ ■
	■ ■		
19	<b>Knowledge of services and activities</b>	Knowledge of services available	■
		Knowledge of activities available	■ ■ ■
		Appreciating variety of activities available	■ ■ ■ ■ ■
		Liking mobile & interactive activities that visit ward rooms	■ ■ ■ ■ ■
		Visiting a place for the activities & entertainment available there	■ ■ ■ ■
		Going to a place to buy things	■ ■
	■ ■ ■ ■ ■		

**Key to domain colours:**

■	Personal experience	■	Organisational considerations
■	Social experience	■	Time
■	Physical environment		

For comparison, a list of the Level 2 themes that resulted from the Hybrid Process in both Tasks A and B are listed in Table 8.2. There is considerable overlap in the themes that resulted from both sections of the data, with more than half being present in both sections.

This process created the first set of findings in relation to concepts, themes and domains for both Tasks A and B. The findings from this process were combined with the findings from a second thematic analysis process (called the second breakdown) in both Tasks A and B, to form the major findings for each section, ahead of completing the major triangulation process.

Table 8.2

*A List of the Level 2 Themes that Resulted from the Hybrid Process from both Tasks A & B*

	<b>Level 2 themes: Task A: Hybrid Process</b>		<b>Level 2 themes: Task B: Hybrid Process</b>
1	Influence of diagnosis on experience	1	Influence of diagnosis on experience
2	Personalisation of bed space	2	Personalisation of bed space
3	Other patients	3	Other patients
4	Staff (includes anyone employed at hospital)	4	Staff (includes anyone employed at hospital)
5	Age-appropriateness	5	Age-appropriateness
6	Family (immediate and extended)	6	Family (immediate and extended)
7	Noticing architectural features	7	Friends from home
8	Variety and difference	8	Variety and difference
9	Awareness of environment as "a hospital"	9	Noise, light and temperature
10	Appreciating aesthetics	10	Appreciating aesthetics
11	Functionality and serviceability	11	Brightness
12	Using places to socialise	12	Wayfinding
13	Contact with nature and outdoors	13	Contact with nature and outdoors
14	Improvements & recommendations	14	Shared versus single rooms
15	Sensitivity to the ambience and welcome	15	Personal safety and security
16	Value for money	16	Information and being kept informed
17	Activities and keeping occupied	17	Activities and keeping occupied
18	Knowledge of services and activities	18	Maintenance issues
19	Food	19	Food
		20	Managing emotional response (coping)
		21	Privacy
		22	Personal control
		23	Response to environment and experience as a whole

#### **Implementing the Hybrid Process**

The experience of doing this kind of analysis is something that it is impossible to understand from the outside. Now at the end of the first process there is the feeling that I can't see the wood for the trees. Breaking things down into such tiny parts has made me very aware of the detail, and of the nature of the data itself but I don't feel closer to the meaning of it all at this point; just overwhelmed by the vast complexity of interconnection - and possibility. Moving between the units, concepts and level 1 themes was reasonably straightforward. There was no feeling that the decisions I was making were being made at the exclusion of other possibilities. This all changed though when creating level 2 themes. These necessarily prioritised and promoted particular themes in the data. I developed several sets of these. The variation that occurred between the sets usually only concerned 1 or 2 themes and the question was really about whether they were robust enough to warrant being credited with level 2 theme status. It's at this point that I became very conscious of making meaning from my data and the power of my role as interpreter. I found it an uncomfortable realisation. I wonder whether a more participatory approach, which involved children and young people in this stage more would alleviate this self-consciousness? Or whether you would always come away from qualitative analysis feeling that you have only acknowledged part of what is in evidence? I definitely feel that I have created only one reading and that others are possible. I was aware of some of them as I went along and explored them each for awhile but in the end, felt that to sustain them would require making too much of too little.

Journal: (19 March 2006, Bk 6)

**Tasks A and B: The Second Breakdown**

The second breakdown of the data in both Tasks A and B were organised based on the instrument that had been used in the interview in each case. For Task A the second breakdown was by area (as depicted in the photographs used as prompts in the interview). This meant that all the discussion that occurred in relation to each photograph was grouped together across all 25 interviews.

In Task B, this meant that all the discussion that occurred in relation to each formal question (from the schedule used in Task B in the interview) was grouped together across all 25 interviews. These groupings were then read for the themes and the resulting list compared with the list generated from the results of the Hybrid Process, so that the most comprehensive list of themes could be generated from the two processes in combination.

Table 8.3 provides an example of the second breakdown of the data in Task A, using the area: *Ward Room* and the data aligned to it from two of the interviews as the example. The coloured arrows indicate the domain or domains for which the theme provides evidence.

Table 8.3

*An Illustration of the Second Breakdown of Data by Area, Task A, Main Study, Using the Data from Two Interviews in Relation to the Area: Ward Room*

Area	Participant	Data	Themes
Ward Room	D11G	<p><b>R: How much time do you spend on a ward and what do you think of it?</b>                      P: On a ward, I spend prob'ly half a day on it.</p> <p><b>R: mmm – in your bedroom?</b>                      P: Yeah, unless I've got tests on or something obviously um... the bedsides are pretty good, it would be nice if they could have some colour and new pin boards 'cause they're like- wrecked. Um yeah I think the rooms are all good there. They could improve on the beds but.</p> <p><b>R: What's wrong with the beds?</b>                      P: The beds, 'cause I'm bony like, the mattresses are really hard and every time I come in I have to get like an air mattress 'cause they're that hard. Be nicer if they could have like...soft mattresses with like plastic on it or something? 'Cause otherwise, you know you can get</p>	<p>Improvements in ward area:                      More colour, new pinboards,                      more comfortable ward beds</p>

		<p>sore backs and tend to go home with aches and sores and...I got bed sores last time I was here...because I was like I'm really bony and like, I know my Dad's a pretty fat dude and he laid on the bed and he was like "gee this is hard!" I'm like "yeah, it's a wonder why I get bed sores!" He's like "gee you should tell them to improve on the beds" I'm like "yeah well I think I am!" So I think the beds are number one and yeah, be nice if they could have these electric ones, you know like Blacktown Hospital? I'm like ohhh I want that bed, 'cause I went to Blacktown Hospital once and I'm like.. I would soo come here if I had doctors here. I would never go back to Westmead, like for the simple reason of the beds and the food. I have to say the food!</p>	<p>← Improvements: Hospital food</p>
Ward Room	K9B	<p><b>R: So what do you think of this space?</b>  P: Bed's a bit small</p> <p><b>R: Length wise or width wise?</b>  P: Both, I mean I've got the extension on but sometimes I still kick my feet up against this so...</p> <p><b>R: How would you make this a space that is better for you?</b>  P: Fix the blind</p> <p><b>R: What's wrong with the blind? Just doesn't work?</b>  P: Yeah although personally my main objection of the room are with sleeping which is the fact that during the night and early morning there is still light coming through here and light coming in through there. Noises there's still noises of people around, they're really the main problems.</p> <p><b>R: So you don't mind anything about this space?</b>  P: Oh well other people have told me it should be brighter but I don't really care. I'm not really fussed about stuff. I mean you've got the TV there...</p> <p><b>R: That's all you need?</b>  P: Yeah and all my crap here. Yeah it's good having this here, 'cause like the bedside table is not very big so it's good having the lounge, to dump all my stuff on.</p>	<p>← Recommendations: bigger beds</p> <p>← Recommendations: repair blind</p> <p>← Not appreciating lack of control over noise and light in ward rooms</p> <p>← Not fussed about ward room environment</p> <p>← Appreciating ward room facilities</p>

**Key to domain colours:**

	Personal experience
	Physical environment
	Organisational considerations

Table 8.4 provides an example of the second breakdown of the data in Task B, using the question on: *Peer Support* and the data aligned to it from two of the interviews as the

example. The coloured arrows indicate the domain or domains that the theme provides evidence for.

Table 8.4

*An Illustration of the Second Breakdown of Data by Question, Task B, Main Study, Using the Data from Two Interviews in Relation to the Question on: Peer Support*

Question	Participant	Data	Themes
Peer Support	E24G	<p><b>R: How important is it making friends in the Hospital?</b></p> <p>P: Um I think it should be important because then you get to bond with everyone and you can like do stuff with them, so you're not like bored, and you get to talk to people with like the same um problem as you. You can like talk about that sometimes and it makes you feel better, and you know, like it just makes you feel like a bit normaler. It's just nice to socialise sometimes.</p>	<ul style="list-style-type: none"> <li> Socialising with friends</li> <li> Seeking peer support</li> <li> Avoiding boredom</li> </ul>
Peer Support	M14B	<p><b>R: How important is it making friends in the hospital?</b></p> <p>P: Very. I'm a very social person, I like to talk a lot um, making friends, I'm more into you know, not making long term friends but it's fun to have friends that you know just chill out and talk with 'cause 24 hours in a hospital, every single day is a whole lot longer than 24 hours at home 'cause sometimes there's nothing to do. In-between doctors you're just sitting here waiting for something, so it's nice you go and have a nice talks with the people and muck around, people your age. I'm really happy there's an adolescent ward here, so it is of importance.</p>	<ul style="list-style-type: none"> <li> Socialising with friends: Entertainment</li> <li> Avoiding boredom</li> <li> Socialising with friends: Coping strategy</li> <li> Consciousness of age</li> </ul>

**Key to domain colours:**

	Social experience
	Time
	Personal experience

The themes identified in this second process in both Tasks A and B were used to supplement the list of Level 1 themes identified as a result of the Hybrid Process in both Tasks A and B. Any additional themes created in the second breakdown were simply added to the records from the first thematic analysis process (as shown in Table 8.1) in the relevant places. This resulted in an additional eight Level 1 themes for Task A and a

further 15 Level 1 themes for Task B. There were no alterations to the Level 2 themes as a result of the second breakdowns for either Task A or Task B.

**2<sup>nd</sup> breakdown**

Before I embarked on this process the first time, I felt that I was probably being over cautious and that this was unnecessary work I had created for myself. However when I actually did it I found it enormously beneficial. The bigger slices of data that were the result of this process allowed me to recognise additional themes. Greater lengths of text had the capacity to make me see things differently and become aware of themes that I had not detected in the tiny units of the first process. It was a great help and in fact it made me feel obliged to go back and read each transcript as a whole again just in case there was another level of theme that I should recognise.

Journal: (30 March 2006, Bk 6)

**Task C: The Game Task**

Four out of the five data analysis processes involved thematic analysis. Task C required quite different analysis. Task C in the interview produced a series of sheets with lines linking the reasons for visiting places with the places in the photographs (See Figure 6.3 in chapter 6 for an example). These results were then tabulated. Each line drawn between a photograph and a reason represented one count. Figure 8.3 shows a summary table of the results. The list of reasons sitting below the table are the “other reasons” given. These are coded by number and area, for example, 1FF means first reason, Front Foyer.

Reasons for visiting	Front foyer	Main Fountain	Starlight Room	Red Pagoda	Chemist	Cafeteria	Total
I sometimes feel bored so I walk around	12	3	2	6	6	5	34
Because I like this place	3	5	7	7	2		24
I like to get away from my ward	8	6	10	12	5	9	50
To spend time with my family	4	10	2	10	2	10	38
to find people to talk to	1	1	7		1	2	12
to be with my friends	1	6	6	6		4	23
Because the place is bright and colourful	1	4	9	4	1	1	20
Because the place has things for me to play with and use there			9		1	1	11
To be outdoors instead of indoors		12		12			24
Other reasons?	4		1		3	1	9
<b>Total</b>	<b>34</b>	<b>47</b>	<b>53</b>	<b>57</b>	<b>21</b>	<b>33</b>	

1FF: It's the entrance  
 2FF: Escape our normal surroundings and be on our own  
 3FF: Starbucks  
 4FF: To access shops  
 1SR: Because it's cool  
 1CH: For cream  
 2CH: to buy things  
 3CH: to buy things  
 1CAF: Eat

Figure 8.3. Tally of games task sheets, Task C, Main Study.

Figure 8.3 shows an overall tally which reveals which of the areas were most popular and for which reasons. The three areas visited most for any reason are the Red Pagoda with 57, followed by the Starlight Room with 53, and then the Main Fountain with 47. The three most common reasons for visiting any area are “I like to get away from my ward” with 50, followed by “I like to spend time with my family” with 38 and “I sometimes feel bored so I walk around” with 34. Table 8.5 lists the results by reason hierarchically based on score.

The single highest score awarded to any one area for any one reason was 12 and this occurred in a number of places including:

- “I sometimes feel bored so I walk around” and the Front Foyer
- “I like to get away from my ward” and the Red Pagoda
- “To be outdoors instead of indoors” and the Main Fountain
- “To be outdoors instead of indoors” and the Red Pagoda

Table 8.5

*List of Results by Reason, with the Concept and Domain Implicit in Each Reason Identified: Task C, Main Study*

Reasons for visiting	Order	No. of results	Concept	Domain
I like to get away from my ward	1	50	Escape ward	Personal
To spend time with my family	2	38	To be with family	Social
I sometimes feel bored so I walk around	3	34	Avoiding boredom	Personal
Because I like this place	Equal 4	24	Using a place because you like it	Personal
To be outdoors instead of indoors	Equal 4	24	Appreciating access to outdoors	Physical
To be with my friends	5	23	Socialising with friends	Social
Because the place is bright and colourful	6	20	Appreciating aesthetics Appreciating brightness	Physical
To find people to talk to	7	12	Visiting a place to socialise	Social
Because the place has things for me to play with and use there	8	11	Visiting a place for what you can do there	Physical
Other reasons?	9	9	Escape To buy things Going to a place because you like it	Personal

Table 8.5 also lists the concept inherent in the reason and the domain for which it provides evidence. “Concepts” listed in the table are the equivalent of Level 1 themes in Tasks A and B. There is no Level 2 theme equivalent in this task.

These findings were used for their capacity to corroborate the findings from Tasks A and B in the process of triangulation.

### **Triangulation**

Having developed findings for all three tasks in the interview, a process of convergent triangulation (Yin, 2003) was used to create a single set of overall findings. In this process, described in chapter 7, major and minor themes were created based on the volume of supporting evidence present in the three sets of findings.

Practicing convergent triangulation (Yin, 2003) is a process that is difficult to describe. Converging findings from one task with another is not a simple process of comparison. This is too simplistic and does not allow for the fact that similar evidence may be present in different tasks but may be packaged in different contextual material.

For example, in both Tasks A and B participants’ discussed the “TV being too expensive to rent”. In Task A this Level 1 theme was aligned to Level 2 theme: *Value for money*, as there was sufficient discussion around this subject to constitute a whole theme in Task A. In Task B however, this was not the case and so this same theme is aligned to Level 2 theme: *Activities and keeping busy*. The challenge of the process was to be able to keep track of themes like this in all tasks in the interview so that the accumulated strength through the repetition of discussion on a subject is not lost. Converging data meant recognising the accumulated conceptual strength within the findings from all three tasks.

Figure 8.4 is a schematic representation of where evidence for major and minor themes could come from within the data in support of these themes during this process.

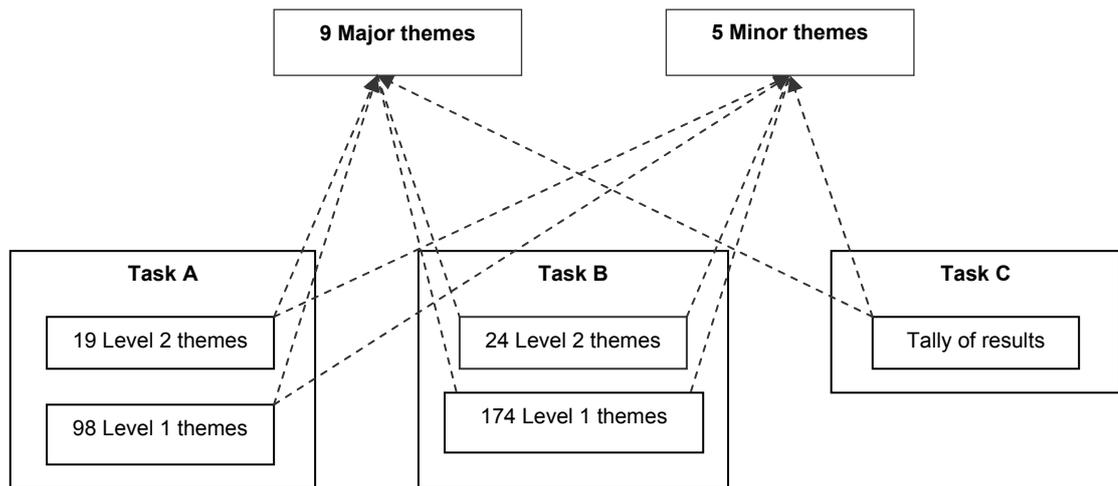


Figure 8.4. A representation of where the evidence for major and minor themes could come from within the findings.

Table 8.6 is a sample of the record created as major and minor themes were developed. Using the example of the major theme: *The key roles and experience of family*, Table 8.6 shows the Level 1 and Level 2 themes aligned to it, and which sections of findings they came from.

In the record shown in Table 8.6, only the Level 1 themes that were immediately relevant to the major theme were listed and they were only listed once, even if they were recorded in earlier records as being involved with more than one of the Level 2 themes listed. This reflected the focus and the point of this record, which was to indicate the strength of the evidence supporting the creation of the major or minor theme.

This process resulted in nine major themes and five minor themes. These themes were then aligned to the domains for which there was evidence in the data. The outcomes of these processes will be discussed in the following chapter.

Following the creation of a preliminary set of major and minor themes, an extensive description of each was written and the salient dimensions identified, along with variations introduced by age, gender or diagnosis as evident in the data and these descriptions formed the basis of the member-checking task.

Table 8.6

*Record Showing the Development of the Major Theme: The Roles and Experience of Family*

Major theme	Level 2 themes	Task of Origin (L2 theme)	Level 1 themes	Task of Origin (L1 theme)
<b>The roles and experience of family</b>	Roles of Family (immediate and extended)	A, B	Family central presence in the experience	A, B
			Family central support	A, B
			Pastimes with family	B
			Relying on family as a go-between with doctors	B
			Receiving special treatment from family & friends in hospital	B
			Socialising with family	A, B
			Needing to get away from hospital and the feeling of being in hospital	A
			To be with family	A, B, C
	Activities and keeping occupied	A, B	Using places for what you can do there	A, C
			Appreciating facilities available	A, B
			Improvements – facilities	A, B
			Using activities as a source of distraction from own situation	B
			Knowledge of activities available	A, B
			Appreciating activities available	A, B
			Pastimes- (wandering on own, with friends or family; people watching; talking on phone)	A, B, C
			TV too expensive to rent	A, B
	Effect of time	A, B	Hardest thing: missing home, friends, family, pets	B
			Length of time in hospital –affects family	B
			Effect of time moves through a progression of responses	B
			Effect of time – gets harder	A, B
			Familiarity vs. homesickness	B
			Effect of time-a balance between things becoming easier with familiarity & missing everything outside more & more	A, B
	Information and being informed	B	Relying on family as go-betweens with doctors & medical staff	B
	Using places to socialise	A	Using places to socialise with family	A, B, C
	Contact with nature and outdoors	A, B	Outdoors – a preferred place	A, B, C
			Appreciating having access to outdoors (to escape, socialise, for variety/change)	A, B, C
	Family comfort	B	Need for more comfortable facilities for family	A, B
			Need for more parking facilities	A, B

### Member-checking Task: Analysis Process

A member-checking task was developed in which a series of prompt cards were developed each containing a strong statement that took a position in relation to a major finding for each of the major and minor themes. Participants were asked to respond to and talk about as many or as few of the cards as they wanted to, as described in chapter 7. This group of interviews provided a new body of evidence, which when analysed, provided additional information for some themes and contributed further to their definition.

Table 8.7 simply indicates the cards that each of the participants chose to talk about. From this table it is possible to see that no theme was left entirely undiscussed, which enabled this task to contribute consistently to the formulation of final interpretations.

The process of analysis used on these interviews was very similar to the second data breakdown used in Tasks A and B of the main study in that it was organised around the research instrument used. The data that occurred in relation to each prompt card were grouped across the six interviews. However, as the prompt cards already represented aspects of the major and minor themes, the discussion was analysed to see if any additional information in relation to the dimensions of the major or minor themes had emerged.

Table 8.7

*The Selection of Prompt Cards Chosen by Participants in the Final Member-Checking Task*

Theme	Card	Participants					
		1	2	3	4	5	6
Influence of illness	Everything depends on how I'm feeling	•	•		•	•	•
Boredom	It gets boring the more time you spend here	•	•	•	•	•	•
Keeping busy	It's important having lots of things to do here to keep you occupied	•	•	•	•	•	•
Family	My family is my main support	•	•	•	•	•	•
Escape	I really like to get away from the ward sometimes	•	•	•	•	•	•
Access to nature & outdoors	I really like being able to go outside	•		•	•	•	•
Friends and roommates	Making friends here is really important	•	•	•		•	•
	Having contact with my friends outside the Hospital is great			•	•	•	•

Table 8.7 (continued).

*The Selection of Prompt Cards Chosen by Participants in the Final Member-Checking Task*

Environmental Aesthetics, welcome & comfort	Having the artwork and colour around is great and makes a big difference		•	•	•	•	•
Personalisation (of bed space)	It's really good to have my own things around my bed		•	•	•	•	•
Being for kids	This place is very welcoming for kids	•	•	•	•	•	•
Age-appropriateness	It's good for kids my age here	•	•	•	•	•	•
	They need to make some changes for kids my age here				•	•	•
Variety and difference	I really like having a variety of things to do and places to go here	•	•	•	•	•	•
Personal control	I can't always do things my way here but it doesn't matter	•	•				
	I wish I had more say over how I have to do things here				•	•	•
Privacy	I wish I could have more privacy here	•			•	•	•
Room configuration	I prefer a single room			•	•		
	I prefer to share a room	•	•			•	•
Food	The food isn't great	•		•	•	•	•
Maintenance, functionality and serviceability	I notice how clean things are and if they are well looked after	•	•	•	•	•	•
Value for money	Some things are too expensive here	•	•		•	•	•
Wayfinding	It's easy to find my way around	•	•	•	•	•	•
Information	I like getting information about my illness	•	•	•	•	•	•
Safety and security	I feel safe here	•	•	•	•	•	•
Improvements & recommendations	I think there could be some improvements			•	•	•	
Not like a hospital	Sometimes it doesn't feel like a hospital	•			•	•	
Other	Anything else you want to tell me?				•		
<b>Patient age and gender</b>		12 G	10 B	16 G	18 G	16 B	14 G
<b>Diagnostic Group</b>		Gas	Sur	Gas	Onc	Res	ED

In Part C of the thesis which follows, the findings from the analysis process will be discussed in detail. This will include a discussion of the main study findings, and the findings from the member-checking task. Chapter 9 will begin by outlining the framework used to report the findings.

## **PART C: FINDINGS FROM THE MAIN STUDY**

### **CHAPTER 9**

#### **DOMAINS, MAJOR AND MINOR THEMES**

This chapter will summarise the overall findings of the main study data, following triangulation. As a result of data analysis and triangulation, a number of domains, and major and minor themes emerged. This chapter will briefly outline these findings.

#### **Domains**

Domains constitute the overarching, interconnected yet independent structures that provide the framework that encompasses children and young people's experience of hospitalisation. These domains are relevant to all participants' experience, however the interaction and relationship that each participant has with all of them varies with the individual.

There is evidence for five major domains being involved in children's overall experience of hospitalisation. These include the domains of personal experience, social experience, physical environment, organisational considerations, and time. The data from Tasks A and B support the presence of all five domains. The data from Task C is more limited and can only provide evidence for three of them: physical environment, personal experience and social experience. Each of the domains will be described here. These descriptions are generated in response to the data.

**Personal experience.** This domain centres on the repercussions of children's own diagnosis and treatment program on their experience of hospitalisation and the hospital environment. It encompasses the evidence concerning their personal response to this experience, as well as the evidence on children's personal coping strategies and their capacity for personal control.

**Social experience.** This domain centres on the social interaction children have whilst in hospital and the reasons that it occurs. It encompasses the evidence associated with the key social groups in children's experience, including who they are and what activities and functions they are involved in during children's hospitalisation. These groups include friends, roommates and family. It encompasses the evidence for children and

young people's motivations for seeking interaction with these groups. It also encompasses the evidence for children's consciousness of their family's experience.

**Physical environment.** This domain centres on children's response to, and use of, the physical environment. It encompasses evidence on key environmental attributes, features and preferences. It includes the evidence on children's use of the environment and their motivations for why they use the environment as they do. It also includes the evidence for the role of the physical environment in children's feeling of well-being.

**Organisational considerations.** This domain centres on aspects of the experience that are the province of organisational decisions, procedures, policies or culture. It encompasses evidence on children's response to rules and regulations, facilities, staff, and management issues such as maintenance. It encompasses the evidence on children's recommendations for change and improvements. It also encompasses the evidence for children's perception of aspects of the hospital that are part of an overall culture of child-friendliness.

**Time.** This domain centres on the effects of time. It encompasses the evidence for children's response to time and their strategies for coping with time in the environment. It also encompasses the evidence for what changes with time in the environment.

### **Major Themes**

Within the five domains, nine major themes were identified. Whilst there is a substantial amount of interconnection between these themes and all the domains, each theme more readily aligns with a particular domain in each instance, based on the data aligned to it and the concept inherent in the theme. Figure 9.1 shows all the connections between major themes and domains, with the main alignment in each instance represented with a stronger line. There is no particular order to themes or domains in this diagram.

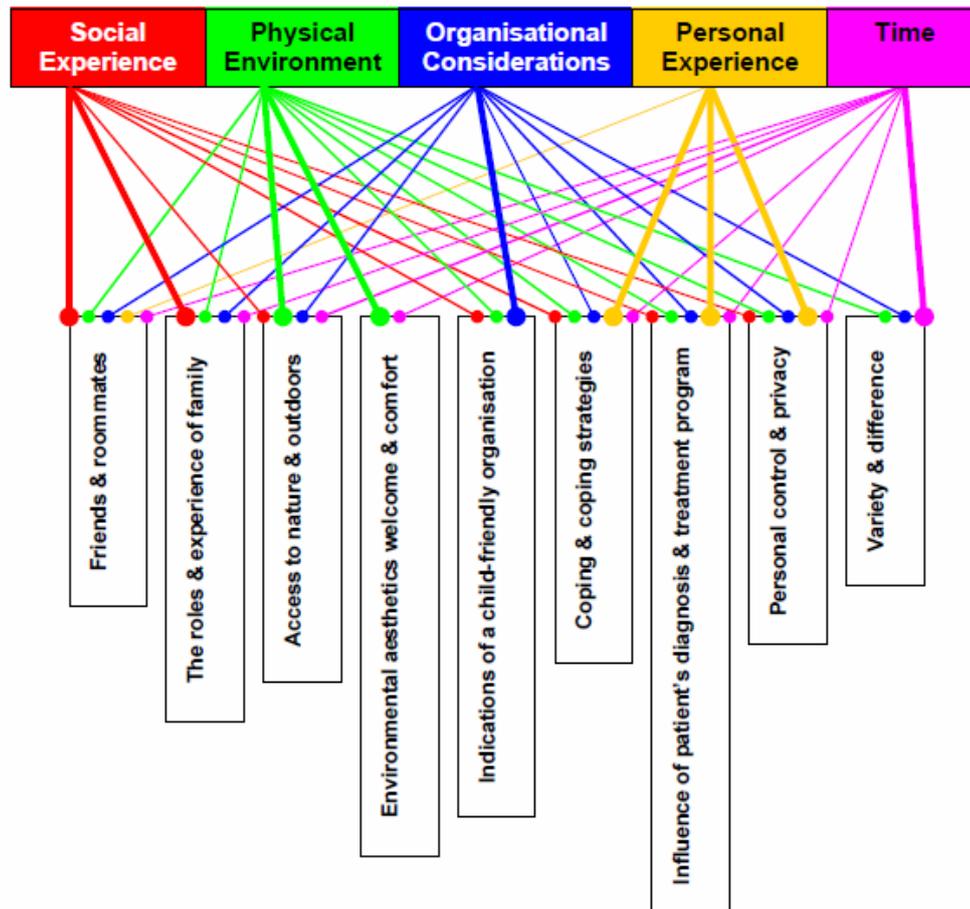


Figure 9.1. All the connections between major themes and domains, with the main alignment between each theme and a domain highlighted.

Within each of the themes, there are a number of dimensions, and in some cases sub-dimensions. The major themes aligned to each of the domains will be listed here. These themes, their dimensions and sub-dimensions will be described and defined in detail in the next chapter. They are not listed in any particular order here.

**Personal experience.** Within personal experience, there are three major themes:

- *Influence of patient's diagnosis and treatment program*
- *Coping and coping strategies*
- *Personal control and privacy*

**Social experience.** Within social experience, there are two major themes:

- *Friends and roommates*
- *The roles and experience of family*

**Physical environment.** Within physical environment, there are two major themes:

- *Environmental aesthetics, welcome and comfort*
- *Access to nature and outdoors*

**Organisational considerations.** There is one major theme aligned with organisational considerations which is:

- *Indications of a child-friendly organisation.*

**Time.** There is one major theme associated with time, which is:

- *Variety and difference*

### **Minor Themes**

Following triangulation, five minor themes were identified with main alignments to three of the five domains. Similarly to the major themes, there is a substantial amount of interconnection between these themes and all the domains. However, there is a stronger alignment between each theme and a particular domain in each instance as indicated by the data aligned to the theme, and the concept inherent in the theme. Figure 9.2 shows all the connections between minor themes and domains, with the main alignment indicated by a stronger line. Neither the line up of themes or domains is in any particular order in this diagram.

The minor themes will be listed here. Within each theme there are a number of dimensions. For the summary description of these themes and their dimensions, see Appendix G.

**Social experience.** Within social experience there is one minor theme including:

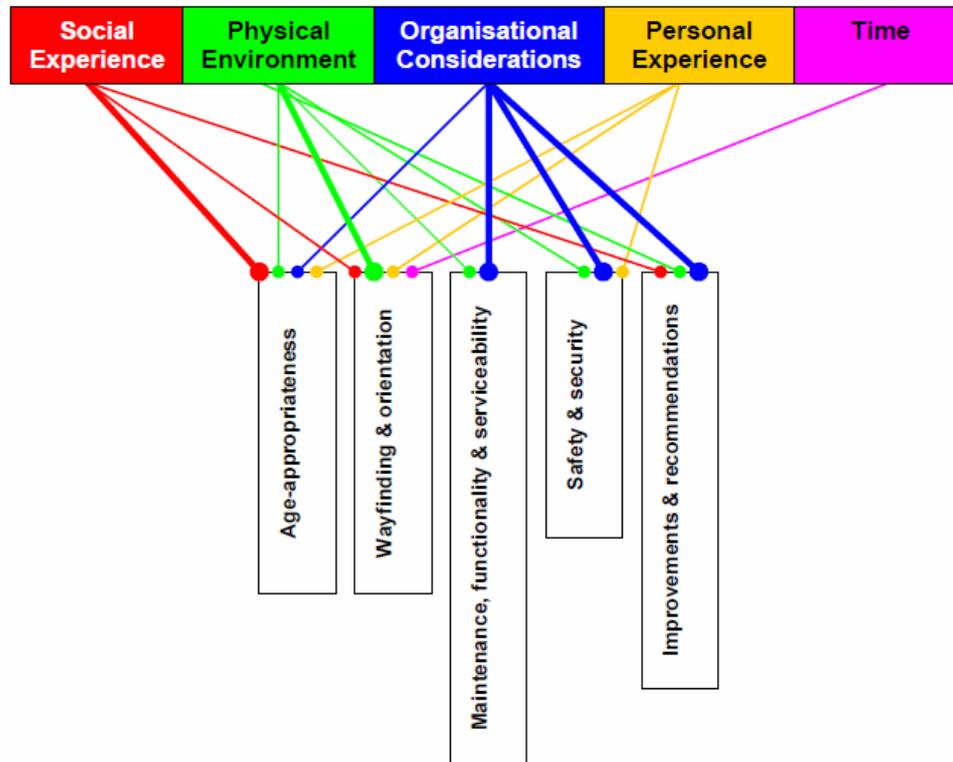
- *Age-appropriateness*

**Physical environment.** Within this domain, the minor theme includes:

- *Wayfinding and orientation*

**Organisational considerations.** Within organisational considerations there are three minor themes including:

- *Maintenance, functionality and serviceability*
- *Safety and security*
- *Improvements and recommendations*



*Figure 9.2.* All the connections between minor themes and domains, with the main alignment between each theme and a domain highlighted.

The aim of this chapter has been to provide simple definitions of the structure that will be used to report on the findings from the main study. Each domain, its themes and their dimensions and sub-dimensions will be defined, described and illustrated in detail, in the following chapter. The findings from the final member-checking task will also be reported in relation to each theme.

## CHAPTER 10

### CHILDREN AND YOUNG PEOPLE'S EXPERIENCE OF A PAEDIATRIC HOSPITAL ENVIRONMENT AND THE ROLE OF THE PHYSICAL ENVIRONMENT IN THEIR FEELING OF WELL-BEING

This chapter will consist of seven sections. The first five will use the five domains to organise the presentation of the findings in relation to the major themes. The findings from the final member-checking task will also be included in these sections as a separate part in the discussion in relation to each theme. The last two sections will contain summaries of the findings in relation to the two research questions for the study.

#### **Personal Experience**

This domain centres on the influence of patients' diagnosis, their experience of control and their strategies for coping. There are three major themes whose main alignment is with this domain. These include: *Influence of patient's diagnosis and treatment program, coping and coping strategies, and personal control and privacy*. All three of these themes are aligned to many of the other domains also. There is no significance to the order in which these themes are discussed here.

**Theme 1: Influence of patients' diagnosis and treatment program.** This theme concerns the impact of participants' diagnosis and treatment program on their response to, and experience of, the sociophysical environment of the hospital. The influence of patients' diagnosis, and how well they feel, is central to their experience of the sociophysical environment of the hospital.

**Alignment with domains.** Apart from the main alignment to the domain of personal experience, this theme is aligned with the other four domains also, including social experience, physical environment, organisational considerations, and time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Personal experience*: The alignment with this domain is indicated by the evidence for a single dimension including *the influence of patient's feeling of wellness on their response to the Hospital (1)*.
- *Social experience*: The alignment with this domain is indicated by the evidence for a single dimension concerning *the influence of a patient's diagnosis on how interested they are in socialising (2)*.
- *Physical environment*: The alignment with this domain is indicated by the evidence for a single dimension concerning *the influence of a patient's diagnosis on their consciousness of the physical environment (3)*.
- *Organisational considerations*: The alignment with this domain is indicated by the evidence for a single dimension concerning *the influence of a patient's diagnosis on their interest in using resources within the environment (4)*.
- *Time*: The alignment with this domain is indicated by the evidence for a single dimension including, *the relationship between a patient's diagnosis, the amount and number of times they have to spend in hospital, and their response to the hospital (5)*.

**Exploration of dimensions.** In total there are five dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: The influence of a patient's feeling of wellness on their response to the Hospital.* Participants' response to, and use of the hospital environment is constantly dependent on the experience of their illness or treatment, and how well they feel as a result. When participants are feeling unwell this side of their experience dominates their response to being in hospital and preoccupies them. "Bad days" are often linked to feeling sick or to struggling with their illness or their treatment routines. The excerpts below give some examples of this.

**Example 1:**

*Researcher: So what's it like being in this Hospital?*

*Participant:* All depends on if you're feeling really sick, or if you're happy, or if you just had enough and you just want to go home. It all depends on what mood you feel like. Different people have different moods so, I couldn't quite say for that 'cause you have different moods all the time so...I just like um, I was being sick a couple of days ago 'cause of um, they hadn't found out what I had, what kind of germs I had, so yeah I was being sick, so I just stayed on my bed and they noticed when I'm well 'cause I'm all happy and that but when I was sick I'm just I don't want to do anything, I don't want to go anywhere, I just want to stay right in my bed.

(Marika, 13)

**Example 2:**

*Researcher: So what's it like being in this hospital?*

Participant: Um well it's alright if your mind's not, if you're not thinking of the stuff you have to go through, but it does get really sad when like, you get told bad stuff and you just want to go home and stuff, yeah. (Vanessa, 11)

**Example 3:**

*Researcher: What makes it a bad day?*

Participant: Feeling sick, no family, no friends, just bored. Just want to go home, just tired of being here. (Kylie, 14)

**Example 4:**

*Researcher: Ok do you have good days and bad days?*

Participant: Um well no for me it's all good days. I try to keep everything good. A bad day would be one that there's lets say I'm stuck here in hospital and I'm told to stay in my bed for the whole day that would be a terrible day. Aside for that I'll have a good day. (James, 17)

However, most participants manage to maintain an independent assessment of the Hospital even when they are not feeling well. Participants are quite able to separate the effect of their medical experience or illness from their impression of the Hospital environment itself. The excerpts below are examples of those participants who acknowledge the distinction they make in their impression of both.

**Example 1:**

*Researcher: So do you have good days and bad days?*

Participant: Yes definitely. Um sometimes you just wake up and feel like crap.

*Researcher: Can you explain that a bit more?*

Participant: I can't explain it, I just don't know why, I don't even know what's caused it, or I don't even know how to explain it, I just feel really, really... crap.

*Researcher: Does that change the way you feel about the hospital when you feel like that?*

Participant: No it's not the Hospital's fault, it's just the whole nature of this.

*Researcher: "This" being the illness you are going through?*

Participant: Yeah. (Peter, 12)

**Example 2:**

*Researcher: So if you could do anything to this Hospital what would you change?*

Participant: Um - I don't think I'd change anything it's just *the thing* that I, like it's just what I do that's bad, like bad like, we've got to be weighed, have blood tests and everything. Yeah it's just the fact that I'm here but the actual Hospital is good. It's good. 'cause it's like bright, it's welcoming, it's like not a boring hospital or anything you know? They've got activities for you to do and everything, so it is a good hospital, I just don't like, you know, what actually we go through and stuff, yeah. (Vanessa, 11)

**Example 3:**

*Researcher: Ok how much does how well you feel affect what you think of being in hospital?*

Participant: Alot I think 'cause um like I have good days and bad days and mostly it depends on if it's a Tuesday or Friday because that's weigh day and also we see the doctors and almost always they give bad news and I'm in a bad mood for the rest of the day or few days and that makes me feel like upset so I don't really enjoy myself as much and I just hate being here and stuff like that.

*Researcher: Ok so does that change the way you feel about the Hospital itself?*

Participant: The environment of the Hospital?

*Researcher: Yes*

Participant: Um doesn't really make me feel that much different towards it, just depends how I'm feeling. Like if it was a worse environment then I prob'ly wouldn't feel as happy and it's pretty good. (Emma, 14)

**Example 4:**

*Researcher:* *Ok do you have good days and bad days?*

*Participant:* Um yes. Well I don't have *days*, I have good moments and bad moments. Because I get stressed 'cause like if I'm in pain, it just annoys me and I just get frustrated but then the nurse just gives me some Panadol or some other tablet stuff and it makes me better.

*Researcher:* *And does that change the way you feel about the hospital, when you're having tougher times?*

*Participant:* Ahh not really, 'cause it's not really the Hospital it's just 'cause I'm sick and just annoyed about being sick and 'cause I'm so like, I'm fit, I'm usually running around everyday of the week, it's annoying laying in bed all day. (Josie, 12)

*Dimension 2: The influence of a patient's diagnosis on how interested they are in socialising.* When feeling unwell, patients do not care about socialising but they do appreciate the presence of family members and friends during this time. The excerpts below reveal the link that participants make between the way they feel, and their interest in interacting with the social environment around them.

**Example 1:**

*Researcher:* *How important is it making friends in the hospital?*

*Participant:* Um...it's good but it depends on, because sometimes you get really tired in here, like if you're sick in here, sometimes you just really don't care, 'cause you have all your other family and friends come visit you, so it's not a great, great deal but sometimes it's good to say 'hello'. (Mandy, 10)

**Example 2:**

*Researcher:* *You like to share a room you mean?*

*Participant:* Yeah more company maybe, if you know the person, but when you're not feeling the best I s'pose it doesn't really matter to you about company. I just like to have my family around when I'm like that. (Kylie, 11)

**Example 3:**

*Researcher:* *How about having contact with your friends outside?*

*Participant:* Um I don't think that's as important because when you're in hospital you don't, you usually don't feel up to talking, like to talking with other people and especially like lately, like using my phone to like text my friends and stuff has been giving me a bit of a headache. (Peter, 12)

*Dimension 3: The influence of a patient's diagnosis on their consciousness of the physical environment.* Participants also report that they do not pay as much attention to the physical environment at times when they are not feeling well. In the excerpts below the participants articulate the impact of their illness on their response to the immediate physical environment around them.

**Example 1:**

*Participant:* When you're recovering you don't really care, or I don't really care what's around me like, as long as my Mum is there to help. (Justin, 15)<sup>12</sup>

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<sup>12</sup> The format of quotations varies as sometimes the excerpts used have been given in response to direct questions on the subject of the answer, and at other times the comments occur in a different context entirely.

**Example 2:**

Participant: Like when I'm in pain, like when my foot hurts, I don't care about the room and stuff, I just want the pain to stop. (Milly, 11)

**Example 3:**

Researcher: *Do you spend most of your time in here? [Ward room]*

Participant: Yeah

Researcher: *What do you think of it?*

Participant: I don't really care, like when I'm just feeling bloody miserable, I don't care or even notice the room. (Daniel, 17)

*Dimension 4: The influence of a patient's diagnosis on their interest in using resources within the environment.* Patients' willingness to interact with the activities and entertainments available in the hospital is also influenced by how well they feel. These excerpts illustrate the link participants make between their feeling of wellness and their interest in entertainment or additional activities.

**Example 1:**

Participant: All depends on how you feel, 'cause um before when I first come down to the Surgical Ward from the ICU, um, I wasn't well, I didn't have the strength, and when the clown doctors come around to make you laugh, I would just lay there and I would not have a grin on my face at all, I would not care, but – it like all depends on your mood and um if you're up to it yeah. (Marika, 13)

**Example 2:**

Participant: Like there are lots of things to do if you feel like it but sometimes you just don't feel like it 'cause you're sick or something. (Luke, 11)

*Dimensions 5: The relationship between a patients' diagnosis, the amount and number of times they have to spend in hospital, and their response to the hospital.* The centrality of a participant's diagnosis and its potential influence on the participant's priorities and experience does not vary across the whole group. However, the nature of the specific illness participants have, and the time they have to spend in the hospital, or the number of times they have to return to hospital as a result does alter the dominance of this side of their experience. This is particularly the case for patients whose treatment is repetitive, invasive and painful. In the excerpts below the participants discuss this link.

**Example 1:**

Researcher: *Being here for 3 months – you must have got so sick of the place?*

Participant: I was actually quite scared at first 'cause it was my first time and knowing that I could have died, like I could of with it, was pretty scary but being here for that long you get sick and tired and you just want to go home, be at home, you just don't want to be here at all. 'Specially when they want to do something to you like stick a needle in you or something like that, you just wish that you're at home. 'Cause when they stick stuff in me or pull stuff out me, all I say to my Mum is that I wish I was at home. I wish I wasn't here, I wish I was at home. (Marika, 13)

**Example 2:**

Researcher: *So you're looking at the front entrance?*

Participant: Yes.

Researcher: *What do you think of it?*

Participant: Hospital, scary....

*Researcher: Mmm does it say that to you? A scary place?*

*Participant: Mmm*

*Researcher: Ok so what makes it scary?*

*Participant: Um being in previous hospitals, needles....Oh just the feeling that you know, you've got to do something. Like they say 'ok we're going to have to give you a needle' and you're like 'oh I don't like needles'. (Jessica, 11)*

For two particular groups of patients including oncology patients and patients with eating disorders, time is very burdensome and makes them increasingly conscious of their diagnosis and its repercussions.

Oncology patients can be in isolation for weeks because of their illness. The need for this makes these patients much more conscious of their illness and its influence on the rest of their experience in hospital. For these patients their diagnosis impacts on all aspects of their experience and is accentuated by time. The excerpts below reflect the frustration that these patients can feel in this situation.

**Example 1:**

*Researcher: What do you find is the hardest thing about being in Hospital?*

*Participant: Not being able to get out of here and run round like all the other kids. Being with your friends and going shopping, things like that. That'd probably be the hardest.*

*Researcher: So it's being in isolation and what that means that's the toughest bit?*

*Participant: Yep*

*Researcher: What would be the thing you would most like to change?*

*Participant: Being able to get out when you're in isolation, you have to stay in the room all the time and that can be for a long time. (Kylie, 11)*

**Example 2:**

*Researcher: Ok what do you think's the hardest thing about being in hospital?*

*Participant: Being stuck in the room for eternity.*

*Researcher: What's the one thing you'd like to change?*

*Participant: Not being isolated. (Luke, 11)*

Patients with eating disorders can also be in hospital for many weeks and they are on a program of privileges and restrictions. With time, their strict treatment program increasingly becomes an issue of contention for them, as it is repetitive and influences their social contact and restricts their movements in the hospital environment. Again, this has the effect of making these patients much more conscious of the influence of their illness and treatment program as the time they spend in hospital increases. The excerpt below reflects the frustration of two of the participants from this group of patients.

**Example 1:**

*Researcher: So when you're in here for a long time, does that change the way you feel about being in hospital?*

*Participant: I think it makes you more want to go home. You just get sick of it. The same thing everyday. The same thing again and again. It gets so boring.*

*Researcher: What would you change?*

*Participant: That I didn't have to be on my program, I could just be in hospital and not be on the program. 'Cause you can't go places and you can't... do really what you want to do it's what you have to do this, and you have to do that. It gets really boring. (Sarah, 15)*

**Example 2:**

*Researcher: So what would you like to change most about being here?*

*Participant: Um I don't really know I think the routine becomes a bit much after five weeks just because it's the same thing every day. If that varied a bit more that would be good. (Jane, 16)*

**Member-checking task.** The prompt card for this theme was: *Everything depends on how I'm feeling.* Further discussion on this theme continued to reveal the centrality of patients' diagnosis and its repercussions and treatment in their use of, and response to the hospital environment.

**Example 1:**

*Participant: Everything depends on how I'm feeling. That's true especially in the hospital, if you're feeling really happy then there's a lot more you can do. Like you would have the energy to get up and go for walks and like do what you want to do but if you're feeling negative and if you're feeling upset you would be like 'oh I just feel like staying in bed' and that's all I want to do. Like that's how I felt when I found out that I couldn't eat for the next couple of days all I wanted to do is lie in bed and just dream of food. That's all I wanted to do. Just lie in bed and just not move because I was like so upset. But now, like if I feel up to it or if I feel really happy and stuff, me and Mum would probably go for a walk down to like the Starlight Room or something and we'll do something fun down there or we'll go down for lunch or something, so it does really depend on how you feel. Especially with what you have depending whether you've got like something really serious or something not that serious it also depends on that so.*

*Researcher: And when you're not feeling great, does that change the way you feel about being the hospital environment itself?*

*Participant: I guess it does. If like when I was feeling negative, I'm like 'I want to go home' always wanting to go home but when I'm happy home just slips out of my mind in a way and I'm just thinking what can I do in the hospital, what can I do now, what can I do later on, what can I do tonight, things like that. So usually it does depend on how you feel a lot of the time I guess. (Melissa, 12)*

**Example 2:**

*Participant: Oh well if I'm feeling sick, then I won't want to leave and I'll just sleep in my bed, but if I'm feeling well, I want to go out.*

*Researcher: Can you do that?*

*Participant: Sometimes. It depends on if I have white cells. The other day I couldn't go to the cafeteria 'cause I didn't have white cells and I wasn't even allowed to wear this mask, it wouldn't work. I couldn't go at all. (Lana, 18)*

**Example 3:**

*Participant: Yeah if it's a bad day because I'm feeling sick or something then I don't want to do anything or go anywhere, just stay in my room. (Toby, 16)*

**Theme 2: Coping and coping strategies.** This theme encompasses participants' strategies for coping with hospitalisation and their approach to coping. The data indicates that coping equates to participants' ability to maintain a positive outlook on

their situation. Coping strategies equate to the activities and patterns of behaviour that participants use to cope with their time in hospital, manage their emotional response to the experience, and maintain a positive frame of mind.

**Alignment with domains.** Apart from the main alignment to the domain of personal experience, this theme is aligned with the other four domains also, including social experience, physical environment, organisational considerations, and time.

**Dimensions within the theme that indicate alignment with the domains.** A summary of these includes:

- *Personal experience:* The alignment with this domain is indicated by the evidence for three dimensions including firstly participants' *personal efforts to maintain a positive outlook (1)*, and to conscientiously manage their emotional response to their situation; secondly, *personal coping strategies (2)* that patients use. This second dimension has one sub-dimension that encompasses the main personal coping strategy, which is *keeping busy*.
- *Social experience:* The alignment with this domain is indicated by the evidence for a single dimension including the *social coping strategies (3)* employed by participants. Within this dimension, there are three sub-dimensions which encompass the three social strategies participants use regularly including *having contact with family*, *having contact with friends outside the hospital*, and *socialising with friends made inside the hospital*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including participants' use of *the physical environment as part of coping strategies (4)*. Within this dimension, there are three sub-dimensions that encompass the principal strategies that involve the physical environment which include *escaping the ward environment*, *personalising their bed area*, and *going to different places in the environment in response to their mood*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for one dimension which includes *the role of information in helping children prepare and cope (5)* with their treatments.

- *Time*: The alignment with this domain is indicated by the evidence for a single dimension including *the influence of time on the effectiveness and need for coping strategies (6)*.

**Exploration of dimensions.** In total there are six dimensions identified in this theme and seven sub-dimensions. Some of the dimensions and sub-dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: Personal efforts to maintain a positive outlook.* Participants place great emphasis on trying to remain happy and positive in the face of difficult circumstances. They feel that achieving this helps them heal and pass the time more quickly. Although in relation to very different questions, the excerpts below all reveal the responsibility participants feel towards managing their own situation.

**Example 1:**

*Researcher: What are your treatments like?*

Participant: My treatments are painful, non painful all the rest of it

*Researcher: All sorts? They don't worry you though? You just accept them?*

Participant: You know, you've got to accept them to get better and if you want to get better you put your mind to it and then you're all set to go home and you're happy 'cause you're not sick and you can do a lot more stuff, so I think that's just the easiest way to think for yourself. (Tina, 14)

**Example 2:**

*Researcher: How much does how well you feel affect what you think of being in hospital?*

Participant: Um it's really important to feel like you belong in here and that like you feel comfortable with your surroundings and the environment 'cause if you don't you'd prob'ly like have a hard time through it all. So you have to like kind of forget that you're in here, think positive and just try and get better as soon as possible and go back to a normal living. (Polly, 14)

**Example 3:**

*Researcher: Ok when things get too much for you, how do you manage that?*

Participant: I just like to keep it to myself. I don't like to talk about it or tell them like what's happening or what I feel, I just like to keep it to my, um, to what I, like how I want to deal with it myself. (Justin, 15)

The nature of the illness or condition that the participants have also influences coping. Participants who are in isolation or on strict treatment programs would like to employ more of the strategies used by other participants to help manage their time in hospital than they are able to. These patients find it more difficult to manage their time and implement coping strategies that are as effective as those who have free use of the whole environment and its resources.

For example, some of the patients with eating disorders speak about their wish to go and walk around the hospital away from the ward when they receive bad news from doctors about their condition. However, this is not possible as they are restricted from leaving the wards on their own as part of their treatment programs.

*Researcher: Ok you have rules and restrictions you've got to live by here don't you? How do you feel about those?*

Participant: Some of them are a bit hard and annoying and others are ok. Some you don't mind but others you just don't like at all.

*Researcher: And which are the ones you don't like at all?*

Participant: Oh some of them are to do with food and other ones are to do with just not being able to go off the ward. 'Cause just sometimes you just want to go for a walk if you're sad. (Sasha, 13)

*Dimension 2: Personal coping strategies.* The most widely acknowledged strategy for coping is keeping busy. Many participants' report that the main function of keeping busy is to keep their minds focused on something other than their situation. The excerpts below illustrate the connection participants make between keeping busy, being distracted from thinking about their own situations, and maintaining a positive frame of mind.

**Example 1:**

*Researcher: How important is it to keep busy?*

Participant: Important. It's really important for me because otherwise, I just think about all my past and how sick I've been lately and it gets on my nerves. 'Cause like, it makes me just you know, like I go downhill, instead of uphill. 'Cause I'm always thinking about it. So having the games and nursing staff, and friends, and being able to go for walks, and not being isolated and stuff is like a good thing. Because you don't put your mind to it, your mind's set on something else instead of the actual sickness and what's going on and stuff. So I think that's good. (Tina, 14)

**Example 2:**

*Researcher: Do you like to keep busy?*

Participant: Yes

*Researcher: Why?*

Participant: Um because if I just sit around and don't do anything then it gets to me and I want to get out more and go home more, so keeping busy keeps me focused so I don't go all crazy and I can take my time to get past it. (Kylie, 11)

**Example 3:**

*Researcher: So you like to keep busy?*

Participant: Yep very much

*Researcher: And why's that?*

Participant: Ok one of the things is, I suffer from extreme headaches and one of the ways I have pain relief is to do something and forget about it. So you know constant doing of different things, if that makes sense, is really important to me. Keeping busy and you know enjoying myself 'cause you know sometimes being in hospital is not easy you know, it does hurt you know, physically and if your mind is not on it the experience can be a whole lot different. (James, 17)

**Example 4:**

*Researcher: Do you like to keep busy?*

Participant: Yeah, just sitting there waiting for the time to go by is really not the thing to do because then you, oh I don't know about other people, but then I just start to think about things that probably aren't the best things to be thinking about. (Peter, 12)

Personal coping strategies consistently include self-directed activities such as reading, listening to music, watching DVDs, watching TV and doing games of some sort usually card games, board games or personal computer games.

**Example 1:**

*Researcher: So what do you normally do to keep yourself occupied?*

*Participant: Um either watch TV, play computer, read something like a magazine, or just talk to Mum or Dad or something. (Peter, 12)*

**Example 2:**

*Researcher: Ok so when things start to get too much for you how do you manage that?*

*Participant: Um I go into, I sit on my bed and I try and take it out by drawing something, like, or I listen to the radio or um just try not to think about it too much yeah... talk to my friends a bit 'cause they usually have good advice or something but yeah. (Polly, 14)*

**Example 3:**

*Researcher: What would you normally do to keep yourself occupied?*

*Participant: Um I make cards. I make collages um I watch TV, um I talk on the 'phone um, I do lots of crossword puzzles. The Sudoku puzzles, I like doing those sorts of things so you have to use your brain. (Sarah, 15)*

*Dimension 3: Social coping strategies.* The social coping strategies participants principally use include seeking social support, seeking social contact with family members, or friends from either inside the hospital or outside the hospital. These considerations will be discussed in detail later in the chapter under the major themes: *The roles and experience of family and friends and roommates.*

*Dimension 4: The physical environment as part of coping strategies.* The main coping strategies that involve the physical environment include personalising their bed area, escaping the ward environment, and going to different places in the environment in response to their mood.

Personalising their bed space increases participants' ability to cope as it increases their comfort in the environment. Having control over this piece of the environment and being able to surround themselves with familiar faces, objects of personal significance which remind them of home, makes them feel more at home in the Hospital environment. Feeling at home equates to feeling relaxed and comfortable in the environment. The participants who know they are coming in for a long time greatly appreciate being able to bring in their own bedding such as Doonas and blankets. They also greatly appreciate the capacity to add colour and interest to this part of the environment. The excerpts below are indicative of the responses from participants.

**Example 1:**

*Researcher: Ok is it important having your own things up around your bed, or to have your own*

*things around you?*

Participant: Yes because then it feels more like your space, um and it just makes you feel more at home really, like more comfortable. (Peter, 12)

**Example 2:**

*Researcher: Ok is it important to be able to have your own things around your bed?*

Participant: Yep, yes because they make you feel like you're at home, like it's your own room, like if there was just nothing it would be a bit bare. So it makes it a bit bright 'cause the room's green, it makes it brighter and makes you feel a bit more comfortable. (Josie, 12)

**Example 3:**

*Researcher: Is it important being able to put your own things up around your bed space?*

Participant: Yes

*Researcher: Why's that?*

Participant: To help you through the hard times, remind you that there's always a better place to go and once you do this you'll get to go home and be with everybody that cares about you. That's what I find. Help you through it. (Kylie, 11)

**Example 4:**

*Researcher: Um is it important to have your own things around your bed space?*

Participant: Definitely. It makes it much more homely and more enjoyable to be in. I think, like I have my own bedding and things, like it's my bedding from home and it doesn't look like a hospital bed so much then. (Sarah, 15)

Figure 10.1 provides an example of a bed area that has been personalised over a number of weeks.



*Figure 10.1.* An example of a personalised bed area.

Needing to escape the ward environment encompasses needing to escape both the social and the indoor physical environment of the hospital. Participants appreciate having access in particular, to the outdoors as an escape from their wards and as a place of

retreat. The excerpts below point to one of the preferred places of escape and retreat, the gardens.

**Example 1:**

*Researcher: So you use the gardens?*

*Participant: Yeah 'cause um, we're always stuck in the room all the time. Like it provides a place where you can just hang out for awhile to just like smell the air um, experience the sun um, just to like talk to other people like, 'cause you don't want to be squashed up in your room all day, not being able to do anything. (Justin, 15)*

**Example 2:**

*Researcher: If you're just trying to retreat from the action type thing do you mean?*

*Participant: Yeah. I would go to the gardens. I would go outside and go for a walk. There are some nice places. I would go to the pond and sit there and draw. I do that, if I want to get away and just chill out for a bit I take some music and just sit in the gardens and draw. It's nice. It's quiet and peaceful. Also the Chinese gardens are pretty cool and yeah, they're not too bad. (James, 17)*

**Example 3:**

*Researcher: Why is it that you like to go out to the gardens?*

*Participant: Oh ok um well it's way nicer 'cause you're out and you just feel more free and everything, specially when you're with your Mum or something. So you just feel I s'pose more kind of happy and more free and like it's a privilege so it's like a step closer to getting home. (Vanessa, 11)*

Figure 10.2 provides a picture of the main fountain area in the Children's Garden.



*Figure 10.2.* The main fountain in the Children's Garden

Visiting different areas in the Hospital environment is also discussed as being dependent on patients' mood and needs from moment to moment. Participants' use of the environment can be linked to their mood and to their need to find distraction as a

way of managing their emotional response. The excerpts below touch on these considerations.

**Example 1:**

*Researcher: Is it important having different places to go in the environment?*

Participant: Um yep just so sometimes, you know, you want to be by yourself and other times you want to be around people, so you can go to either one sometimes.

*Researcher: And what places do you prefer to go?*

Participant: I like outside 'cause it's usually pretty nice out there and you can have a sit down and be out in the sun. (Sasha, 13)

**Example 2:**

*Researcher: Do you think it's good to have different places to go to in the hospital?*

Participant: Yeah

*Researcher: Why's that?*

Participant: 'Cause like there are all different sections like I don't know like, if you feel different, if you feel like, I don't know, if you have like, I can't really explain it but...Um like it depends how you're feeling like you can go to different places. Do you know what I mean? And like there's all different places for that. (Amelia, 14)

*Dimension 5: The role of information in helping children prepare and cope.* Apart from having access to information about the opportunities in the Hospital, it is important to most participants that they are kept informed by hospital staff and doctors about their own illness and their treatment program. Participants report using this information to prepare for what is ahead for them, to understand their situation better, and to reduce the chance of unpleasant surprises. The responses below are representative of participants' discussion on this.

**Example 1:**

*Researcher: Is it important to you that they tell you what's going on?*

Participant: Yeah, so that I can know what I have to, how I can um, it's just that I want them to tell me so that I can know what I have to do to prepare myself for what's going to happen. I understand what's going to happen to me, so that I know how things are going, like if I'm recovering or if something else is to happen to help. (Justin, 15)

**Example 2:**

*Researcher: Does it make a difference being told what's going on?*

Participant: Yeah so there's no nasty surprises anywhere and you can know what's going to happen next. (Sophie, 16)

**Example 3:**

*Researcher: Do the doctors and nurses tell you what's going on?*

Participant: Yep they're good

*Researcher: Is that important to you?*

Participant: Yeah it is. I like being told stuff like what's going on an usually I ask a lot of questions too so if they're doing something to me I'll be like, "will it hurt?" Or "why am I doing it?" Or "what's it going to do to me?" Or stuff like that. I usually ask a lot of questions 'cause it can help me. (Josie, 12)

*Dimension 6: The influence of time on the effectiveness and need for coping strategies.* For all participants, the importance of having effective coping strategies increases with time as boredom and homesickness become more of an issue for participants, however

the capacity of those strategies to be effective diminishes. The excerpt below captures this sentiment.

*Researcher: When you're in here for a long time does that change the way you feel about being in hospital?*

Participant: Yeah. It makes you want to get out of this place.

*Researcher: So you get more- how would you describe that feeling?*

Participant: You get more bored and I feel you know I think of it like a kid you know who's you know goes to church for few hours, you know the first hour and a half they'll cope, let's say they'll be drawing and playing and doing something for the first hour and a half, they'll keep themselves busy but eventually you just can't keep yourself busy with the same things. And you have exhausted everything there is to do and you get restless and make a lot of noise and you get into trouble and eventually you get used to it by running away. (James, 17)

**Member-checking task.** There were a number of prompt cards used to span this theme including: *It's important having lots of things to do here.* This produced agreement amongst participants for similar reasons to those given by participants in the main study. These include providing distraction from personal situations and enabling patients to remain positive and engaged in the experience.

**Example 1:**

Participant: *It's important having lots of things to do here.* That's important.

*Researcher: Ok how does that help having lots of things to do?*

Participant: It helps like to keep your mind off what's wrong with you and to keep your mind off treatment if it's painful or if you're worried about it. So like today I'm going to see if I can do something like go for a walk to keep my mind off tomorrow because I'm a bit scared about tomorrow. (Melissa, 12)

**Example 2:**

Participant: It's important to have lots of things to do here to keep you occupied. Number 2 that's um very true. Very important so you can keep your mind off things again, so you don't just focus on being ill.

*Researcher: What sort of things do you do to help yourself keep your mind off being ill?*

Participant: Oh well just keep yourself, well I personally keep myself informed, I like to just have things to do and bring things from home that are a bit familiar and my family come, and yeah just do things that you'd do at home. (Annabel, 16)

Another prompt card used for this theme was: *It's really good to have my own things around my bed.* This produced a mixed reaction from participants depending on the time they were spending in the environment, which is consistent with the findings from the main study interviews. Participants who are in the hospital for a long period value it because it helps them to feel more comfortable in the environment, and it allows them to surround themselves with things that are of personal value, familiar and make them feel closer to home. Those patients in hospital for a shorter time do not care about this aspect as much. These findings are consistent with the findings from the main study also.

**Example 1:**

Participant: The only real things that are mine that are around my bed I guess are well, nothing really, but then again I am only here for about a week so what's the point of having, of bringing all my stuff here and then taking it all back after a week, then again my sister had a lot of her stuff because she stayed for five weeks. (Melissa, 12)

**Example 2:**

Participant: It's really good to have my own things around my bed, so I feel a little more at home and a little more comfortable.

Researcher: *When you say you bring your things in feel more at home and to feel more comfortable, how does feeling at home help?*

Participant: Just feeling more at home helps by just not focussing on being in hospital so much and being like stuck really. (Claire, 14)

**Example 3:**

Participant: My own things around my bed. Yeah when I was here for a month um, a lot of the nurses said that my room was the most interesting because I made it the most personal. I had stuffed toys lined up all along the back, so many that they were like falling down and there was no room for any more and there was like a snake curled up at the front and I had my own doona and there was my paintings and stuff like stuck everywhere. It felt like my own little room outside of home.

Researcher: *And what's the importance of doing that to your space?*

Participant: Well it makes it more personal and you don't feel so isolated and like you know you have like your own little space, I don't know how to describe it but it's something about making it personal. (Lana, 18)

Another prompt card used for this theme was: *I really like to get away from the ward sometimes*. This was used to explore the importance of being able to leave the ward environment and for what reasons. As in the main study, the answers suggest that being able to leave the ward is important for contrast in experience and in environment.

**Example 1:**

Participant: I really do like to get away from the ward sometimes, yeah, just go for walks with my Mum up and down and probably go and Mum would buy lunch we would just sit down and talk and she what she did during the day or something like that. (Melissa, 12)

**Example 2:**

Participant: I really like to get away from the ward sometimes. That's true.

Researcher: *Where do you like to go when you go?*

Participant: The chapel

Researcher: *Why do you choose the chapel?*

Participant: It's peaceful and I like to pray and meditate sometimes and it helps me feel better and just appreciate everything more.

Researcher: *When you go down there are you on your own or?*

Participant: I go with Mum and we chat with the chaplains, they're lovely.

Researcher: *How often would you go down there?*

Participant: We used to go about once a week but now we can't go but we'll be able to go again soon enough. (Annabel, 16)

**Example 3:**

Participant: Um I did feel that the other day, it's understandable, I don't get fussed about it, but I would like to leave the ward sometimes ah just to go to the cafeteria downstairs or something. Yeah just to leave, yeah just escape for awhile. (Toby, 16)

A final prompt card used for this theme was: *I like getting information about my illness.* All participants agree that this helps them to cope with their situation and prepare for treatment, which is also consistent with the findings from the main study.

**Example 1:**

Participant: I do really like getting information about illness because then it helps me um to know what I can eat and what I can't eat um what type of tablets I have to take if I have to take steroids and things like that. They've given me a lot of information but a lot I've gotten from my sister and when she was in hospital I used to listen to the doctors to her, but now seeing I have the same thing all I really have to do is recap and try to remember what they told her, not to worry and stuff like that. (Melissa, 12)

**Example 2:**

Participant: I like getting information about my illness.

Researcher: *Right so do the Doctors come and chat to you and tell you what's going on?*

Participant: Yeah, I like to see how I'm going and it helps me to know what's going to happen. (Adam, 10)

**Example 3:**

Participant: Um number 27, I like getting information about my illness, so that I can help myself as well as everyone else helping me. (Annabel, 16)

**Theme 3: Personal Control and Privacy.** This theme concerns the capacity for both personal control and privacy and the influence that both of these have on children and young people's response to hospitalisation. They are joined in this theme because they are frequently joined by participants in their discussions.

**Alignment with domains.** Apart from the main alignment to the domain of personal experience, this theme is aligned with all four other domains, including social experience, physical environment, organisational considerations and time.

**Dimensions within the theme that indicate alignment with the domains.** A summary of these includes:

- *Personal experience:* The alignment with this domain is indicated by the evidence for a single dimension including *the individual's need and desire for privacy and control (1)* which encompasses the sub-dimension of maintaining *dignity and respect.*
- *Social experience:* The alignment with this domain is indicated by the evidence for a single dimension concerning *control, privacy, roommates and their families (2)* and the impact of patients and their families on the desire for privacy and personal control.

- *Physical environment:* The alignment with this domain is indicated by the evidence for two dimensions including the desire for *greater control over environmental attributes including light and noise (3)* and, the impact of *wardroom configuration (4)* on privacy and control, which encompasses the sub-dimension of *shared versus single rooms*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a single dimension including patients' *capacity to participate in their own healthcare management (5)* which includes the sub-dimensions of *being consulted and being heard*, and *being kept informed*. This dimension does not include a reference to privacy but it has been included here as it is a dimension of personal control.
- *Time:* The alignment with this domain is indicated by the evidence for a single dimension, which includes the *influence of time on patients' desire for privacy and control (6)*.

**Exploration of dimensions.** In total there are six dimensions identified in this theme and four sub-dimensions. Each of the dimensions and sub-dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: The individual's need and desire for privacy and control.* The individual desire for privacy and for personal control varies across the participant group. Privacy is discussed mostly in relation to the respectful treatment of staff and their observance of the participants' need for dignity and respect. Treatments and daily care routines can be potentially undignified and confronting for participants. Their dignity in the situation is linked to the staff's recognition of this. The excerpts below discuss this.

**Example 1:**

*Researcher: Is your need for privacy respected here?*

Participant: Yes 'cause the nurses, 'specially they'll come help my Mum. My Mum can do it herself now but if I need to go to the toilet on the pan or in the commode they'll help but then they'll just go out so they already know to just go out like, you don't have to tell them. So they just go behind the curtain or something so they are pretty good. (Josie, 12)

**Example 2:**

*Researcher: How about your privacy do you feel that it is respected here?*

Participant: Oh some of the nurses do, some of them, like when they come in to do things most of the nurses will close the curtains behind you, less of them will close the door after that as well, so some of them go they'll close the door and they'll close the curtains as well.

*Researcher: But do you get enough privacy when you want it?*

Participant: Yeah 'cause I have the curtain closed almost all the time, 'cause I don't like people seeing me like this. (Daniel, 17)

**Example 3:**

*Researcher: Is your need for privacy respected here?*

Participant: Um...mmm...to an extent it is but like sometimes when they've had to do check ups or on the body it feels a bit weird 'cause like it hasn't happened before. Like um people haven't come and just looked around or, to breach your privacy but, it's alright, they try not to make you feel uncomfortable. (Justin, 15)

Being able to access privacy is enmeshed in participants being able to exercise personal control over their social and physical environment as illustrated in the excerpts below.

**Example 1:**

*Researcher: What about your privacy is that respected here when you need it?*

Participant: Yeah except it's pretty hard with the curtains sometimes 'cause every time they walk past they undo

*Researcher: Ahh they just open do they?*

Participant: No when they walk past the side they walk past and it drags it round a bit. (Scott, 15)

**Example 2:**

*Researcher: So is your need for privacy looked after here? Do you think you get enough privacy?*

Participant: No

*Researcher: What would you change?*

Participant: Like when you have to share a room with people and you don't get enough privacy.

*Researcher: What don't you like about sharing rooms?*

Participant: Because like if you're trying to sleep it's noisy. (Mandy, 10)

**Example 3:**

*Researcher: So is your need for privacy respected here do you think?*

Participant: Um yep, like most of the time, like sometimes you do want to be by yourself and you've got like people around you but they usually like, they know how you feel 'cause they want some privacy as well so usually everyone's got a bit of their own time. (Sasha, 13)

**Example 4:**

*Researcher: Is your need for privacy respected here?*

Participant: Um yep. You ask someone and they'll help you and you can go somewhere, there's that quiet room place, the chaplains place that's nice. Yeah privacy exists here. (James, 17)

*Dimension 2: Control, privacy, roommates and their families.* Daily life in larger wardrooms produces situations in which participants wish they had greater control over other patients and their families' behaviour. Participants do not like noisy roommates and families, or rude, thoughtless behaviour of other patients and their families, mostly because this behaviour affects their privacy and it is outside of their control. This is discussed in the examples below.

**Example 1:**

*Researcher: Would you rather share a room or be on your own?*

Participant: I prefer being on my own, in my own room.

*Researcher: Why?*

Participant: 'Cause they're noisy, they're all noisy. Or at least I spent maybe two nights or three in the public room with two other people, one had an accident while trying to get to the toilet in time. Because you know, other people use it and they weren't very considerate. Other people weren't very considerate of the noise that they were

making for other people trying to sleep, such as watching the TV rather loudly in the middle of the night. (Daniel, 17)

**Example 2:**

*Researcher: Would you rather share a room or be on your own?*

Participant: Be on my own

*Researcher: And why's that?*

Participant: Because the mothers and fathers they get, they're rude to me and the children, I'm not used to them, some of them. I only like being by myself because they shout at me and that.

*Researcher: They shout at you?*

Participant: Yeah when I was in a double room, they shouted at me and that.

*Researcher: The patients or the...*

Participant: Their father and mother and when they use the toilet they keep the whole toilet for theirself. I told the nurses they keep the toilet to theirself can you please move me and they did. (Luke, 11)

**Example 3:**

*Researcher: Does noise bother you?*

Participant: Yes, like with some people, it just like doesn't really matter but some people just have the (pointing to family on other side of curtain) they have this instrument and they can be really loud and they just bang, bang, bang on it and I'm trying to watch TV or trying to talk to Mum and Dad or something and there's like bang, bang, bang happening. (Peter, 12)

*Dimension 4: Greater control over environmental attributes including light and noise.*

Participants who share their wardroom want greater provision for privacy, which is more substantial than the curtains around their bed. This is to enable them to exercise more control over the amount of noise, light and social contact with other patients and their families. Whilst some find the curtains adequate for a feeling of privacy, none find them adequate for controlling other environmental stressors like light and noise. Many participants lament their lack of control over the amount of light and noise in the environment, especially at night, because it interferes with their ability to sleep, as discussed in the following excerpts.

**Example 1:**

*Researcher: Ok is the Hospital noisy?*

Participant: Yes.

*Researcher: And does noise bother you?*

Participant: Yes, especially when you're trying to sleep

*Researcher: And what sort of noise bothers you?*

Participant: Um I can hear babies crying through the wall um, the buzzer of people calling for the nurse, people's machines beeping. Also, it's light, there's um at night there's a light on in the corridor so it's never dark in your room which makes it hard to sleep. The nurses, you can hear them walking up and down the corridor and that's the part I find hard. (Sarah, 15)

**Example 2:**

Participant: Oh another thing um sometimes I wish there was a way to block off the light though. 'Cause whenever there's, sometimes they'll have the lights on in the corridor at night 'cause they'll be going, like 'cause there's so yeah so much like mirrors and that, 'cause these curtains aren't too good with the whole light thing, 'cause you know they're white so I don't know, that's one thing that's a bit of a bother sometimes,

*Researcher: Light coming in from the corridor through the night?*

Participant: Yeah. (James, 17)

**Example 3:**

*Researcher: Do you ever use the curtains around your bed?*

Participant: Um I'm in a two room now, so I just go to the bathroom. But if I was in a four room, I'd use them. It depends how I feel at night. If I want to sleep I'd close them.

*Researcher: Do they make a difference?*

Participant: Yeah they give the feeling of privacy. It can block out light a little bit too, but sound, it doesn't help sound which can be a problem at night. (Zoë, 16)

*Dimension 5: Wardroom configuration.* Control over noise, light, and contact with other patients are the three most commonly given reasons for preferring a single room. As in the excerpts below, most of the participants are seeking more control and a more protected personal space for themselves and their families, in which they can retreat from contact with other patients and their families.

**Example 1:**

*Researcher: Would you rather share a room or be on your own?*

Participant: I prefer being on my own, in my own room.

*Researcher: Why?*

Participant: 'Cause in a public room you couldn't really close the door to block out the sound of the other activities and if you wanted to go to sleep you'd turn off your light but someone else would still sit there with their light on and you know you'd still have that light shining around plus if they had machines, and, so basically it's just more um the noise and the sounds. (Daniel, 17)

**Example 2:**

*Researcher: What do you think of this space?*

Participant: Um I reckon it's good having my own room, I like that because the first couple of times I was in here I was with babies and they were crying and they were keeping me up at night, but I like having my own room 'cause I can fit all my stuff and 'cause no babies wake me up at night, 'cause it's hard getting to sleep and they wake me up. It's really annoying but now it's good, I like being in this room, being by myself. And um because, because I have a pretty big family because like I've got like two step dads -my dad's side and my mum's side - so it's kind of like four different families, so when they all come in it's not really disturbing anybody, like if I was next to someone with a curtain, you have to be real quiet and with the TV I can turn the TV up so my Mum can hear it too and my step dad and, 'cause I can fit all my stuff! (Josie, 12)

**Example 3:**

*Researcher: Does noise bother you?*

Participant: Sometimes, when I'm trying to go to sleep and stuff like that. I liked it better when I was in a single room.

*Researcher: For the noise?*

Participant: Yeah

*Researcher: Ok would you rather share a room or be on your own?*

Participant: Be on my own

*Researcher: And you've said that's because of noise, are there other things?*

Participant: Mmm, 'cause it's like your own little space and you don't have all these curtains around you and it's just better, 'cause there's a bit more room and everything like that too. I don't know, it's just easier to be on your own and you can go to the toilet and stuff and it's not like people might walk past and look in 'cause it's like your own little space. (Milly, 11)

*Dimension 6: Capacity to participate in their own healthcare management.*

Participants' response to the questions concerning their capacity to participate in their own healthcare management produced a range of responses. Some are happy with their level of inclusion and their control over their involvement, as indicated in the following examples.

**Example 1:**

*Researcher: And do you feel they listen to you?*

Participant: Yeah they always give the right amount of information. Like if you don't want to know you just want to, like you don't want to know anything you just want to have the treatment and get through it then that's fine, they don't have to tell you anything but if you ask they will tell you. (Peter, 12)

**Example 2:**

*Researcher: And you feel they listen to you and consult you enough about the way things are for you?*

Participant: Yep, yep because they're good, like the doctors for my legs they tell you what's the matter with you and stuff, so that's good because like because it's *me* I need to know what's the matter with me like, so it's good that they tell you. (Josie, 12)

**Example 3:**

*Researcher: Do you think they consult you enough about how you're feeling? Do you think they listen to you?*

Participant: Yeah um they're always around like asking like if I have any questions, they're always there to answer the questions um, even though I don't have any major questions to ask them, they're always still asking. I never, I never think that they don't think about you. Like they're always um making sure that you've got all your um questions answered and they're always wanting to know how you feel and like what you're thinking to make sure that they know what stage we're at. (Justin, 15)

For others, consultations with doctors can produce intimidating situations. Participants of all ages at times do not feel in a position to ask questions about their illness or their treatment for fear of seeming stupid or because they are afraid of what they might be told, or because they feel disempowered in the situation. The following examples touch on these considerations.

**Example 1:**

*Researcher: Do you think they listen to you and consult you enough about the way you feel?*

Participant: Um sometimes, sometimes they don't really ask me much and then other times they do.

*Researcher: And what would you rather?*

Participant: Um I am not very sure

*Researcher: Do you mind if they ask you or don't ask you?*

Participant: I don't mind sometimes. But sometimes they don't really tell you what's going on and you want to know what's going on and you can't, you don't exactly want to ask them.

*Researcher: And why's that?*

Participant: Because you're worried about what they might say to you or something. (Sasha, 13)

**Example 2:**

*Researcher: Do they consult you? Do you feel they listen to you?*

Participant: Listen to you? Definitely not. It's always what they want. They don't consider you very much. It's like these are our rules blah, blah

*Researcher: And I'm assuming that's not what you'd like?*

Participant: No I think they should actually, and it's like there's the same rules for like everyone and I think they should have a little bit more um like leniency if that's a word to let some like assess each person as they come and not just say "you're just like the rest of them".

Researcher: *Ok, what's the effect of "you're just like the rest of them"?*

Participant: You just feel like you're not really being judged as an individual. It's like you've got this illness and you have to do this, this and this and it's not very fair. They don't really, I find here they don't really deal with the emotional side of anything. It's always just medical and if you don't get fixed emotionally then anything they do medically is not really going to help you anyway. (Sarah, 15)

Others feel resentful when their own knowledge of their situation is not given due respect by the medical staff, especially adolescent patients who visit the hospital regularly. As indicated in the following excerpts, some of the regular patients do not tolerate any level of exclusion from the decision-making process in relation to the management of their diagnosis.

**Example 1:**

Researcher: *Do you think you get consulted enough about the way things are for you? Do you think they listen to you enough?*

Participant: No like my doctor's do, like, the ones that have known me but when I come and see a new doctor there's none of that respect. 'Oh he's just a stupid kid he doesn't know what he's talking about'. Like I had to argue with one of them when I first came in about getting a cannula. They wanted to give me something called a long line only my veins have collapsed up here and he didn't, he wasn't going to, he was arguing with me about it and I do know best about myself sometimes. I've been doing this for five years now, the cannula thing. And I think it was terrible that I had to argue with him about such a stupid thing and the fact that to him I was just a stupid kid who doesn't know what he's talking about. (Troy, 16)

**Example 2:**

Researcher: *Now do you get enough info from the doctors and nurses?*

Participant: I do. Yep 'cause I'm always nagging them what's going on, what's my results blah blah blah,

Researcher: *Are they happy to give it to you?*

Participant: They are happy to give it to me 'cause they know that if I don't get it I'll go home! Like if I'm sick they'll be like 'yes, blah blah blah this, that, this, that.' (Kylie, 14)

**Example 3:**

Researcher: *What's the hardest thing about being in hospital?*

Participant: Nurses. When you get nurses who um just don't match with what you're trying to do. You know once last week I had a fight with a nurse just to get disconnected and you know it's terrible, it's difficult sitting here and I used to have a trolley that didn't roll at all. And we got into an argument and I called my doctor and he told her off.

Researcher: *Yeah that's not fun to do.*

Participant: Yeah and when you get really difficult nurses who don't allow, or if any of them are rude to you, you know there's one nurse here and I'm not going to say her name she is very power hungry. Like she's nice sometimes but because she's a nurse you know she doesn't show any respect for, you know, kids you know, and some of these people are quite mature kids, you know, I'm 17 you know, I'm not too, I believe I should be treated as that sometimes. Also I don't seem to, I can't always make my own choices. ...Let's say at home, I'll do my self –with medication, it's my responsibility I'll go get my own medication, I'll do it all myself. I've been doing this for the past years and years and I come in here and they don't allow me and they'll be like 'oh no we can't let you, you call your parents'. And my parents have a life you know, they've got other kids and work and that's really difficult. Restrictions and boundaries are important but some you know...(James, 17)

*Dimension 7: Influence of time on patients' desire for privacy and control.* Most participants are very tolerant of many of the restrictions that are associated with their illness and the lack of control they have over their circumstances. However, for some participants this changes with time. Those who spend a long time in isolation increasingly resent their lack of control over their situation. Similarly, participants on repetitive treatment programs also become restless with time, with the nature of their treatment over which they have no control. The example below captures this.

*Researcher: Ok now when you're in here for a long time, does that change the way you feel about being in hospital?*

Participant: Yeah very.

*Researcher: What changes?*

Participant: Boredom, I get sad I really want to go home and all that, to my own bed and eat anything I want, mostly because they keep on telling me what I am allowed to have in here and that's getting annoying. (Tom, 12)

Tolerance for lack of privacy also becomes more of an issue with time. This is especially the case with older participants.

*Researcher: Ok when you want to be by yourself where do you go?*

Participant: Um at the moment I don't really have anywhere to go when I want to be by myself 'cause there's always people in my room and they're talking and then there's not really a quiet spot to go.

*Researcher: And do you miss that?*

Participant: Yes I miss that a lot and I've asked the nurses to move me into a quieter room and they haven't done so yet but I think they will. You get really sick of having no privacy. (Sarah, 15)

**Member-checking task.** A number of prompt cards were used to span this theme. These included: *I can't always do things my way here but it doesn't matter* and *I wish I had more say over how I have to do things here*. These cards were deliberately used in conjunction with each other to explore the indication that had arisen in the main study data that the desire for greater personal control increases with age. The findings from the member-checking task indicate a similar pattern, which is that children and young people become increasingly conscious of their personal control and privacy, and seek greater agency and control as they get older. The two excerpts below are representative examples.

**Example 1:**

Participant: *I can't always do things my way here but it doesn't matter.* That's true 'cause here I can talk to [name] or um if I can't go down to the Starlight Room, I'll probably watch them up on the TV or something anyway so yeah it doesn't really matter if I can't do things my way. There's not really much to say about 18 [*I wish I had more say over how I have to do things here*] 'cause I don't really wish that. (Melissa, 12)

**Example 2:**

Participant: More say in how to do things here. Um if I was better informed, then I'd feel like I could have a say in what was happening but um in terms of what treatment I get like, for example I have to have radiotherapy I don't really like that, um and so I

did research on it and I talked to the lady about what it is, so I can't really get away from what happens to me and how I'm treated. I like to, well it's nice to be informed um about what they're going to do to you instead of just telling you on the day, like "oh you're going to have this operation." And it's like "oh really?" Like that happened to me and I was kind of angry why I wasn't informed um beforehand. I was having a [treatment] and I had no idea what that was and I was only told two days prior they were going to do that to me. (Lana, 18)

A further prompt card was used for privacy including: *I wish I could have more privacy here*. The findings appear to be consistent with the findings from the main study in that privacy is enmeshed with personal control over patient behaviour and environmental attributes such as noise and light. In addition, as in the findings from the main study, the importance placed on this consideration varies across the group but not in a consistent way, such as based on age or gender for example.

**Example 1:**

Participant: You do have a lot of privacy around here it's just the very odd like if [name roommate] can't sleep she'll leave her light on and I probably can't sleep until she falls asleep or something but that doesn't worry me much. I do get a lot of privacy like if I want to do something like religious or something I would probably just like shut the curtain, so [name-roommate] like you know, she just doesn't like wonder or start making accusations and stuff. Privacy doesn't really worry me much anyway so Number 20 [*I wish I could have more privacy here*] doesn't really count for me. (Melissa, 12)

**Example 2:**

Participant: I can understand not having enough privacy yeah because I have to be constantly checked with my drip. I'm like attached to it so I can't really get away from that. The nurses usually just come in but it doesn't bother me. Yeah I can understand why I don't have a lot of time alone. But like in your own room, I get some and like I don't have other patients in here with me and it's not crowded or noisy or anything so it's ok. (Lana, 18)

A further pair of prompt cards was used to revisit wardroom configuration and the reasons for patient preferences. These included: *I prefer a single room* and *I prefer to share a room*. The findings reiterated the link between selecting a single wardroom for greater personal control over environmental attributes and social interaction, and for greater privacy for patients and their families. The findings also support the link established in the main study between preferring to share a room for company and to avoid loneliness.

**Example 1:**

Participant: Um I would prefer to share a room 'cause you do tend to get lonely in hospitals especially if you're in a single room or isolated. You really tend to get lonely and I find I've gotten lonely even though I share a room with [name-roommate] 'cause she doesn't really talk much and I don't get much visitors so yeah. (Melissa, 12)

**Example 2:**

Researcher: *Ok I prefer to share a room, why's that?*

Participant: Just so you can talk to someone and make friends and stuff. (Adam,10)

**Example 3:**

Participant: Number 21 means something, I do prefer to have a single room so that I can have my privacy and so just in case my mother stays with me at night or because she can stay here too, that's always good to have just someone close by and um yeah.

Researcher: *Ok so it's mostly for privacy? So you can just have quiet time with family?*

Participant: Yeah and just do whatever you want to do like if you want to have your music on or whatever. (Claire, 14)

**Social Experience**

This domain centres on the social experience of being in hospital and the key social groups within that experience and the roles that they play. There are two major themes whose main alignment is with this domain. These include: *The roles and experience of family*, and *friends and roommates*. Both these themes are aligned to many of the other domains also. There is no significance to the order in which these themes are discussed here.

**Theme 1: The roles and experience of family.** This theme concerns all aspects of the family's involvement in participants' experience of hospital. It includes the activities and use of the environment, which results from participants' interaction with their families. It also includes the discussion that reflects participants' consciousness of their families' experience of having a child in hospital, and the implications of this for the family.

**Alignment with domains.** Apart from the main alignment to the domain of social experience, this theme is aligned with three other domains also, including physical environment, organisational considerations and time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Social experience:* The alignment with this domain is indicated by the evidence for two dimensions including the *family as the central source of support (1)*, and *socialising with family (2)*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for two dimensions including *needing places to socialise with family (3)* and *family comfort in the environment (4)*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for two dimensions including *family as buffer between*

*children and organisation (5) and the impact of cost and inconvenience on families (6).*

- *Time:* The alignment with this domain is indicated by the evidence for a two dimensions including *missing family (7) and familiarity versus homesickness (8).*

**Exploration of dimensions.** In total there are eight dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: Family as the central source of support.* Family is a central presence in the experience for most of the participants. Family members contribute to patient care, liaise with medical staff, provide distraction, entertainment, comfort and support for their children. Family also provide a link with the outside world and contact with familiar routines enjoyed by participants. Most participants have daily contact with their families in some form such as by telephone, or text message, or in person. For the younger participants there is a family member present at their bedside almost all the time.

One of the most vital roles families play in the experience is in providing support. Most participants nominate their Mum or Dad in particular as the first people they would turn to if they needed support. Following Mum and Dad, siblings are the next most nominated people, ahead of friends in the Hospital, and then nursing staff. The responses below illustrate the role of family in providing support.

**Example 1:**

*Researcher: So if you need support, who would you normally turn to?*

*Participant: My Mum, mostly my Mum, 'cause she's always here and all that and practically she knew me since I came out, so practically I would always turn to her for advice 'cause she knows what to do and if she doesn't she just asks the doctor and tries to find out. (Tom, 12)*

**Example 2:**

*Researcher: Um, and your Mum's here all the time?*

*Participant: Yeah, my Mum's been here all the time. She hasn't left since we came. Mum's just been all, like she helps me when I need to get out, she's always there, she's always there to help with whatever, um we talk about stuff, 'cause like I didn't understand what they did, like what they operated, so she was like explaining. (Luke, 11)*

**Example 3:**

*Researcher: If things get too much for you how do you manage that?*

*Participant: Um basically just have a bit of a cry and then Mum or Dad help me through it. (Peter, 12)*

**Example 4:**

*Researcher: Ok if things get too much for you how do you manage that?*

*Participant: Well they haven't really got that bad, but if they do I'll just probably, my Mum would help me or my step Dad or my Nan. (Josie, 12)*

Family, as the central source of support, changes for adolescent patients. For this age group, family is still a key supportive presence but family members do not always spend as much time in the hospital with them. This age group accepts that their families have competing commitments such as work and other siblings. (These patients often turn to their friends in hospital for support. This will be discussed under the next theme, *friends and roommates*). The excerpts below provide examples of participants' sensitivity to their family's circumstances.

**Example 1:**

*Researcher: Ok does your family come and see you?*

*Participant: Yes every second to third day for the simple reason my Mum has six kids and a lot of them, like three are sick and, I've got one brother with cerebral palsy, one brother with diabetes, a sister that's going for a claim for her neck, 'cause she broke her neck while in foster care, anyway that's a whole different situation, and the other two are fine. So there's a lot of stuff Mum goes through. (Tina, 14)*

**Example 2:**

*Researcher: What about family?*

*Participant: I talk to my Dad about once or twice a day, 'cause he doesn't come up here very often to visit me, because he is very busy, he has a hard job. And my Mum calls me sometimes. She usually calls me if she's not coming to tell me that she's not coming.*

*Researcher: But she comes a lot of the time?*

*Participant: But she comes almost every day. (Libby, 16)*

*Dimension 2: Socialising with family.* Socialising, talking, watching TV, wandering around the hospital environment with family members are common pastimes for many participants. These activities range from simple bedside games to having meals in the hospital cafés. The excerpts below represent the simple past times patients carry out with family members.

**Example 1:**

*Researcher: What do you do there to keep yourself occupied?*

*Participant: Well Dad bought a TV so we just watch that and I have a portable DVD player and we plug that in and we just watch DVDs. (Scott, 15)*

**Example 2:**

*Researcher: So what do you normally do to keep yourself occupied?*

*Participant: Um either watch TV, play computer, read something like a magazine, or just talk to Mum or Dad or something. So Mum and Dad are a big role in all of this. (Peter, 12)*

**Example 3:**

*Researcher: So what things do you find to do?*

*Participant: Building, I'm interested in building*

*Researcher: Building with what?*

*Participant: Barnacles*

*Researcher: Barnacles ok, yes I can see them*

Participant: Yeah they're very, I like the really big ones that I do. That big box, there's three parts to it. I've only did the first part and it took me about an hour and me and my Mum are going to work on the other parts, the other two parts. So I like to have something to do like that. I also like to watch TV a lot, reading also passes the time and helps me use my imagination and of course playing games with my Mum, I love doing that a lot. (Tom, 12)

**Example 4:**

*Researcher: And what do you normally do?*

Participant: Um I've been playing board games with Dad and Nan and playing on those bubble machines, sometimes. (Milly, 11)

For younger participants, the family is the key social group in their experience. Younger participants do not place the same importance on making friends in the hospital as they rely more heavily on the presence of family members to provide distraction and entertainment and for social contact. The excerpts below state this.

**Example 1:**

*Researcher: Ok do you make friends in the Hospital?*

Participant: Yep

*Researcher: How important is that?*

Participant: Not really because you get your family visiting all the time and like I get visitors every second day. My sister comes up every second day, like say if she comes on Monday she'll come on Wednesday and then she'll come on Friday and then she comes on Sunday, then Tuesday. She keeps on coming every second day and my Mum and Dad are here all the time. (Mandy, 10)

**Example 2:**

*Researcher: How important is it making friends in the hospital?*

Participant: um... it's good but it depends on, because sometimes you get really tired in here, if you're sick in here, so sometimes you just really don't care 'cause you have all your other family and friends from home come visit you so it's not a great, great deal but sometimes it's good to say hello. (Josie, 12)

*Dimension 3: Needing places to socialise with family.* Wandering around with family members and looking for places to sit and talk or activities to do together is one of the most common ways that leads to participants' exploration of the environment. As indicated in the excerpts below, the outdoor areas are often the places that participants prefer to spend time with family.

**Example 1:**

*Researcher: Right, so where do you head off to?*

Participant: Well, when I'm with my Mum I'm usually, I just go for a walk outside or just anywhere really. It's really nice out there [Chinese Gardens], just when you're wanting to get away from everything for awhile

*Researcher: What do you like about it there?*

Participant: Um it's really pretty and like it's, no one's really ever here so when you come here with your Mum no one's really listening, it's just peaceful and it's outdoors for a change and it's you know nice, it's nicer. (Vanessa, 11)

**Example 2:**

*Researcher: So what else do you like to do here that's on offer?*

Participant: Um go outside for a walk with Mum round the gardens and stuff. (Libby, 16)

**Example 3:**

Participant: And...the Chinese Garden. I love the Chinese Garden

Researcher: *You love it?*

Participant: Yes I do.

Researcher: *How much do you use it?*

Participant: Every time family come. I take my Nan out there to have a smoke, and we sit in the little hut. It takes her awhile to get up the stairs though, nice if there was a ramp. 'Cause like she's got a wheelchair. (Tina, 14)

Figure 10.3 shows the main feature of the Chinese Gardens referred to in some of the excerpts above, the Red Pagoda, where it is possible to sit and talk.



Figure 10.3. The red pagoda in the Chinese Gardens.

The recreation or common areas are well used for this purpose also. For example, the Wade ward common room is a place that many adolescent patients choose to spend time with their families because of the activities available there. Figure 10.4 shows the Wade Ward common room.

**Example 1:**

Researcher: *What do you think of it as a space?*

Participant: Um I reckon it's a good idea 'cause you can like play pool and stuff.

Researcher: *Do you use it for that?*

Participant: I go down with my Dad sometimes to play pool and my Mum with air hockey. Sometimes we play Monopoly. (Sasha, 13)

**Example 2:**

Participant: Um the common room is great. I love the um, we have Pool and I love playing pool with my mum and my sisters and we also have Ice hockey, or no air hockey, air hockey and that is really good and we eat in the common room and we can listen to the radio in there... and it's good. I don't think anything can change about it. (Sarah, 15)



Figure 10.4. Wade Ward common room.

The formal social opportunities such as the cafes and shops are also well used by participants and their families. These environments are appreciated for their contrast to the rest of the hospital environment, and these experiences are appreciated because they reflect the participants' lives at home. Going to the Bear Café is discussed in relation to these reasons in the excerpts below.

**Example 1:**

Participant: The Bear Café, I like it there.

Researcher: *You've been there? Do you go there much?*

Participant: I've been there like three or four times. It's really nice.

Researcher: *What do you like about it?*

Participant: The food, and it's like it kind of puts you like away from the Hospital. You know what I mean like, you think you actually are in a restaurant but you're at the Hospital. So yeah that's pretty cool.

Researcher: *Is it important to have places that feel like that in the Hospital?*

Participant: Yes 'cause when I was in here, I was in here for six weeks the first time and it was driving me nuts and like I just wanted to go out and go to, 'cause like we normally went to restaurants every second weekend or whatever, like with my family. (Amelia, 14)

**Example 2:**

Participant: Um the Bear Café um I really like this place.

Researcher: *Do you?*

Participant: Yeah I went there yesterday and spent \$25 bucks

Researcher: *And when you go there are you with family or on your own or with friends?*

- Participant: Family, friends, I don't go eat by myself like in the restaurants. Family, friends.  
 Researcher: *Yeah and how often would you use this café?*  
 Participant: Um I don't know, like let's say I'm staying in the hospital for two weeks I'd probably use it once or twice. Every now and then when I come for clinic, you know Dad and I may go in there.  
 Researcher: *Now you say you really like it. Why's that?*  
 Participant: I don't know it's like a restaurant. It's the only place with real food. It's good to have a place like that in a hospital, 'cause it's something that you would normally do outside the hospital – go to restaurants with your friends or family or whatever. (James, 17)

**Example 3:**

- Participant: I've been to the Bear Café to have lunch and it's really good.  
 Researcher: *So who did you go there with?*  
 Participant: Um my Mum and my Dad.  
 Researcher: *And what did you think of the café?*  
 Participant: I reckon it looks good and it's a good idea that it's there because normally you wouldn't get a café in a hospital so it's just nice if you want a different atmosphere from the surroundings. (Sasha, 13)

Figure 10.5 shows the Bear Café, discussed in the previous excerpts.



Figure 10.5. The Bear Café.

*Dimension 4: Family comfort in the environment.* Most participants are very conscious of the experience of the hospital environment also from their family's perspective. Environmental comfort is one aspect of their family's experience they are concerned with as discussed below.

**Example 1:**

- Researcher: *What do you think of your ward room?*  
 Participant: It's nice, it's a bit small. It's good that they've put the pictures on the walls so you can see them. But most of the time you're just staring at the roof.  
 Researcher: *Yeah? How would you make it better?*

Participant: I would put things on the roof, like dangly things and stuff to look at and make them a tiny little bit bigger (chair/beds) so that that Dad is more comfortable. (Milly, 11)

**Example 2:**

Participant: Also, I like the idea of how our parents can stay with us, sleeping on the couch oh well the couch opens up into a single bed for staying overnight. Like they can help us and it's more um, it's more, what word can I use...it's more comforting for us knowing that our parents are there with us all the time. I think their chair-bed thing could be more comfortable though. (Justin, 15)

**Example 3:**

Researcher: *Ok, do you mean that your bed is not comfortable?*

Participant: No it's pretty comfortable but my Mum has to sleep on that thing and it's not very comfortable. I wish hers was more comfortable. (Josie, 12)

*Dimension 5: Family as buffer between children and organisation.* Families also provide a buffer for patients between themselves and the medical world. The excerpts below reveal the role of the family as a screen for medical information.

**Example 1:**

Participant: Um at the beginning I didn't really want to know anything 'cause it just didn't interest me I just wanted to get better and get out but then I started asking questions and yeah they started telling me stuff

Researcher: *And is that a good thing or?*

Participant: Um yeah, I don't like hearing news, like before people, like if a doctor came in and my Dad weren't, like, now and told me something I would be like freaked out but if he spoke to my Dad before and my Dad knew what was happening and then came and talked to me, like you know what I mean, get another person.

Researcher: *You'd rather have someone else with you when you're hearing...*

Participant: Yeah, I don't want to hear it like... Yeah I don't want to be the first to hear it.

Researcher: *Ok why's that do you think?*

Participant: I don't know, I'm just scared of what they're going to say. (Amelia, 14)

**Example 2:**

Researcher: *Ok do the doctors and nurses tell you what's going on?*

Participant: Yep.

Researcher: *Do you like to know?*

Participant: Um some of it because some of the stuff like I don't want to know. Like they just tell my Mum and Mum and Dad can tell me later or something like that. (Milly, 11)

*Dimension 6: The impact of cost and inconvenience on families.* Overall, participants show a great respect for their family's perspective and involvement in their experience. Most willingly acknowledge the important role their families are playing in helping them through the experience and most remain very conscious of the impact of the experience on their families. The excerpt below was made by a participant who has spent many months in hospital and who has siblings with a similar condition.

Researcher: *When you're in here for a long time does that change the way you feel about being in hospital?*

Participant: Yep

Researcher: *What changes?*

Participant: Like I don't know

Researcher: *Does it get easier or does it get harder or?*

Participant: It gets harder for my mum. She's done two kids that have had operations and she's got another one that was the bone marrow. (Luke, 11)

Many of the participants comment on the price of services and products in the environment being too expensive for their families to use, such as the Bear Café, and the coffee cart in the front foyer and the TV rental. Improvements suggested by participants often concern considerations that would benefit their families such as increased access to car parking and a reduction in the cost of it. The excerpts below consist of comments on cost in relation to the family's circumstances.

**Example 1:**

Participant: Um I've seen the Bear Café but I've never been to it because the food's too expensive and my Mum doesn't like spending money on things like that, well she doesn't have the money to spend so yeah we've never been there. (Libby, 16)

**Example 2:**

Participant: And we have eaten here

Researcher: *That's just a section of the café on level 1*

Participant: Yeah we get food from here. I think it's good it's cheap. I think it's pretty good, it's clean and it's good. My mum likes it too, she likes the coffee and she buys it from there and not from Starbucks 'cause Starbucks is too expensive for her. (Karina, 13)

**Example 3:**

Researcher: *Ok wish list, dream time, what would you like?*

Participant: Well I wish that we didn't have to pay for TV. That's a real killer, it's really expensive. You know I personally can't afford, you know 'cause I pay for it 'cause my parents can't always be here to pay for the thing and it's really expensive. It's too expensive for them to afford anyway. (James, 17)

*Dimension 7: Missing family.* When asked about the effect of time, many participants discuss it in relation to becoming increasingly homesick for their family, and for their normal routines and homes. The loss of contact with familiar people, family routines and places are often listed as the hardest things about being in hospital. The excerpts below are examples of the participants' discussion.

**Example 1:**

Researcher: *What do you find the hardest thing about being in hospital?*

Participant: The hardest thing um...not being in my own house and around like my friends and family as much. I like going out and having fun and I don't like it because usually I go to the football on the weekends or something or somewhere on the weekends usually with my step Dad or my Mum so it's really annoying laying in hospital. (Josie, 12)

**Example 2:**

Researcher: *What do you think is the hardest thing about being in hospital?*

Participant: Um... being away from everybody.

Researcher: *Everybody being?*

Participant: Mum and Dad, or Mum, my sisters and my friends and family. (Mandy, 10)

*Dimension 8: Familiarity versus homesickness.* When participants discuss the effect of time they often represent it as a balance between becoming increasingly comfortable and familiar with hospital routines and becoming increasingly homesick as in these two excerpts

**Example 1:**

*Researcher:* So when you're in here for a long time. How does that change the way you feel about being in Hospital?

*Participant:* Um sometimes you just really want to go home, 'cause you haven't been there for a long time and you just feel a bit, you just really want to go home and see your family. I don't know, it gets easier too 'cause, it's just kind of you've done, you've been here for awhile so you just get used to it. (Sasha, 13)

**Example 2:**

*Researcher:* Ok so when you're in here for a long time, does that change the way you feel about being in hospital?

*Participant:* Mmm kind of because I just want to go home

*Researcher:* Ok so what happens? As you spend more time here does it get easier? Or does it get harder? Or?

*Participant:* Well it gets easier like being in hospital 'cause you get to know everybody like all the nurses but it gets harder because you miss everything like you're friends and family and stuff, so a bit of both. (Milly, 11)

**Member-checking task.** There were two prompt cards used for this theme including: *My family is my main support.* The discussions in the member-checking task support the initial findings from the main study in that all participants acknowledge the central role of family in supporting them during their experience, with younger participants reporting a continual presence by their family members.

**Example 1:**

*Participant:* Number 3, my family is my main support, 'cause my sister she went through the same thing, except she had different symptoms but like she's reassuring me about tomorrow and what I'll go through afterwards with medication wise and things like that because she was put on the same medication and she went through a lot of the same aspects like the endoscopy and being put on steroids and special diets and things like that. So she's been, and my Mum has been here every single day right by my side from 9am in the morning to 9pm at night so she's been, my Mum's been really good. (Melissa, 12)

**Example 2:**

*Participant:* Yeah, number 3, my Dad is here all the time. (Adam, 10)

**Example 3:**

*Participant:* Yes, my family is my main support and they're important to me.

*Researcher:* Are they here all the time?

*Participant:* Yeah. (Annabel, 16)

The second prompt card used was: *Some things are too expensive here.* These discussions also reflected the findings from the main study in that this prompt card led to discussions on the cost of things in the environment in relation to the family's capacity to afford them and participants' consciousness of their family's experience.

**Example 1:**

*Participant:* Some things are too expensive here. I find that um if like me and Mum went down to the canteen just to get lunch, Mum would pay a lot just to get like a sandwich is \$4.50 which I find is pretty expensive and um even Mum just paying for the TV, I feel bad watching TV because Mum's spending her money on TV, but then again she doesn't really mind. (Melissa, 12)

**Example 2:**

*Participant:* Some things are too expensive.

Researcher: *Ok what things are they?*

Participant: Um the TV thing, the Foxtel's cheaper than that. My Dad thinks it costs too much.  
(Adam, 10)

**Example 3:**

Participant: Yeah the TV's too expensive to rent. Like Dad pays for it but it costs too much.  
(Toby, 16)

**Theme 2: Friends and roommates.** Friends and roommates is a theme that is concerned with the social interaction participants have with these groups. 'Friends' encompasses two groups including friends made in hospital and friends from participants' lives outside hospital. This theme encompasses all aspects of participants' response to, and interaction with, friends and roommates, and the roles that they play in participants' experience.

**Alignment with domains.** Apart from the main alignment to the domain of social experience, this theme is aligned with three other domains also, including physical environment, organisational considerations and time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Social experience:* The alignment with this domain is indicated by the evidence for three dimensions including *friends as source of support (1)* and *socialising with friends (2)*. Both of these have the same two sub-dimensions which include *friends from home* and *friends made in hospital*. The third dimension is *roommates for company (3)*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including *needing places to socialise with friends (4)*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a single dimension including *availability of age-appropriate social activities (5)*.
- *Time:* The alignment with this domain is indicated by the evidence for a single dimension including *the influence of time on the need for friends and company (6)*.

**Exploration of dimensions.** In total there are six dimensions identified in this theme and two sub-dimensions. Each of the dimensions and sub-dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: Friends as source of support.* Friends consist of two groups, those made inside hospital and those from participants' lives outside the hospital. Both provide support. Friendships made with other patients have the capacity to provide greater support for participants' as these friends are often familiar with the actual experience that participants are going through. Friends from their outside lives have the capacity to be supportive by keeping participants linked to their lives outside the hospital and to ensure they are not excluded or forgotten.

These support networks are particularly important for adolescent participants. This may be linked to the fact that this group do not usually have a family member present all the time, as is usually the case with younger participants. In this age group, friends are often accorded the same roles that are filled by family members for younger participants. The excerpts below illustrate the importance of supportive friendships from both groups of friends.

**Example 1:**

*Researcher: So you say you have contact with your friends outside the hospital?*

Participant: Yep

*Researcher: And how do you do that?*

Participant: The phone and my mobile.

*Researcher: And how often is that?*

Participant: Um usually every night, but right now I don't because they're away, but before they went away, every night at least one of my friends would call me, so that was nice.

*Researcher: And it's an important thing to have happen?*

Participant: Yes, very important. I can tell them my problems and I can find out what's going on out of the Hospital and it just makes me feel better I think. (Sarah, 15)

**Example 2:**

*Researcher: Ok do you have contact with your friends outside the Hospital?*

Participant: Yes um the other day two of my friends came and visited me for about an hour after school, and another one came with his Mum the day before. And also one of my teachers came as well.

*Researcher: And is that a pretty important thing?*

Participant: Um yeah. I find it, like friends that I know, it just gave me that extra boost to see them and they were saying that they want me to go back to school um, that they like, um that it's quiet without me and stuff like that.

*Researcher: What kind of things did you do with them when they were here?*

Participant: Um we just talked, I caught up with what they've been doing, like what work I've missed out, um how they've been, what they've been doing. (Justin, 15)

**Example 3:**

*Researcher: So do you make friends with other patients in here?*

Participant: Yep, it helps a lot 'cause I don't feel alone and I don't feel like I'm by myself in this illness. Makes me feel like there's someone like supporting me 'cause my friends support me, like we support each other so it makes me feel like I'm welcome and like I fit in, so it's important. (Polly, 14)

**Example 4:**

*Researcher: How important is it making friends in the hospital?*

Participant: It's really important.

*Researcher: And why's that?*

Participant: 'Cause if you're here for a long time you want to have something to do and people to talk to and also it can be hard at times so you want support and stuff. (Jane, 16)

*Dimension 2: Socialising with friends.* Older participants especially, if feeling reasonably well, enjoy the social opportunity to meet new people and to form new friendships whilst in hospital. Socialising with friends is a key coping strategy as it provides distraction, entertainment and fun, and helps to alleviate boredom. The excerpts below reveal this.

**Example 1:**

*Researcher: Ok would you rather share a room or be on your own?*

Participant: Share a room

*Researcher: Mmm why's that?*

Participant: It's more fun. I don't know, get to know people more, but yeah. It's boring in your own room.

*Researcher: And you've done that, if you've been in isolation.*

Participant: Yeah. I have to go to isolation again for the bone marrow, and I'm going to go crazy. (Luke, 11)

**Example 2:**

*Researcher: How important is it making friends in the Hospital?*

Participant: I think it's very important because then you get to bond with people and you get to do stuff with them, so you're not like bored and you get to talk to people with exactly the same um problem as you. You can like that sometimes and it makes you feel better and you know, like it just makes you feel a bit normaler. It's just nice to socialise sometimes. (Sasha, 13)

**Example 3:**

*Researcher: How important is it making friends in the hospital?*

Participant: Very. I'm a very social person, I like to talk a lot um, making friends, I'm more into you know, not making long term friends but it's fun to have friends that you know just chill out and talk with 'cause 24 hours in a hospital, every single day is a whole lot longer than 24 hours at home 'cause sometimes there's nothing to do. In between doctors you're just sitting here waiting for something, so it's nice you go and have nice talks with the people and muck around, with people your age. I'm really happy there's an adolescent ward here, so it is of importance. (James, 17)

*Dimension 3: Roommates for company.* The friends made inside the hospital are further distinguishable from roommates who may or may not become friends. For some participants roommates play a vital role in simply providing company. Participants often say they would rather share a room for the company, even if they do not talk with their roommate, than be alone. In the excerpts below, the participants talk about the value of just having company.

**Example 1:**

Participant: Mum asked me if I wanted to go to my own room, but I didn't want to 'cause like, that atmosphere in there is different than being on your own, like um there's a little girl across, like one across on the beds, no a little boy and his sister. She's very funny she makes me laugh, so like I like being in there with her, 'cause I get to laugh a bit of the time.

Researcher: *Do you actually talk to the other patients or do you sort of, just interact with them? Whatever's going on for them kind of just rubs off on you?*

Participant: Yeah like I don't really talk. I haven't spoken to any of them, only my Mum speaks to like the other parents but I don't, I don't like to interact with the others. And plus they're a bit younger than me so, they're just busy playing their games and watching TV. (Justin, 15)

**Example 2:**

Researcher: *Alright would you rather share a room or be on your own?*

Participant: Ok it depends who I'm sharing the room with. Um I think that it's nice to share a room with one other person. That's what I did last time. It was just me and another person and I found that good. Just to have one other person there.

Researcher: *And how does that help? Why would you choose that?*

Participant: You don't feel so alone, um it's, there's not that dead quiet and someone to talk to and you still have your own space I think with two people in the room. With four people, not really. (Sarah, 15)

*Dimension 4: Needing places to socialise with friends.* Moving around the environment to meet with friends, or to find a place to hangout with them, or to find activities to do with them were common motivations for exploring the environment and using the facilities available. This is discussed in the excerpts below. Figure 10.6 is a photograph of the Bed Rest area, Wade Ward as it was at the time of this research.



Figure 10.6. The Bed Rest area, Wade Ward.

**Example 1:**

Researcher: *Yeah that's the front foyer, how often do you go there?*

Participant: Um, well prob'ly every night, 'cause me and my friends get bored in the wards and we're like 'oh let's go for a walk' and then we go upstairs and just sit at the rocks drinking our Starbucks coffee. (Tina, 14)

**Example 2:**

Participant: Yeah the Bed Rest area isn't too bad.

*Researcher: How often would you use it?*

Participant: Um I'm there everyday, sit and talk, 'cause the anorexic girls sit in there so I just chill out with them there. (James, 17)

**Example 3:**

Participant: I've been to the Chinese Garden. I like that. It's a nice walk. When my best friend come down that's where we went. (Marika, 13)

**Example 4:**

*Researcher: Yep so what draws you there [Starlight Express Room]?*

Participant: I don't know, I've been there like when we have movie night and it's good like, they've usually got something going on, and you can colour in or sit down and talk to people and see your friends. (Milly, 11)

*Dimension 5: Availability of age-appropriate social activities.* Opportunities for participation in age-appropriate social activities are much more prevalent for younger participants than they are for older ones. Many of the social activities that are available such as those in the Starlight Express Room, the Book Bunker, play therapists and the Clown Doctors, appeal much more to younger audiences than they do to older participants.

Within the adolescent group of participants, boys frequently do not attend the formal social activities that the girls enjoy, such as Group. This is a social opportunity that happens daily during the weekdays. Some of the activities include art and craft and support groups amongst others. Very rarely do the boys attend or talk about this opportunity. The girls on the other hand appreciate this opportunity, in particular for its social contact.

*Researcher: How important is it to you making friends in the Hospital?*

Participant: Very. You get bored otherwise. Or maybe if you're like me and you don't have to be in bed all the time, all you do is go to school, go to group, you make friends at Group because that's what group is s'posed to be. It's good for that. (Zoë, 16)

*Dimension 6: The influence of time on the need for friends and company.* The length of time in the hospital also influences participants' interest in making friends. Surgical patients usually know they will be in for a limited time, and their experience is usually dominated by the ramifications of their particular problem. These participants place little importance on the need to make friends inside the hospital or the need to maintain contact with friends outside the hospital. They are mostly concerned with coping with the nature of their problem. The excerpt below clearly expresses this balance for one of these patients.

*Researcher: How important is it to you making friends in the Hospital?*

Participant: I don't find it majorly important to make friends in the room that I'm in 'cause like I don't, I think everyone's more worried about their own recovery and not, - just like doing their own thing. I don't know, that's what I think. Like I'm not in the mood to

make friends. Like I don't, I don't want to know, it's not like when you um. It's like I don't want to interfere with them. I don't get the time to make the friends. As long as my family is round me it's ok. (Justin, 15)

Participants who are regular inpatients to the hospital and who have spent considerable time in the hospital environment, rely on the social opportunity to help them pass the time. This is in contrast to participants who are visiting the hospital for the first time. These participants are less relaxed in the environment and more reliant on formal activities such as school and Group to facilitate their social contact and the development of friendships with others.

**Case study: A patient with a history of admissions**

Tina is a 14 year old girl with cystic fibrosis. She has been coming to the hospital on a regular basis since she was five years of age.

*Researcher:* Do you make friends with other patients?

Participant: I do

*Researcher:* Does that help?

Participant: Mmm I think it makes your time in here more enjoyable and 'cause like if you're bored and - there's lots of things you can do here, but then if you get bored of it, 'cause you've seen everything and, like me I've been in and out, I think you'd like to find friends. And when it's, when you're able to find friends that like have the same as you or, you know, like things that you do, its easy to make friends and then you've got more fun here. Sometimes I don't even feel like going home! It's that fun! I've got good friends here.

Her network of friendships throughout the hospital is extensive. She has friends amongst all the staff, including the security personnel and the owners of the shops and cafés.

Participant: I'm all over the place sometimes. I go up and down and all around and everywhere but like everyday I go maybe Chinese Garden, out to the Pergola area, out there, in the...(pointing)

*Researcher:* Children's Garden?

Participant: Yeah that's it or out to the aviary or upstairs to see Security, I'm everywhere. I go everywhere, 'cause I've got lots of friends 'cause I've been coming here ever since I was five – well, I haven't *been* here, I've been in and out since I was five, so yeah.

Her social life in the hospital is much more sophisticated than other patients. Tina maintains contact with the friends she makes in hospital, her "CF buddies", conscientiously outside the Hospital and their social activities simply continue when they come into the Hospital. Hospital is clearly just one of the contexts in which they meet to do the activities they would normally do together.

*Researcher:* Alright do you have contact with your friends outside the hospital?

Participant: I do. We always get our emails and phone numbers and write letters and, meet at each other's house so if they're far away we write letters or send emails, if they're not far away we like do everything.

*Researcher:* Do they come and visit you here?

Participant: Yeah we go out shopping and do the things girlies do

*Researcher:* And that is a key thing?

Participant: Yeah, it's important. I think I could tell you one more thing. I reckon there should be a newsagents here. There used to be one and I used to shop every day. Me and my CF buddies, which is cystic fibrosis, we're full collect stickers and little toys and rings and buckets of stuff, bucket loads of stuff and um we really miss our newsagent. We also go to number 5, The Bear Café.

*Researcher:* Ok how often to do you use it?

Participant: Not very much but I know the lady that work's there, she's pretty nice, like when we, well, 'cause all my CF buddies, we always go up for lun-, not always but occasionally if we come into clinic or something we might go for a bit of lunch and we think urgh downstairs isn't nice so we'll go to the second level and she's pretty nice, like she comes out and bes nice yeah, 'do you want a menu' blah, blah, blah, and she's yeah, it's all good.

**Member-checking task.** There were two prompt cards used for this theme including: *Making friends here is really important.* This produced findings consistent with the main study in that younger participants place importance on this for companionship, and older participants place importance on this because seeking support from peers is a major coping strategy for this age group, particularly for girls. The excerpt in the third example makes the point that the importance of making friends is linked to the time the participant is in the hospital, which is also consistent with the findings from the main study.

**Example 1:**

Participant: Number 8 is really important, making friends here is important 'cause you do tend to feel lonely, like I made friends with one and I found out that we have a lot in common, like we have the same birthday and she likes a lot of movies but it is really important to make friends. (Melissa, 12)

**Example 2:**

Participant: Making friends here is really important because so you can have someone to talk to. So you don't feel like you're the only one going through what you're going through. Just knowing that other people have their problems too. (Claire, 14)

**Example 3:**

Participant: Making friends here is really important um I don't know if it's *really* important. It's important but not *really* important. It really depends on how much time you're going to be here. I guess it's more important if you're going to be in here for a long time. (Lana, 18)

The second prompt card used was: *Having contact with my friends outside the hospital is great.* This produced a similar response to the findings from the main study. Similarly to making friends in the hospital, the importance placed on this varied with the age of the participant and the length of time they are in hospital. Younger participants and those who know they are only staying in hospital for a short time do not value contact with friends as much as older participants, and those who are in hospital for long periods. The reasons given for why it is important also reflect the findings from the main study. It provides a social life and keeps patients in-touch with the outside world.

**Example 1:**

Participant: Number 9 [*having contact with my friends outside the hospital is great*] I can't exactly relate to that much because I haven't really told that many of my friends but I do have a friend that calls me every now and then just to see how I am so yeah, but it is good to um stay in contact with my friends. (Melissa, 12)

**Example 2:**

Participant: Having contact with friends outside the hospital is great because they can come in and visit when you're well enough and um they can keep you updated and whatever, for social life, they can give you something to think about, something to look forward to when you come out of hospital. (Annabel, 16)

**Example 3:**

Participant: It's really important, so you don't feel isolated, like you're just here with a whole bunch of people who you don't really know very well. It's good to have like that other part of your life so you feel a bit normal and not so excluded from like, real life. (Lana, 18)

### **Physical environment**

This domain centres on the key attributes and characteristics of the physical environment of the hospital from patients' perspectives. There are two major themes whose main alignment is with this domain. These include: *Environmental aesthetics*, *welcome and comfort*, and *access to nature and outdoors*. Both these themes are aligned to other domains also. There is no significance to the order in which these themes are discussed here.

**Theme 1: Environmental aesthetics, welcome and comfort.** This theme concerns the discussion that occurred on the aesthetics of the environment, in particular on colour, artwork and brightness. It encompasses the discussion on the importance of these attributes in patients' feeling of welcome and comfort in the environment.

**Alignment with domains.** Apart from the main alignment to the domain of physical environment, this theme is aligned with one other domain, time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Physical environment:* The alignment with this domain is indicated by the evidence for three dimensions including *artwork (1)*, *colour (2)* and *brightness (3)*.
- *Time:* The alignment with this domain is indicated by the evidence for one dimension, *the influence of time on the response to environmental aesthetics (4)*.

**Exploration of dimensions.** In total there are four dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: Artwork.* The artwork is linked to the aesthetic appeal of the environment, and it is linked to providing colour, brightness and a source of entertainment, or at least

an engaging, uplifting distraction. It is also linked to welcome and comfort for some participants. All of these considerations are discussed in the excerpts below.

**Example 1:**

*Researcher: Ok, what do you think you notice as you move around the Hospital?*

*Participant: Um...it's very colourful. Lots of colours everywhere and paintings and collages and stuff on the walls. Like even in the rooms you have like paintings on the walls, like the turtle and the dolphin, so it's very colourful.*

*Researcher: Mmm does that make a difference?*

*Participant: Well it changes a boring room into a bit more interesting, so yeah it makes a bit of a difference. (Tom, 12)*

**Example 2:**

*Researcher: What do you think you notice when you go around the Hospital?*

*Participant: What do I notice? The paintings on the walls, yep that's it.*

*Researcher: Does it make a difference having them?*

*Participant: Yeah it's funny like, they're just like spots of paint or whatever and I was asking my sister what she saw in the picture and she said something completely different to what I saw. It was really weird 'cause I think it's your mood, whatever you think, like you know, and then you make the picture out. It was really good. I was like trying to convince her, like "no, look at this" and she's like "no". It was funny. (Amelia, 14)*

**Example 3:**

*Researcher: Ok you think you notice pictures and sculptures on the way around, do you think it makes a difference having them?*

*Participant: Yes it allows us as the kids to um, to make connection for a minute to people who have made the artworks. Like it helps us to um, to sort of like to interact with the Hospital. Makes us feel like um we're welcomed and we're um we're, it's like um...that we, it's a good place to be here.*

*Researcher: And that applies to the artworks in general? Or just the artwork done by kids?*

*Participant: No, the artworks in general. It makes like the atmosphere a good atmosphere. Like there's always pictures everywhere, they're always happy and they make you smile all the time. (Justin, 15)*

**Example 4:**

*Researcher: Ok now you've said you noticed the pictures and sculptures around the Hospital, do you think they make a difference?*

*Participant: Yep a lot*

*Researcher: What's the effect of them?*

*Participant: It's just like it doesn't make you feel like you're in a gaol or something, or closed in to a place and you're not allowed out or it just kind of gives you I don't know some kind of feeling like you can always like um get like a feeling or um you know an idea from a painting or sculpture, and it makes you react to it and it's just something that adds a little touch to the Hospital. It's good. There's heaps of colour like because of the statues they put up and the paintings that have been brought in, just like add to the Hospital to make everyone more comfortable in it so it's a really nice environment, I enjoy it. (Polly, 14)*

*Dimension 2: Colour.* Colour is acknowledged for making the environment memorable and distinctive, and because it adds variation to the environment. Participants also say that colour helps with their mood and their ability to maintain a positive frame of mind.

**Example 1:**

*Researcher: Do you think you notice colour?*

*Participant: Yep it's very bright, there's always like the brighter colours used. I never see any blacks or um greys um there's always blues and yellows and reds.*

*Researcher: And that's a good thing or?*

Participant: Yeah I think it makes us feel happier, or it doesn't like, it um boosts our self-esteem to, like that we're here to recover and not to get worse and that we need to get out more, like it helps us to recover so that we can get out more quicker. Like if it was dark colours we would always be sad and we wouldn't want to recover like 'cause we just wouldn't be in the mood to do it. Where the brighter colours just um, help us. (Justin, 15)

**Example 2:**

*Researcher: Colour, you said you notice colour, what do you think you notice about it?*

Participant: Colour? Well they put a lot of, they've designed a lot of colours into everything; how they mixed the signs up of the colours, to make animals look different.

*Researcher: And is that a good thing?*

Participant: Yeah very. 'cause sometimes little kids think of a bird as purple or something like that, like sometimes I think of a flying fish or something and it's something to keep the kids very imaged in the rooms. Like they might be sad and they like to think of a picture "mmm wow a purple looking duck" or like a weird sort of things. (Tom, 12)

**Example 3:**

*Researcher: You said you notice colour?*

Participant: Yes lots of colour. It's not just grey boring wards. I think it makes it more lively and makes people feel happy and, having colours, so I think it's nice. (Marika, 13)

**Example 4:**

*Researcher: Now you say you notice the paintings and colour. Does it make a difference having them?*

Participant: Yeah for sure yeah. Like it's variation, you know? The fact that each corridor doesn't look the same is a real big difference. That's one thing why the floor bothers me 'cause the floor looks the same everywhere and 'cause you're in here for sometimes you in here for a long time and you know change is really important. You know it keeps you 'cause for me health is not just physical it's mental so if you're happy and you're in a nice looking place you'll be healthier you know. (James, 17)

*Dimension 3: Brightness.* Participants are also very conscious of what they describe as the brightness of the environment. Most often brightness is associated with the presence of colour and artwork. However, it is also linked to the presence of light, the attitude of people, the volume of plants, and the décor such as the curtains and furnishings.

It is during discussions about what constitutes brightness that participants reveal how much they notice architectural, interior and landscaping features such as: the presence of long windows in their ward rooms, the sky light in the front foyer, the darkness of the back corridors overlooking the Chinese gardens, the placement of gardens in relation to walkways and views, the variation in furniture (when and where it occurs). The examples below touch on the complexity of the concept of brightness.

**Example 1:**

*Researcher: What do you think makes something bright?*

Participant: Windows. Lots of natural light is really important. And also you know colour. I find the floors like that's another thing, I don't know if you know, you know on the way to pathology and X-ray? You know how all those windows see the garden? Sometimes that same place even though it's really bright it does feel dark because there's a dark colour on the floor – sorry interior design yeah um, and you know it

really does affect it I believe. You can't defeat the actual fact that it really is a bright place but it does feel kind of dull because you know boring floor and those walls also have got little or no actual paintings on anything on it. It's a bland wall and that kind of adds to the brightness feel, um but you know nice colours, paintings really make things feel nice and colourful and feel bright and nice. And also um staff and people. When you go into um certain places everyone is like you know 'hi,' 'hi' and they're all happy, nice and you know - feels like a bright uplifting place. (James, 17)

**Example 2:**

Participant: Yeah and it's bright and that's really important.

Researcher: And by 'bright' what do you mean?

Participant: Like just the amount of outside you can see and also the colours on the walls are light. (Jane, 16)

**Example 3:**

Participant: I like the idea of how they have coloured the curtains and tried to brighten the area [ward room] up a bit just to make it a more rel, not relaxing but like um, I don't know how to put it, like um, an area where we'd like to stay, we don't, we're not forced to stay in like, 'cause it's not dull and boring. (Justin, 15)

*Dimension 4: The influence of time on the response to aesthetics.* With increasing time in the environment participants become more conscious of sameness and increasingly appreciate aesthetic variation throughout the Hospital. Participants' responses to the environment's aesthetics are linked to their capacity to maintain a positive frame of mind. The influence of the aesthetics of the environment becomes more important as participants spend more time in the environment. This is especially the case for those participants who are spending a lot of time in one place such as in their wardroom. The blandness of the aesthetics of these spaces is criticised, along with the limited opportunity to make changes.

**Example 1:**

Researcher: If you could do anything to that room what would you do?

Participant: I'd change the curtains. I get sick of those curtains, I've looked at them for ages.

Researcher: How would you change them?

Participant: Put different ones up

Researcher: So it's just that you're sick of them? There's nothing particularly wrong with these ones, you've just had enough of them?

Participant: Yep. And I'd put above the beds, like they've got the boards there, I'd put an extra one up the top and you could go in and change different posters. 'Cause they've got paintings above our ones and I'm sick of looking at the same paintings. They need to change it. (Karina, 13)

**Example 2:**

Researcher: Your ward room. How much time do you spend here?

Participant: Heaps. I've been in here for ages.

Researcher: Heaps? What do you think of this room?

Participant: Boring.

Researcher: Boring? How would you make it better?

Participant: By putting more decorations around here.

Researcher: Where would you put them?

Participant: All on the walls and changing the curtains, because they have them all around and you get sick of seeing them. All wards should have different curtains. (Mandy, 10)

**Example 3:**

*Researcher: If you could change something about this room what would it be?*

*Participant: Um...if I could change something it would be making it like have more pictures, like, you can see like a dull wall over there where it could have a nice picture over there and um, have the rooms a bit more colourful and like welcoming for like sick people and stuff. Need more stuff to look at 'cause you can be in here for a long time and it gets boring. (Marika, 13)*

**Member-checking task.** The prompt card used for this theme was: *Having the artwork and colour around is great and makes a big difference.* Whilst some of the participants continued to reinforce the findings in relation to this theme, example one reveals ambivalence in this participant's response. This is based on her perception of the age-appropriateness of the aesthetics, which indirectly supports other findings from the main study, including participants' sensitivity to the age-appropriateness of aesthetics, and the role of artwork in providing a distraction.

**Example 1:**

*Participant: Um the artwork it doesn't really make a difference to me it's just like decoration but may be to other kids like younger, it might entertain them and then it might take their mind off what' wrong with them and might calm them down if they are getting like needles or blood tests.*

*Researcher: So you don't think you notice the pictures and the colour around the place?*

*Participant: Maybe not me because I'm a bit older and a bit more mature but maybe to like a five year old kid it might make a lot of difference, especially if it's something that would entertain them, like in this room they're like eggshells that might entertain them, the young kids. So it depends what ward you stay in as well, like um last year when I visited my sister her ward is covered in butterflies and I though that entertained me, Wade ward, that entertained me a lot so I was thinking to myself if I was in hospital that would entertain me because I could go for a walk up and down the ward and just look at the butterflies. (Melissa, 12)*

**Example 2:**

*Participant: Having the artwork and colour is great it does make a big difference, 'cause if the walls were plain it would be boring. It just gives you something to look at. (Annabel, 16)*

**Example 3:**

*Participant: Yeah I think all the brightness in this hospital really does make a difference. I love all the artwork everywhere. There's um a famous artist right at the front of this ward, maybe it's Paul, maybe it's Klee. He's an Australian artist and it's really impressive.*

*Researcher: What difference do you think it makes having artwork and colour?*

*Participant: Um I think like thinking of colour therapy and stuff, I think colour does something to your mind like if I was in a room that was all orange I would tend to be more happier than if the room was just the grey colour. Yeah so I think colour influences your moods. (Lana, 18)*

**Theme 2: Access to nature and outdoors.** This theme includes the discussion on the importance of being able to access outdoor areas and in particular, to have contact with nature. It includes the role of these spaces in participants' socialising and coping strategies also but these roles have already been discussed as part of earlier themes.

**Alignment with domains.** Apart from the main alignment to the domain of physical environment, this theme is aligned to three other domains including social experience, organisational considerations, and time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Physical environment:* The alignment with this domain is indicated by the evidence for two dimensions including *the need for environmental contrast (1)* and *the need for contact with nature (2)*.
- *Social experience:* The alignment with this domain is indicated by the evidence for one dimension including *accessing familiar social outdoor activities (3)*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for one dimension including *having access to outdoor activities (4)*.
- *Time:* The alignment with this domain is indicated by the evidence for one dimension, *the need for contact with nature and outdoors across time (5)*.

**Exploration of dimensions.** In total there are five dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: The need for environmental contrast.* Being able to experience different environments in and around the Hospital is greatly appreciated by participants. Many participants are conscious of using the outdoor areas as places of escape and retreat. Participants also greatly value having access to outdoor areas for the contrast in environmental qualities. The excerpts below provide discussion on this issue.

**Example 1:**

Participant: I think that's like really good that they put that [Children's Garden] there because um it kind of like gives it more like nature it's not just buildings and like really precise like buildings like it's got some kind of you know life to it too. And it's got that, it's got trees around it at the backyard. It's peaceful and I like to get away a little bit - like makes you relax and it's like free. (Polly,14)

**Example 2:**

Researcher: Are there reasons that bring you out here [Children's Garden – where interview took place]?

Participant: Um just to get away from inside and feeling cooped up and it's really, the air-conditioning in there is yuk and to feel the sun and just to, it's nice to breath fresh air. (Sarah, 15)

**Example 3:**

*Researcher: And why do you think it is so important to you to be able to go outside?*

*Participant: It's just not good to be kept inside all the time. Like it's nice to go outside to have some fresh air and some sun. I hate being away from the sun. I just love like lazing around and stuff like that. (Emma, 14)*

**Example 4:**

*Researcher: Ok is being able to go out into the gardens important to you?*

*Participant: Yep, Yeah! You've got to have outside access! Yep I love outside. I'd live outside if I could but I just like having a break.*

*Researcher: So how often would you go outside?*

*Participant: I've been out everyday.*

*Researcher: Have you? To this [Children's] garden or?*

*Participant: Oh not necessarily the garden, I've just been outside*

*Researcher: And where do you go when you go outside?*

*Participant: Outside the main entrance, I don't know, there's a little place at physio, I go out for physio. I make sure I go out for physio everyday. (Zoë, 16)*

*Dimension 2: The need for contact with nature.* Outdoor garden areas are some of the most preferred places in the environment and having access to them is linked by participants to feeling healthier. Many participants acknowledge using the outdoor areas as part of their coping strategies. As discussed in the excerpts below, for many of the participants the contact with nature and outdoor environments both literal and through windows is fundamental to their feeling of well-being.

**Example 1:**

*Researcher: How important is it to be able to go outside in the gardens?*

*Participant: Very important, 'cause being stuck in one little room is like torture, its...how would you put it...umm...let's just say I had flu last time I came in and I was fully isolated like I had to have my door shut and everything 'cause I was so sick and I was contagious and whatever else and ...to me I felt like I was being put in gaol...and it was really bad 'cause like you have no TV and I couldn't borrow the like the Starlight fun centre which goes around to all the rooms 'cause I was like in isolation, and all I had to do is sit there in pain, thinking about it 'cause I had nothing to do and it was like the worst thing ever. So being outside, like being able to go upstairs, was like a privilege, a good privilege and I was happy with that, 'cause I wasn't bored and I wasn't thinking - like I don't think - when I was actually isolated I thought um, non-positive things and when I'm outside and stuff, you think positive, like you don't think about all your bad illness and everything else and what's going on, but being outside and stuff, you're able to not think about it and then it helps you all to get better I think. Like humour wise and stuff, so yeah. (Tina, 14)*

**Example 2:**

*Participant: And I like going outside to the gardens.*

*Researcher: Is being able to go out into the gardens important to you?*

*Participant: Yep 'cause I like the brightness and I like being outside because like you're stuck in here 'cause I play so much, or I did play so much sport, I'm usually out in the sun lots and then being stuck in here, so when I go out to the gardens or the bird aviary or something it's good. It makes me feel a bit better. (Josie, 12)*

**Example 3:**

*Researcher: Ok now where do you prefer to go to?*

*Participant: Down here, the Children's Garden. I like the grass there, 'cause I used to play soccer and so like I love grass so yeah I just sit there. It was funny 'cause I was in my room for like 2-3 weeks straight and my boyfriend and my sister came and we were just sitting on the grass right and I was obsessed with the grass right, 'cause I was used to*

being on it three times a week, like every week and I was just playing with the grass and she was like “leave the grass alone” but yeah. (Amelia, 14)

**Example 4:**

Participant: The Chinese Gardens...personal favourite, every time I go for a heart thing when I'm waiting for the doctor to come in I always look at it ...nice place to visit.

Researcher: *Mmm what do you like about it?*

Participant: Um the native looking sort of habitat, surrounded by gardens, nice shady place to eat lunch. It just makes you feel better. (Kylie, 11)

*Dimension 3: Accessing familiar social outdoor activities.* Being able to maintain familiar routines with family and friends greatly improves the experience of hospitalisation for patients. Many patients talked about their normal routines including regular activities outdoors, as illustrated in the previous set of excerpts. Being able to continue some of the simple ones is appreciated by patients.

**Example 1:**

Participant: I've been to the Courtyard heaps.

Researcher: *Ok what takes you out there?*

Participant: We used to go out there, me and my Mum and my sister used to go out there every night and talk to my Dad and my brother.

Researcher: *Mmm on a mobile?*

Participant: Yep, yep and when I was allowed to eat, we'd go out there and have lunch. It was good to be able to do that, 'cause we'd normally do that. (Karina, 13)

**Example 2:**

Researcher: *Ok so when you come out here [Children's garden], what do you come out here for?*

Participant: For fresh air and when my friends come we also come here to um eat lunch, but the courtyard I just have never used before. I don't think it's a very welcoming sort of place with the cement on the ground. We just prefer to sit over here [points to tables] or on the grass. Yeah I prefer the grass and we just hang out, it's good. (Rebecca, 15)

**Example 3:**

Researcher: *So what did you think of the Children's garden as a whole?*

Participant: Oh it was a lot, it was nice, I like the statues and everything, the way how they set things out. It was nice, like very peaceful, it's nice to have a family picnic. It would have been nice if we could have had a family picnic out there, it would have been nice. We would have had them if I was allowed to eat. (Tom, 12)

*Dimension 4: Having access to outdoor activities.* Apart from the social activities, participants also like the activities that are available to them outdoors such as playing with water, kicking a football around, feeding birds and visiting the aviary, and roller-blading around the courtyard. Similarly to the social activities, sometimes the joy is in simply being able to do something they would normally be able to do, and at other times, it is linked to the activity itself. In the excerpts below, some of these activities are discussed.

**Example 1:**

Researcher: *That's just a courtyard. It's still in the Children's Garden, have you been there?*

Participant: Yeah I have been there. My Dad took me.

Researcher: *And what was it like?*

Participant: It was cool, we played footy. (Luke, 11)

**Example 2:**

*Researcher: How often would go out there [Aviary]?*

*Participant:* Um, when I have a lot of visitors, 'cause like most of my family like birds and they breed birds and stuff, so they always like have a look at the aviary and we go to sit out there and look at all the different birds in there...it's pretty good but I think they need more cement and stuff it would be good if they could improve that. (Tina, 14)

**Example 3:**

*Participant:* Um aviary, been there, one of my favourites.

*Researcher: Yeah? Why is that?*

*Participant:* There's a bird in there that you can feed and it lets you scratch its head... (Kylie, 11)

**Example 4:**

*Participant :* I like the aviary, just the birds there. It's just fun to see them.

*Researcher: Do you spend time out there or just walk past?*

*Participant:* Um usually when I go for a walk with my parents we usually go past there and even if we go like for a walk outside the front entrance we come down to have a look at the birds and see 'cause one of them had um eggs and we got to see how that was going and stuff like that. (Sasha, 13)

*Dimension 5: The need for contact with nature and outdoors across time.* Having access to outdoor areas makes a great impression on how participants respond to spending a lot of time in the Hospital. If participants lose the ability to access outdoor areas due to their own condition or their treatment program, it is greatly missed. This needs to be understood in light of the earlier discussions on the role of environmental use in patients coping strategies in particular. These three excerpts are from patients on programs that restrict their movements in the Hospital environment. Patients with this experience are very conscious of the value of being able to go outdoors.

**Example 1:**

*Researcher: Do you think it's good to have different places to go to in the hospital?*

*Participant:* Yep, I think it's really important so that you're not kind of stuck in the same place for weeks.

*Researcher: Do you have a preference for the sorts of places you like to go to when you leave the ward?*

*Participant:* Outside um somewhere that's clean and like leafy. (Jane, 16)

**Example 2:**

*Researcher: Do you think it is important having access to outdoors specifically?*

*Participant:* Um yeah because if you're shut like inside for a long time then you get you know, kind of, feel like you're all shut in and you need to go outside for a little while. (Vanessa, 11)

**Example 3:**

*Researcher: Do you think it's good to have different places to go to in the Hospital?*

*Participant:* Yes definitely. Especially if you are in here for a long time like I am.

*Researcher: And why's that?*

*Participant:* Because you've got somewhere different to be um, 'cause I think hospitals are very boring and if you have something new to go to or different to go to it could make your time here a little more less stressful and I think it takes your mind off where you are and maybe what's happening um...yeah I think it's a good idea to have lots of different places to go to.

*Researcher: What are your preferred places?*

*Participant:* Um I like going outside definitely 'cause I'm not allowed to go out very often. I like walking in the gardens. (Sarah, 15)

**Member-checking task.** The prompt card used for this theme was: *I really like being able to go outside.* The findings in relation to this theme in the main study were supported in this exercise. Participants' of all ages greatly appreciate being able to go outside for the contrast in environmental qualities and experience, to have contact with nature, and for the perceived restorative properties of natural environments. Consistent with the main study findings, those participants that are unable to go outside due to the restrictions of their diagnosis and its treatment miss not having this opportunity.

**Example 1:**

Participant: I would really like to go outside. I haven't been outside since they transferred me from Canterbury hospital, so I would really like to go outside.

Researcher: *Why would you really like to go outside?*

Participant: I would like to enjoy the fresh air. (Melissa, 12)

**Example 2:**

Participant: I really like being able to go outside especially just to catch some fresh air mainly, just to look outside and be at one with nature.

Researcher: *How does that help?*

Participant: It just well for me it um helps me just feel normal again. (Annabel, 16)

**Example 3:**

Participant: Yeah I would really like to go outside. Um these doors are locked and we can't go out but there's a balcony and it can't be used by us because, immune systems, we don't have them so, and there's pigeons out there and stuff that make it dirty and they carry disease so they wouldn't want us to go out there. But it's kind of like a tease, there's like this balcony there and you can't use it. (Lana, 18)

## **Organisational considerations**

This domain centres on the influence of characteristics of the organisation such as the perception of a culture of child-friendliness from patients' perspectives. There is one major theme whose main alignment is with this domain. This includes: *Indications of a child-friendly organisation.*

**Theme 1: Indications of a child-friendly organisation.** This theme encompasses the discussion in which participants reveal their conscious assessment of the hospital environment as a whole in relation to its appropriateness for children and young people. This encompasses participants' overall response to the hospital and their response to particular aspects of it which indicate the organisational focus on caring for kids.

**Alignment with domains.** Apart from the main alignment to the domain of organisational considerations, this theme is aligned to two other domains including social experience and physical environment.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Organisational considerations.* The alignment with this domain is indicated by the evidence for two dimensions including *a culture of child-friendliness (1)* and *the volume and type of activities and facilities (2)*.
- *Physical environment.* The alignment with this domain is indicated by the evidence for two dimensions including *the importance of not looking like a hospital (3)* and *kids supporting kids through the environment (4)*.
- *Social experience.* The alignment with this domain is indicated by the evidence for one dimension including *sensitivity to the welcome from staff (5)*.

**Exploration of dimensions.** In total there are five dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: A culture of child-friendliness.* Participants have a sense of this Hospital being special simply because it was designed specifically for kids. This is captured in the excerpt below.

*Researcher: Ok what makes it a good hospital for kids?*

*Participant: Um prob'ly because it's like it's all kids like there's not adults here besides the nurses and the doctors but it's like, kind of like our hospital, like a kids hospital um yeah so that's prob'ly why. (Polly, 14)*

Many of the participants feel that an extra effort has been made to make the place 'a good place for kids'. The excerpt below captures this sentiment.

*Researcher: Why do you say you like the Hospital?*

*Participant: This whole thing is oriented around kids, it's great. It's like one thing you know, the hospital doesn't seem to um...they don't, it's not 'sacrifice', it's another word, um compromise! They don't compromise, like they try not to compromise with you know aiming towards making things like really for kids. You can go up to pathology and everything is nice, plush toys everywhere, you know TVs everywhere. X ray's got this big playground there. Everything is you know, oriented, I keep enjoying it, even though I'm 17, and I'm like one of the oldest patients right now here in the hospital and it still lasts, you know. I'll take my brothers to muck around with me you know. It's still fun you know. (James, 17)*

Overall assessments of the hospital invariably encompass a range of organisational and environmental attributes. Dividing them up to define them is artificial and many of the illustrative quotes used will include information on other aspects being discussed also. Below are several examples of these sweeping assessments made by participants that encompass multiple dimensions that they assess as being indicators of a child-friendly environment.

**Example 1:**

*Researcher: Do you think it's a good hospital for kids?*

*Participant: Yeah, they just, I don't know, they try and offer a lot of support and there's a lot of activities available for different age groups and... I don't know... a lot of the architecture seems kind of friendly, like the colours and the spaces and the yeah the decoration on the walls and stuff. (Jane, 16)*

**Example 2:**

*Researcher: Do you think it's a good hospital for kids?*

*Participant: Um yes because the staff is friendly, and they just don't ignore you, they do what you ask and because I like the X-ray rooms 'cause they're nice and they've got all pictures on the walls, so I reckon they're pretty. The X-ray rooms are really good. They've got all pictures on them, and um I like it because I like it how they have the gyms, I like the physio 'cause it makes it be fun like when I went there today there were people that like me that were working on their knees and stuff but they were playing bowling and doing all stuff like that. And I was kicking a ball so that was a fun way of doing it. I like the idea of having a gym and I like the Starlight Room 'cause it's fun and I like the other playrooms, probably haven't got one here on this ward but yeah that's what I like. (Josie, 12)*

**Example 3:**

*Researcher: Do you think it's a good hospital for kids?*

*Participant: Yes because they make it a bit happier, they've got lots of varieties of shops and all that, not too much, but, not a lot, but they make it look nice the way how they think of other ways to make kids happy, such as the Starlight Room. It has games in there and how they say if you want to request a movie, you can request, and CDs, and talk about jokes, and the food, like the menu's very nice, the gardens they also make it look very nice, they make it happy. They try to make every little detail happy here and even by just looking at the Hospital you can tell that it's like a very great place to be. (Tom, 12)*

*Dimension 2: The volume and type of activities and facilities.* When participants acknowledge the environment as being appropriate for kids, the volume and type of activities and facilities available is one of the key indicators they use in their assessment. Some also enjoy the novelty of the activities on offer at the hospital, such as the Starlight Express Room. In the excerpts below, the participants identify this aspect as well as others.

**Example 1:**

*Researcher: In terms of the Hospital itself how would you describe it to somebody?*

*Participant: I would say that this is better than an adult hospital 'cause it's more colourful um it's more like for kids and when you just go over to the adult hospital it's dull and you know that it's the adult hospital and I just – it's pretty good here.*

*Researcher: What do you think makes it more like for kids? When you say that what comes to mind? What makes you think it's for kids?*

*Participant: Well – the stuff that they do, and how they have the clowns come around and um how they have people to make children laugh and, like the Starlight room and just the pictures and, and all the other stuff that I can't quite think of. (Marika, 13)*

**Example 2:**

*Participant: I reckon it's a pretty good hospital for kids because it's like it's really bright and colourful and friendly, than like other hospitals and like there's like lots of other kids here and there's like things that you can do, like Group and stuff and you wouldn't normally do the stuff you do in Group.*

*Researcher: If you were in another hospital you mean or?*

Participant: Like in another hospital or at home and you've got, you try out all sorts of different things here that you wouldn't normally do at other like hospitals or at home or at school. (Sasha, 13)

**Example 3:**

Participant: Um I think the best thing is that they try not to make it all bad for you and everything, like they try and keep you busy, they try and you know, it's, it is really a children's hospital like for children. They make it you know?

Researcher: *What makes it that?*

Participant: Um well even, just I mean they have a Starlight Room here, you know, they have a school, they have um physiotherapy - well every hospital has that - but they just go to extra effort like this little room, if you get bored you can come here. (Vanessa, 11)

Finding sufficient age-appropriate activities to remain busy and engaged is a constant challenge, especially for older participants.

**Example 1:**

Researcher: *Do you think they have good places and activities for your age group in the hospital?*

Participant: Um the movies and stuff are good like on the purple fun centre thing that they have, they have all movies for our age. They put a password in and like (M)15 movies, they have and that's good for my age group and there could be more like some people don't like, like they have a lot of colouring in and stuff like that and arty stuff, some people my age don't like that but um it doesn't really appeal to me that much but I do it, it entertains me.

Researcher: *So do you think that is a section that could be improved for you?*

Participant: Yeah like there's not as many kids my age in the hospital I don't think. I think there's more younger kids and they more aim to entertain them. Like on the TV they put all younger kids shows on the Starlight channel and stuff like that. (Emma, 14)

**Example 2:**

Researcher: *What would you really like to change?*

Participant: I wish there was high speed internet not just you know um, I reckon not just normal where you dial up, but you know high speed internet would be nice. It would be really good. Actually I reckon particularly in Wade ward if there was like 3, 4 computers set up so people could come in and surf the web and if they want, play a game or two, I don't know. And also 'cause all the consoles they don't have games. I was speaking with [a nurse] and he said he was going to get some but a bit more, you know, older games, um like the Book Bunker would be good if they had older books. That's one reason that I don't go to the Book Bunker because everything's for kids. There's nothing my age reading wise. I wish there was a newsagency here. There used to be one but now it's gone. There are no magazines and I can't get out of the hospital unless it's a gate pass. That's a real bother. (James, 17)

There are a range of formal and organised activities such as visiting entertainers, school, Group, those available at the Starlight Room, and mobile activities including entertainment and services such as the play therapists, the clown doctors, and the Book Bunker trolley. Most participants appreciate all the activities and facilities available to them. Most participants have a very good knowledge of what is available even if they choose not to use them. However, most take advantage of all activities if they are able to, even if they would not normally engage in them because it helps them remain distracted and busy and to take their mind off being in hospital. This link is discussed in the excerpts below.

**Example 1:**

*Researcher: Now do you think they have good activities and places for your age group here?*

*Participant: Um well I haven't been to the book bunker but I've heard that it's like a library so that's a good thing if you want to read and they've got the school which is really good and they've got Group which is where we do fun activities which like takes our mind off our illness and we can escape to like another place where we can do whatever we want to in terms of artwork and you know. We can express our feelings and emotions through our artworks which is good. (Polly, 14)*

**Example 2:**

*Researcher: Do you think there are enough activities and entertainment for kids your age here?*

*Participant: 'Cause I'm in the adolescent ward there's quite a few like we have the pool table the, ice - ah air hockey, we also have two 'eggs' which have got like Playstation and*

*Researcher: Those purple things?*

*Participant: Yeah those purple things um Playstation and movies and um one of the nurses gets pirated copies of movies that are on in the cinema at the moment and she brings them in and we watch them at night and that's good because you're focussing on the movie. (Sarah, 15)*

**Example 3:**

*Researcher: You were talking about having things take your mind off what's going on? What else does that here? Is there enough of those sorts of things?*

*Participant: Um well, school, when you're having school you're doing work so you're not really thinking of it, um, I don't really know, yeah just normally when you're um, maybe doing artwork or something or yeah I don't know. When you've got time to yourself you tend to get more lonely and sad and stuff 'cause you're thinking 'oh I want to go home' and you know.... So it's just better to do stuff. (Vanessa, 11)*

*Dimension 3: The importance of not looking like a hospital.* Not looking like a hospital both surprises and pleases participants. Environmental attributes such as colour, light and artwork, help to provide an atmosphere of welcome and comfort as previously discussed. Additional attributes are also suggested in the excerpts below such as scale, design configuration, the age of the building and the presence of a variety of cultural influences in the environment. Together these attributes undermine the identity of the building as a hospital and promote the child-friendliness and welcome of the environment for participants. This is discussed in the excerpts below.

**Example 1:**

*Participant: Well it's pretty like modern for a hospital but I s'pose it has to be 'cause it's like a kids hospital so, yeah it can't be too boring*

*Researcher: Do you think it's noticeably a kids' hospital?*

*Participant: Yeah.*

*Researcher: What do you think makes it....*

*Participant: 'Cause I've been to like mostly private hospital which is like back up there. And it's so boring 'cause like this one has lots of colour and paintings and stuff and like that one had pretty much nothing. It was all like dull but this one there's like colour everywhere. (Tina, 14)*

**Example 2:**

*Researcher: Do you think it's a good hospital for kids?*

*Participant: Yes I think it's a nice hospital. I have visited people in other hospitals and it's nowhere near as nice as this one. This hospital doesn't smell like a hospital, it doesn't look like a hospital from the outside um in the inside it's very colourful and lots of pictures and artwork and I think it just makes it a nice place to be in. Like it's not nice to have to be here but it makes it nicer having the um, artwork and the colours*

and everything. I think it would help people to find it more, like more like home and more comforting. (Zoë, 16)

**Example 3:**

Participant: 'Cause I don't like that I have to be here, I like it, but I would prefer not to be here, so, but being here I like the environment.

Researcher: *And what would you say you like about it?*

Participant: I like the colours, I like the artwork, um I like it that it's not just like row after row of corridors and rooms um it's got some movement in the structure. Um I like the gardens and how there's that Chinese garden, from a different country. Interesting to see what a garden would be like in another country. Um I also think that if you didn't know that this was a hospital you probably wouldn't think it was one, I think that the designer did a very good job of that, making it not look like a hospital.

Researcher: *And what kind of difference do you think that makes? That is doesn't look like a hospital?*

Participant: Um I think...it's not like ugly and those square things with rows of windows and it's like that, 'this is this awful skyrise building that I have to go to'. It's more, it's like flowing and maybe, it's nice to look at and maybe even be there with knowing that you're not in this square building with rows and rows of windows. (Sarah, 15)

**Example 4:**

Researcher: *So how would you describe the Hospital environment to a friend?*

Participant: Well um it's not always like good to be in hospital 'cause like it's never good to be in hospital but um like I thought that it would have been worse, like I was pretty surprised when I came here 'cause like we had a garden and lots of trees and places where I could play and I had like a nice room and where I was welcome and like the whole hospital is like modern and new so like it wasn't broken down or anything, it's pretty good. (Polly,14)

*Dimension 4: Kids supporting kids through the environment.* Many participants also like the idea of children being involved in the creation of the environment and leaving their mark behind as a message of support to other children, through legacies like their artwork. The excerpts below capture the impression that the presence of children's artwork makes on these participants. It also illustrates how much of an impression something so simple can make on children and young people's feeling of ownership and welcome in an environment.

**Example 1:**

Researcher: *What do you think you notice as you walk around the environment?*

Participant: I notice that there's lots and lots of pictures that are done by kids.

Researcher: *That's a good thing? Or it's not or?*

Participant: That's a good thing, a very good thing. I think it's great that you just haven't stuck some famous person's artwork up there; that kids actually got to be involved in the artwork. (Sarah, 15)

**Example 2:**

Researcher: *Do you think you notice the pictures and the sculptures?*

Participant: I always look at them, yeah 'cause my pop's an artist, like a full on artist.

Researcher: *Do you think it makes a difference having them?*

Participant: Yeah, it makes it look more...like...you know you wouldn't like be walking down this dull hallway, you'd be like "oh wow that was a nice thing that some girl did" and like most of it's done by the kids and I like that too. It's like kids giving support to other kids. (Tina, 14)

**Example 3:**

Researcher: *What do you think you notice as you go around the Hospital?*

Participant: All the pictures, like that people have painted, that kids have painted.

*Researcher: Does it make a difference that kids have painted them?*

*Participant: Yes I reckon it does.*

*Researcher: What sort of difference does it make?*

*Participant: I think 'cause it's like you know people getting involved with the Hospital and it makes it brighter and it gives you something to look at. (Milly, 11)*

A popular project completed by patients at the Hospital across a period of time and by the community at large is the butterfly project. In the hallway outside one of the wards, thousands of butterflies all hand decorated and signed with messages of support and well wishes line the walls. Figures 10.7 and 10.8 are of the butterflies project installation.



*Figure 10.7. Butterflies installation.*



*Figure 10.8. A close up of the butterflies.*

*Dimension 5: Sensitivity to the welcome from staff.* The friendliness, welcome, warmth and willingness of staff to assist patients and their families is also a key indicator of child-friendliness from participants' perspectives.

**Example 1:**

*Researcher: Um ok, do you think this is a good hospital for kids?*

*Participant: Yes*

*Researcher: And why do you think that?*

*Participant: Understanding doctors, nursing staff's great, um facilities are really good, they aim at what is best for the kids and they love doing it. They don't just do it for the money, it's 'cause they really like doing it and that makes a difference. (Kylie, 11)*

**Example 2:**

*Researcher: Do you like the Hospital environment?*

*Participant: Yes*

*Researcher: Ok why do you think you like it?*

*Participant: Um because, um because, it's a whole bunch of things, a whole bunch of little things, just put together.*

*Researcher: Can you say a few of them?*

*Participant: Again everybody is nice to everybody and it's really nice and um you can, if you have a questions you can always talk to the doctors and stuff and um and they'll and if you need anything you ask like the nurses or the doctors and um like they'll do whatever possible to um like help you with that. (Peter, 12)*

**Example 3:**

*Researcher: So you said just a minute ago that this is a room [Starlight Express Room] that says "kids first" to you.*

*Participant: Yeah*

*Researcher: What says that to you?*

*Participant: You know just the whole Starlight thing, you know as soon as you walk into the room it's all about you. 'Cause the people in Starlight are like 'Oh hey! Welcome how are you?' Everyone is so nice to you and nothing, you can almost like, like everything is for free you know, they're not trying to be nice to you because they're trying to get something out of it. There's no gain for them, it's all about the kids, it's great. (Troy, 16)*

For some participants there is a direct link between the friendliness of staff and the fact that it is a children's hospital. There is a clear expectation that this should be the case.

The excerpt below indicates this.

*Researcher: Alright so how would you describe the hospital environment to a friend?*

*Participant: Um it's pretty good for a hospital like most people expect something really horrible and really 'hospitably' but I think the adult hospital's prob'ly more like that, but it's more friendly since it's a children's hospital*

*Researcher: Ok so do you think this is a good hospital for kids?*

*Participant: Yeah*

*Researcher: And why would you say that?*

*Participant: Um because the staff are all nice and they're all really caring and stuff, like apparently, people don't talk very nice about the adult hospital sometimes. (Emma, 14)*

**Member-checking task.** There were three prompt cards used for this theme including: *This place is very welcoming for kids.* As in the findings from the main study, participants describe the hospital as a welcoming place and use the same organisational considerations such as the friendliness of staff, and the bright aesthetics of the environment to explain this.

**Example 1:**

*Participant: The place is very welcoming for kids. They welcome us a lot and they give us a lot of support if you need it and um like they like if you get upset they try and comfort you which is really good 'cause I find that the nurses do that a lot. They try and make things happy than what they really are, like inspections and like temperature tests and things like that. Instead of making them be all boring they try and make it fun which is very welcoming. (Melissa, 12)*

**Example 2:**

*Participant: This place is very welcoming for kids, yep.*

*Researcher: Ok what makes it that?*

*Participant: Um just that it's a kids hospital and it's a good place for kids, 'cause you get heaps of help from the nurses and doctors. (Adam, 10)*

**Example 3:**

*Participant: The place is very welcoming for kids. That's true, because it's very colourful, very polite, very inviting and kids like colour, yeah it's just better with colour. Also the staff are very friendly and very caring, especially the nurses. It's very like welcoming and supportive. They make you feel comfortable which is good so you're not afraid of asking them something, so that's good. (Annabel, 16)*

A second prompt card was used which included: *It's a good place for kids*. As in the main study, these conversations revealed that participants do feel this hospital is a good place for kids and that this assessment is comprised of their response to the behaviour of staff, the volume of activities available and the aesthetics of the environment. In Example 1, the participant also adds new dimensions referring to the capacity for kids to feel safe and to be able to exercise their own agency in the environment and in their experience.

**Example 1:**

Participant: It is a good place for kids. They have a lot of activities like the Starlight Room and I've found downstairs outside they have like a chess board with pieces and things like that so it's a good place for kids if like if you want to get up and do something you can, if you're allowed to. But and if you just want to stay in bed it's like, it's really a kid living his own or her own life, um the way they want to practically but they're being taken care of so it's a safe living environment which is a good place for kids but they get to do what they like so if I wanted to go for a walk now all I'd have to do is notify the nurses that I'll be back in about 10 minutes and I can even take a nurse with me if I wanted to so... I like it. (Melissa, 12)

**Example 2:**

Participant: It's good for kids here, yeah.

Researcher: *What makes it good for kids here?*

Participant: Well the nurses help and it's a kids' hospital and the adult hospital doesn't probably have as much fun stuff. Um just all the things they can do, all the kids stuff. (Adam, 10)

**Example 3:**

Participant: Yeah this is a good place for kids.

Researcher: *And what makes it that?*

Participant: Um the colours and the activities that they have for kids and the general way that um doctors and staff treat kids. I think they're very friendly, they're more friendly towards them and very...like how you play with kids and you're bright around them. (Lana, 18)

A third prompt card was used in relation to this theme, which included: *Sometimes it doesn't feel like a hospital*. This produced similar findings in some instances as the main study in that 'not looking like a hospital' helps them to maintain a positive frame of mind and to remain engaged with the experience and the environment. Others however were more ambivalent about this card.

**Example 1:**

Participant: Um 30 [*Sometimes it doesn't feel like a hospital*] is true, sometimes it doesn't feel like a hospital, sometimes it just feels like a social place, where people mingle and things like that which is a good thing and then again it could be a bad thing, 'cause people get side tracked and get away from their illnesses which could be bad, but anyway, I guess in my opinion it's good that sometimes it doesn't feel like a hospital because then it gets people away from negative tracks of what they feel and like negative opinions of their disease or what they have and it's good to feel like, it's good to feel that they're not just in some boring hospital stuck here for ages and that they have to take medication. It's good to feel that they're in a place where they can meet people or they can just like you, know, um interact with others. (Melissa, 12)

**Example 2:**

Participant: Oh sometimes it doesn't feel like hospital, my friends have actually said this!

Researcher: *How about you? How does it feel for you?*

Participant: It's just because I think it's a children's hospital and there's so many little games and clowns running around everywhere. I don't know, I'm not sure. Sometimes and sometimes not. (Lana, 18)

**Time**

This domain centres on the influence of time on the experience of hospitalisation and participants response to the Hospital environment. There is one major theme whose main alignment is with this domain. This includes: *Variety and difference*. This theme is aligned to other domains also.

**Theme 1: Variety and difference.** This theme includes the discussion on the need for variation, change, and contrast in all areas of participants' experience which occurs as participants spend more time in the environment. It also encompasses the evidence for the effect of sameness and boredom.

**Alignment with domains.** Apart from the main alignment to the domain of time, this theme is aligned to two other domains including organisational considerations and physical environment.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Time:* The alignment with this domain is indicated by the evidence for a single dimension including *the impact of boredom and sameness (1)*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including *the importance of environmental variation (2)*. This includes the sub-dimensions of *variation in aesthetics*, and *variation in areas, their functions and opportunities* and *variation in spatial qualities*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a single dimension including *the need for a varied routine (3)*. This includes the sub-dimensions of *a variation in treatment programs*, *variation in activities* and *variation in food*.

**Exploration of dimensions.** In total there are three dimensions identified in this theme. Each of the dimensions identified within the theme will be explored and illustrated here.

*Dimension 1: The impact of boredom and sameness.* Feeling bored is expressed as the major effect of time in hospital. Boredom comes as a result of sameness in participants' experience and lack of opportunity to find new experiences. Boredom is perceived as a problem by many participants because feeling bored is closely linked to feeling homesick and frustrated with their situation.

**Example 1:**

*Researcher: So when you're in here for a long time does that change the way you feel about being in hospital?*

Participant: I think yeah, it does a bit because it's still a hospital, no matter what you do to change that, it's not home. You can make it feel more like home but it's not the same, so you get bored and you kind of get sick of being in hospital after about a week and a half. (Peter, 12)

**Example 2:**

*Researcher: When you're in here for a long time, does that change the way you feel about being in hospital?*

Participant: Yep

*Researcher: In what way, what happens?*

Participant: When you stay for a short time you think I'm going to be out of here soon, who cares. A long time you think 'oh my god', you get really bored and you want to get home. (Zoë, 16)

**Example 3:**

*Researcher: Ok when you're in here for a long time, does that change the way you feel about being in hospital?*

Participant: Um the beginning, ok, it's like in three sections. The beginning is like you just come in here so it's alright, the middle you get really, really bored and frustrated, then the end is like you're used to it so....

*Researcher: Now how quickly do you get from the beginning to the middle?*

Participant: Um...a week, for me it's a week

*Researcher: And how long does the middle section last?*

Participant: Um maybe another week and then the end is just whatever. (Amelia, 14)

**Example 4:**

*Researcher: When you're in here for a long time, does that change the way you feel about being in hospital?*

Participant: Um only because you feel like you want to go home. Like you're sick of being here because it's just not your normal house and bed and everything and it's just 'cause you're sick and bored and you get restless. So that's mainly the only reason I want to go home, probably most people 'cause they're sick of being here and they want to go back to their comfortable bed. (Kylie, 11)

*Dimension 2: The importance of environmental variation.* Variation in the environment is appreciated in a number of ways, some of which have already been discussed, including variation in aesthetics, and the value of being able to escape to the outdoors for variation in experience and in spatial qualities. Variation in the type of spaces, their function, and their spatial qualities is increasingly appreciated with time. This is

because variation in the areas of the environment makes variation in experience possible.

**Example 1:**

Researcher: Do you think it's good to have different places to go to in the Hospital?

Participant: Yes because then you can like have a walk and stuff and it's and you don't just have to sit in the room all the time. It's just nice that you can get out and have a walk and see all the different places and it's just, it's not boring. You just walk around the Hospital because there is so many things to see. (Peter, 12)

**Example 2:**

Researcher: *Ok do you think it's good to have different places to go to in the Hospital?*

Participant: Yes because sometimes I do get bored here, just sitting in here and it's good for exercise and all that. The shops are nice because well they have nice varieties of food and all that, like soup and all, and gift shops, the Starlight room again it is very nice for kids to just go and have a little play or do or say a joke or something, when the jokes things are on. (Tom, 12)

**Example 3:**

Researcher: *Alright do you think it's good to have different places to go to in the Hospital?*

Participant: Yep

Researcher: *And why do you think that is?*

Participant: Do you mean like, do you think it's good to have different places like the Starlight room, the gym...?

Researcher: *That could be one thing, sure.*

Participant: Yes I reckon that's good because sometimes it can take your mind off being sick, so if you're laying here you know you're sick and it gets really boring. But then if you're going out there and playing like the Playstations or going to the gym, it's fun and takes your mind off being sick and stuck in hospital. (Josie, 12)

*Dimension 3: The need for a varied routine.* The desire for greater variation in treatment routines and programs has already been discussed, as has the need for a variety of activities. Other attributes of the organisational routine also attract attention because they become boring and repetitive with time. This especially includes the food.

**Example 1:**

Researcher: *Um food again. A problem?*

Participant: Yeah a bit. Like you know, I do know for my family and friends some of them think, 'oh the food here is' you know, like 'cause it's not good quality, like some of the meat, I am surprised you know that it's actual meat. You know I'd be like yeah whatever, 'meat' so it doesn't taste that good. There also isn't a big variety which isn't good if you're here for awhile you know. (James, 17)

**Example 2:**

Researcher: *What's the thing you'd most like to change?*

Participant: The food.

Researcher: *Yeah? Don't like it?*

Participant: No, it's boring and like when you're in here for a long time you get the same food again and again. (Scott, 15)

**Example 3:**

Participant: Well they stuff up the food, it's boring and not good quality. You just can't eat some of it.

Researcher: *You mean the hospital kitchen?*

Participant: Yeah and they don't have much variety I don't think. (Zoë, 16)

**Member-checking task.** Two prompt cards were used for this theme, which included: *I really like having a variety of things to do and places to go here.* The findings from these discussions indicate the significance of time in the environment and familiarity with the opportunities in the environment. They also indicate the link between the need for distraction to avoid thinking about their personal situation, which supports the findings from the main study.

**Example 1:**

Participant: Um number 16, *I really like having a variety of things to do and places to go here.* Um there's not really much of a variety of things to do because around here um I think it's just a bit boring for me. I find that's there's not really many things to do because the nurses do get busy a lot which means that they're usually with other patients or um they like, there's not really, I don't know I find that, Um I've been here that long probably or I've known this, I've gotten to know this hospital a lot that there's not really much exciting things to do now. (Melissa, 12)

**Example 2:**

Participant: Ok, 16 yes I agree with that.

Researcher: *And why's that? What's the importance of variety?*

Participant: The importance of variety is just that so you don't get bored and having things to do all the time takes your mind off things so you're not just focussing on your illness. I think having a variety of places to go is also good so that if you're mobile enough you don't hang around the same area and get bored, just the same really. And just meeting people too that's always good. (Annabel, 16)

**Example 3:**

Participant: There's not really a great variety of things to do or places to go here, or maybe it's just that I've been here a number of times now and I've gotten used to everything. It would be good if there were more like places for kids my age and things to do but I don't see how. You can only do so much in this space. I don't know how they would change it but I know like how they were making a labyrinth in the garden somewhere. I thought that would be interesting, that would be cool. (Lana, 18)

The second prompt card used in this theme was: *It gets boring the more time you spend here.* This card was designed to provoke further discussion on the ways children's perception of the experience and environment changes across time. The findings were similar to those in the main study. The novelty wears off quickly and the struggle to remain engaged and to avoid boredom becomes increasingly difficult with time.

**Example 1:**

Participant: At the beginning it was fun because it's my first time in hospital and I got to explore the hospital and different aspects of it, like the Starlight Room and things like that, but now I'm bored because I barely get any visitors and there's not much to do, so yeah.

Researcher: *What things would you like to add, what things would you like to be doing if you could?*

Participant: Um more chances to do things, I guess because usually the nurses come like every hour or so to check my temperature or so more, I guess more um chances to do stuff.

Researcher: *At your bed or somewhere else in the hospital?*

Participant: They could add stuff like, bring in like colouring books or fun things to do, instead of just leaving us just to lie here and watch TV or just lying here.

Researcher: *And do people come round, play therapists come round to you and people like that?*

Participant: Um sometimes they do like yesterday um people came round with dogs and like they got the dogs to sit up on the beds and things like that. I guess you know they could have done something like that earlier, especially because me and Mum have been in here for quite a while now. They could have done something like that a bit more earlier in the week.

Researcher: *So when did it change from being sort of interesting to being boring? How many days had you been here by then?*

Participant: Say about three, four days, 'cause I got used to everything and started to know where to go and things like that and then, then there was like problems with food and things like that. (Melissa, 12)

**Example 2:**

Participant: Number 1, I think that's true, it gets boring the more time you spend in here.

Researcher: *And how much is boredom a problem for you?*

Participant: Not that bad 'cause I haven't been, like I've only handled a month of being in one place at one time, so I don't think it's that bad.

Researcher: *What about the effect of time? How does that register with you?*

Participant: Um perhaps you get used to it as time goes by but um, I like to just find things to keep myself occupied so you don't really notice the time. (Toby, 16)

For a summary table of domains, major themes, their dimensions and sub-dimensions see Appendix H. The next two sections of this chapter will provide summaries of the findings in relation to the research questions.

### **Summary of Findings: Research Question 1**

**What is the experience of children and young people of the sociophysical environment of a paediatric hospital?** Children and young people's experience of the sociophysical environment of the Hospital is a dynamic and changeable relationship which is moderated by the wellness of the patient, and the time spent in the environment.

The experience of hospitalisation for the children and young people can be described in relation to five major domains including personal experience, social experience, the physical environment, organisational considerations, and time. Within the five domains there are major themes which are interconnected and reflect the major aspects of children's experience.

Central to patients' experience and underlying patients' needs from moment to moment is the influence of their own diagnosis. This has the capacity to alter their impression and perception of their experience, and of the environment itself. The evidence reveals that if patients are unwell then they make few demands on the sociophysical environment of the hospital because their focus and energy is absorbed by their own

situation and minimises their interest in becoming involved in the wider context. When patients feel well, they approach the hospital environment expectantly in search of new experiences, new people and positive engagement with the environment.

For all patients, personal experience is interconnected with the social, physical and organisational domains. Together these three domains make up the components of the sociophysical environment with which patients engage.

The social considerations include patients' need for company, support and social contact with friends, roommates and in particular, family. These needs vary according to the patient's age and length of time in the environment. For most participants, family members are the central source of support.

For adolescent patients, friends from both inside and outside the hospital are also an important source of support and social contact. This however, is dependant on the length of time the patient is in hospital. If the patient is only in hospital for a limited time, the importance of contact with friends is reduced. If an adolescent patient is in for a long period the need for social contact and support from peers greatly increases.

The considerations for the physical environment include the importance of aesthetics, in particular, colour, artwork and brightness. As the findings reveal, participants acknowledge the influence of colour, artwork and brightness in the environment on their feeling of welcome and comfort, and on their perception of it being a child-friendly environment.

A second consideration includes having contact with nature and having access to outdoor environments, which is greatly appreciated by participants of all ages. As the findings reveal this is because of the contrast in environmental qualities such as the ability to have fresh air and sunlight, but it is also linked to the aesthetic appeal of these environments, their peaceful quality and capacity for privacy and personal restoration.

The organisational considerations include the importance of a child-friendly environment. Child-friendliness as it is revealed in the findings encompasses organisational characteristics within the hospital, which make children, and young

people feel that this is an environment for kids and that this is ‘a good place for kids’. Estimations of child-friendliness and the indicators of a child-friendly environment include the volume and age-appropriateness of activities available, the friendliness of the staff, and the brightness and colourfulness of the environment.

Encompassing the interplay between individual experience and the social, physical and organisational domains is time. The amount of time that patients spend in the environment and the number of times patients have been in the environment alters their approach and response to the experience greatly. Time spent in the environment introduces the need for the major theme in this domain, which is variety and difference. Children and young people’s need for variation and change in their experience, environment, and routines, greatly increases with time.

Being able to meet the need for variety and change reduces children and young people’s level and burden of boredom. Boredom is described as a corrosive force, which participants acknowledge as having the capacity to undermine their positive mental state and threaten their ability to cope. The findings indicate that this is one of the major impacts of time and the reason that having access to variety and change is so important.

The final two major themes not yet discussed include coping and personal control. These two themes belong in the domain of personal experience. Through the evidence aligned with these themes another major aspect in children’s experience is introduced, which is the influence of children and young people themselves. From the evidence presented in these themes it is clear that children and young people are not passive recipients in this experience but are active participants. They expect to actively manage and shape their own experience and to take responsibility for coping with their time in hospital, and for maintaining a positive attitude whilst in hospital. The findings in these two themes reveal the expectations children and young people have of themselves in the situation. They expect that they will be able to find ways to manage it. Participants actively negotiate their experience continuously in response to their changing circumstances and the changes in situational demand placed on them in the hospital environment.

The findings also reveal that participants value experiencing control during their hospitalisation. One of the principal ways that patients can be given some control is through the receipt of information about their diagnosis and its implications. Most of the participants appreciate being included in their own healthcare management. This invitation to participate as experts in their experience is greatly appreciated and functions as an indication of staff's recognition of children and young people's need for dignity and respect as individuals.

Participants increasingly seek greater personal involvement and control as they get older. They have a greater expectation of participation in decision-making processes and are not comfortable when this does not happen. Patients with chronic conditions expect to be accorded greater authority on their own situation based on their age and experience with their condition and are not tolerant when this is not given. Appropriate and respectful treatment from staff is one of the main dimensions of a larger concept that also increases in importance for older participants, which is age-appropriateness.

Understanding the experience of children and young people of the sociophysical environment of a paediatric healthcare setting means appreciating the dynamism in the relationship between the patient and the hospital context. As revealed in the findings, both act on each other continuously, driven by the patient's need to feel comfortable in the environment and to meet their personal and social needs from moment to moment.

As time in the environment increases, the capacity of the environment to provide satisfying and engaging experiences diminishes and patients' restlessness increases. This becomes contrasted with the comfort that increasing familiarity with the environment and with hospital routines brings. The complexity and changeability of these struggles provide the dynamism in the relationship that exists between the patients and the context of the sociophysical environment of the hospital. This dynamic, changeable relationship between patients and the sociophysical environment of the hospital is the experience of children and young people in this study.

### **Summary of Findings: Research Question 2**

**Is there a relationship between children and young people's feeling of well-being, and their interaction with the physical environment of the hospital?** This question

has two parts. In answering it, it is necessary to firstly identify from the findings what constitutes a preliminary definition of *feeling of well-being* so as to argue secondly, for the role of the physical environment in relation to it.

A review of the findings suggests that children's feeling of well-being is a holistic concept and encompasses a positive, subjective assessment of the experience of hospitalisation as a whole. The findings also suggest that it is comprised of three major considerations, including children's ability to *feel comfortable* in the environment, their ability to *maintain a positive frame of mind*, and their ability to *remain positively engaged* in the experience. These three overarching considerations recur in the findings across all major themes. They provide either the motivation or basis for children's interaction with the environment, or they provide the desired outcome for children's interaction with the environment. They indicate the centrality of the concept of feeling of well-being and of patients' struggle to achieve it. They also indicate that feeling of well-being is subjective and achieving it involves the patient, the environment and the interaction between them.

These three considerations each involve all domains of children's experience but in answering the second research question, the focus remains on the involvement of the physical environment in relation to each of them and therefore to patients' feeling of well-being. The remaining discussion will focus on the aspects of the physical environment that influence patients' feeling of comfort, ability to maintain a positive frame of mind, and remain positively engaged.

The findings reveal that children's ability to feel comfortable in the environment is linked to several considerations for the physical environment, including having control over environmental attributes such as noise and light. Ambient noise and light are two of the greatest sources of irritation for patients in the hospital environment, particularly for patients in shared rooms. Being able to have greater control over these two environmental attributes were two of the most commonly given reasons for preferring to be in a single room.

Feeling comfortable in the environment is also linked to patients' capacity to personalise their bed space with things from home. Having control over this piece of the

environment and being able to surround themselves with familiar faces and objects of personal significance which remind them of home, makes them feel more at home in the hospital environment. Feeling at home is linked by participants to feeling relaxed and comfortable in the environment. Being able to personalise their bed area becomes more important as the time that patients spend in hospital increases. Missing home also becomes more of an issue with time.

Feeling comfortable with the aesthetics of the environment is a further consideration. Participants often spoke about the aesthetics of the environment in relation to their ability to feel comfortable in the setting and in their assessment of it as a welcoming environment. Being surrounded by artwork and colour and brightness contributed to patients' comfort.

Maintaining a positive frame of mind is a key consideration for managing time in hospital. Participants link the need to maintain a positive frame of mind with supporting their own healing process. They volunteer many coping strategies designed to achieve this, several of which rely on attributes of the physical environment. Personalising the bed area is one of them and this has already been discussed.

A second strategy involves being able to go outdoors for the contrast in environmental qualities, to find privacy, and to feel restored. Participants regularly link their environmental use with their mood and their emotional needs from moment to moment. Participants acknowledge using the outdoor areas as restorative environments in their experience.

A third strategy involves being able to escape or retreat from the ward environment (both physical and social). The outdoor areas are some of the most preferred places of escape in the environment because of their beauty, peacefulness and capacity to provide a restorative experience. However, other areas in the environment such as entertainment and shopping zones are also appreciated for this.

The fourth strategy involves exploiting the opportunity of having different places in the environment that have different atmospheres, functions and spatial qualities (to their wardrooms) which allow patients to participate in activities that they would normally

do. Participants appreciate being able to maintain routines whilst in hospital that they would usually do with their families in their lives outside the hospital. Being able to visit cafes, shops and play games in common room areas with both friends and family brings a semblance of normality and ‘keeps their mind off’ their illness. Being able to enact this strategy is contingent on having these opportunities physically available in the environment.

Remaining positively engaged with the experience and the environment is the third consideration in children’s feeling of well-being in hospital and possibly the most difficult for patients to maintain. The findings reveal that remaining engaged is largely contingent on being able to find engaging experiences within the environment. Engaging experiences are often new and novel opportunities such as going to the Starlight Room, experiencing the clown doctors, or attending Group. The physical environment contributes to children’s capacity to remain engaged by providing a number of different areas, which offer novel experiences for children and their families. The obvious limitation, which is also revealed in the findings, is that the novelty wears off and the environment cannot keep presenting patients with novel areas and facilities.

The physical environment also contributes to patients’ ability to remain engaged by providing visual interest, which varies around the hospital in the form of artwork on the walls. Participants acknowledge that this reduces the potential feeling of sameness in the environment and provides them with an absorbing distraction, which can fuel their imagination. Going for walks around the hospital environment is a common pastime for patients and their families and it is on these occasions that the variation in the environment is appreciated. The variation in artwork occurs all over the hospital. If this attribute is appreciated by patients, it has the capacity to be a sustaining distraction and form of engagement across time.

The presence of colour and its variation also plays a role in providing a feature in the environment with which patients’ can engage, but to a much more limited extent. The variation in colour around the hospital is perceived to be much more limited by participants than the variation in artwork.

Overall the findings reveal that time in the environment undermines children and young people's interest in the opportunities and areas within the environment. This means that remaining engaged becomes increasingly difficult and the environment, instead of providing novel and supportive experiences, becomes boring which directly undermines children's capacity to maintain both a positive frame of mind and to remain positively engaged. Opportunities for adaptation and flexibility in the environment are greatly appreciated such as the capacity to alter material around their bed areas.

The physical environment mostly consists of features that remain constant and therefore as the findings reveal, it has the capacity to be both a positive and a negative contributor to children's feeling of well-being, depending on the patient's circumstance and the length of time they must spend in the hospital. Examples of particular experiences include children in isolation who report getting very sick of being in the one room all the time and state that this directly undermines their overall satisfaction with their experience of being in hospital. Children with the capacity to visit any part of the hospital, report remaining engaged with the experience more readily and for longer. This is largely due to being able to implement a larger range of coping strategies, including those that involve seeking variations in environmental experience that has the capacity to help sustain patient's positive engagement.

Overall the findings reveal that patients' interaction with the physical environment of the hospital is involved in their experience of comfort, and their ability to remain positive and engaged, and therefore in their feeling of well-being. In the next section of the thesis aspects of these findings will be discussed further.

## **PART D: DISCUSSION, CONCLUSIONS, RECOMMENDATIONS**

### **CHAPTER 11**

#### **WHAT IS A SUPPORTIVE PAEDIATRIC ENVIRONMENT FROM CHILDREN AND YOUNG PEOPLE'S PERSPECTIVES?**

The discussion chapters are centered on the three aims that were stated at the outset of the study. These include: describing what constitutes a supportive paediatric hospital environment for children, young people and their feeling of well-being; identifying the key attributes within the physical environment and their function within a supportive environment; and identifying the advantages of participatory research to paediatric design. Chapters 11, 12 and 13 each focus on one of the aims and discuss each of them in relation to the literature and findings of the study.

#### **Supporting Children and Young People's Feeling of Well-Being**

**Feeling of well-being for children and young people in hospital.** The findings of this study reveal that children's feeling of well-being represents their response to the experience of hospitalisation as a whole. Similarly to the nature of subjective well-being as described by Ash and Huebner (1998) children use information from both their inner (self) and outer (environmental) worlds to construct their appraisals of their feeling of well-being. It is an important assessment akin to patients' overall satisfaction with their experience of hospitalisation. Feeling of well-being also appears to be a negotiated and fluctuating state, which an individual can influence and manage, and which the environment can influence also. Supporting children's capacity to achieve a feeling of well-being in a paediatric setting is a major dimension of a supportive environment.

Feeling of well-being as it emerges in this study shares many characteristics of subjective well-being as defined by Diener (1984, 1994). These include that it is subjective and resides within the experience of the individual. Secondly, it involves the assessment of both the absence of problems as well as the presence of positive considerations in children's estimation. Thirdly, it is a holistic assessment rather than a narrow assessment of a single domain of experience.

Whilst feeling of well-being is a holistic subjective response for participants in this study, it is comprised of three principal components. These include children's ability to *feel comfortable* in the environment, their ability to *maintain a positive frame of mind*, and their ability to *remain positively engaged* in the experience. The last two considerations are not entirely distinct from each other. Each of these has been discussed in the previous chapter in relation to the implications of each for the physical environment. However each has dimensions beyond the implications already discussed.

**Feeling comfortable.** Feeling comfortable is more than feeling physically comfortable. This study reveals that feeling comfortable is as much about finding a place of emotional equilibrium and social acceptance and welcome, as it is a physical experience. The findings from the discussions with participants relating to the importance of being able to personalise their bed spaces reveal that comfort is a complex notion involving the experience of control, the capacity to adapt the environment to meet their needs, the capacity to introduce things of personal value to themselves into the environment and to remain in touch with things they value outside the environment. The significance of these things is linked by patients to finding both physical and emotional comfort and solace in the environment.

Research with adults on the influence of patient-centred models of care where patient comfort, empowerment and control are understood as central to their well-being shows the importance of these concepts in patients' satisfaction with hospitalisation (Martin et al., 1998). Comfort in these models is focused specifically on environmental comfort. This study found that children's conceptualisation of comfort encompasses physical comfort, but it also includes the importance of finding emotional solace and social support.

Participants indicate that feeling comfortable in the environment reflects their perception that the environment is an appropriate one for them and that the community response to them is also appropriate. The friendliness of the staff, the perception of the availability of age-appropriate activities and entertainments, and the appeal of the environment's aesthetics, are all contributors to patient comfort that emerged from this study. These three considerations amount to patients' perception of the child-

friendliness of the environment and of environmental congruence, both of which are part of children's overall assessment of their experience and feeling of well-being.

The importance of social support from friends, family and staff, and the capacity to socialise with friends and family for patients' comfort is a major theme in this study. The importance of social support has been acknowledged by others. Ulrich (1991, 2000) lists it as one of his three principal characteristics of a healing environment that supports wellness. He argues that access to social support and facilities that facilitate social support actively support healing, although he states that the evidence in support of this is limited. Other research carried out with children and young people has revealed the importance of family and staff support (Carney et al., 2003), and having access to peer support, particularly for adolescents during hospitalisation (Blumberg & Devlin, 2006; Hutton, 2005; Kari et al., 1999).

Finally the findings reveal that patients' comfort in the environment also reflects their perception that their family's needs and experience is well supported and anticipated in the environment. Children and young people can be anxious about the inconvenience and cost to their families of having a child in hospital. They reveal that it is important to them that the environment is supportive of their family's needs as well as their own. Other research has shown the importance of accommodating families' needs, so that they can fulfil their role in supporting their children (Hall, 1990; Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2005; Sheldon, 1997). The findings from this study emphasise the importance that children and young people themselves place on this aspect for their families.

**Maintaining a positive frame of mind.** The findings indicate the emphasis that children and young people place on staying positive about their situation and their capacity to cope with it. Maintaining a positive frame of mind encompasses two key components: minimising the impact of difficulty and boredom, and maximising the opportunity of having positive and entertaining experiences.

Children and young people readily report actively managing their emotional response to their situation using the opportunities in the environment. Managing to cope with the situation is a major aspect of maintaining a positive frame of mind. Managing to cope is

a goal for patients, and is part of their estimation of competence in the experience. It could even be described as a measure of personal success for some participants. This supports findings from Band and Weisz's (1988) study where in 96.5% of instances, children showed a strong inclination to cope with everyday stress.

The findings from the current study also reveal that the coping strategies children and young people use vary in response to each situation (Band & Weisz, 1988; Griffith et al., 2000) and that these strategies become more complex and diverse with the age of patients. This is also in accordance with the findings in the literature (Carney et al., 2003; Causey & Dubow, 1992; Griffith et al., 2000).

In relation to the question posed by the coping research literature as to what motivates children's selection of coping strategy and whether it is linked to the perception of control and capacity for change (Lazarus & Folkman, 1984; Moos, 1984), it could be argued that as Griffith et al. (2000) suggest, that perceptions of control appear to indicate the relative use of approach rather than the absolute level of use of each strategy. Band and Weisz's (1988) definition of secondary control coping best describes the kind of coping that children and young people use in a hospital environment. Children and young people recognise that they have a very limited capacity to alter the objective conditions of their experience, however they do what they can to maximise their goodness of fit with conditions as they are.

Apart from coping with the problems and difficulties of the experience, the findings indicate that the other dimension to maintaining a positive frame of mind is experiencing positive distractions, fun, socialising, and capitalising on the opportunities that exist in the environment for engagement. Children and young people view their experience of hospitalisation as more than being treated for some kind of medical or surgical problem.

The findings reveal that children and young people clearly bring with them a much more positive attitude to the potential of the experience of hospital. They look at their time in hospital as a collection of new opportunities. Interaction with the environment both social and physical is often motivated by the wish to meet new people, explore new things and take advantage of the novelty of the situation. They approach the

sociophysical environment of the hospital expectantly and seek interaction with it. This supports other research in which children indicate that they prefer active use of space (van Andel, 1990) and that part of their initial assessment of any environment is 'what can I do here?' (Francis, 1988).

Participants indicated that being able to behave as they might in normal circumstances or pursuing activities that they would normally do outside of hospital helps to maintain a positive frame of mind. For example, being able to attend school, functions in this way for children in hospital. Children appreciate not falling behind at school and participating in activities that make them 'feel normal'. This supports the findings in other research with children in hospital where having access to school was considered important (Kari et al., 1999; Liabo, Curtis, Jenkins, Roberts et al., 2002).

Attending cafes and restaurants also functions in this way for children and young people. Participants greatly appreciate being able to attend these areas, have good food and spend time with their family as they might do in their lives outside of hospital. These experiences are appreciated because they help patients feel that they are not in hospital. They provide a complete contrast and a notional escape from the feeling of being in hospital. Having such experiences available in the environment helps to maintain their positive frame of mind and capacity to manage their emotional response to their situation. This is supported by other studies, Carney et al. (2003) for example, found that children commented favourably on things which could be linked with home life, and provide some continuity between their hospital experience and their normal environment.

**Remaining positively engaged.** The findings reveal that remaining positively engaged is an active process and is one of the motivating forces in children's self-help strategies. It is an expression of the self-management employed by children and young people whilst they are patients. As with maintaining a positive frame of mind, it is more than employing coping strategies to alleviate the impact of the experience of hospitalisation. It is not simply about minimising problems. Instead it is a very active stance which involves exerting control, experiencing competence and empowerment in their experience of hospitalisation.

Children and young people actively seek to remain engaged during their hospitalisation. Mostly they use the opportunities provided by the organisation such as the entertainment areas, the shops and the mobile play and library services. They use the environment itself, using their exploration of it and the variation in spatial function, aesthetics and spatial qualities as a source of engagement. Older participants also use the opportunities for social interaction with their peers. These experiences have a function that is greater than distraction, and children's motivation for seeking these experiences is more substantial than just keeping busy or purposefully occupied to pass time. They seek the satisfaction of having real, everyday things to do and the feeling of competence, control and empowerment that accompanies participating in them and completing them successfully.

Previous studies and commentators have indicated the importance of experiencing control, competence, social interaction, and engagement in new and stimulating activities for children in hospital (Hutton, 2002, 2003; Liabo et al. 2002; Lindheim, Glaser & Coffin, 1972; Olds, 1991; Rivlin & Wolfe, 1985; Runeson et al., 2002; Tivorsak et al., 2004). The participants in this study indicated that all of these considerations are shown to be relevant to their capacity to remain engaged for prolonged periods in the hospital environment.

Olds' (1991) discussion of the concepts of competence and control is framed within the need to support children's feeling of well-being in a paediatric setting and is therefore extremely relevant to this study. She argues that "children need a deep sense of mastery, a sense of their ability to try something new or do something well today that they could barely do at all yesterday" and that paediatric environments "must communicate to children a sense of their own self-worth and ability to interact with and explore everything that is in it" (p.113). She argues that "the environment is their food and nourishment. Everything in it matters. It communicates something to children about who they are, where they are, what they can do, and what their potential may be" (p. 112).

The emphasis of Olds' (1991) conceptualisation is on an interactive environment that supports children's capacities to experience control, movement, competence and

mastery, which invites them to engage with it. The findings from this study would confirm the emphasis she places on these characteristics and experiences.

Remaining positively engaged in the experience across time is one of the greater challenges in children's ability to maintain a feeling of well-being in this context. Failing to remain engaged leads to boredom. This study reveals that boredom is the most corrosive force in children's experience across time and that boredom is linked to negative thoughts, homesickness and restlessness with being in hospital. As a result it threatens children's feeling of comfort, positive state of mind and therefore their overall satisfaction and feeling of well-being in the environment. Boredom represents a struggle by patients to remain engaged. Other studies have revealed the importance of avoiding boredom in patient experience also. Hutton (2003) also found that engaging adolescents in activities was linked to their capacity to feel good about themselves and to avoid boredom.

The final dimension to children and young people's capacity to remain engaged, lies in their capacity for participation in their own healthcare management. Receiving information pertinent to their situation, being consulted and listened to by their medical practitioners and nursing staff, is greatly appreciated by children and young people. When these considerations are managed well, patients report being actively involved in the decision-making process that surrounds their own situation and this becomes an effective part of their coping and self-help strategies. When it is not managed well, they report leaving the decisions up to their family and their doctors and disengaging from these processes because they perceive that their participation is not valued or sought.

In their study into decision-making during hospitalisation, Hallstrom and Elander (2003) state that "having a voice in decision making helps the child to develop a sense of himself as a person" (p. 367). In the current study children used their inclusion in decision-making processes as an indication of the staff's respect for them as individuals and for kids in general. The importance of information in children's experience of hospitalisation has been the subject of previous research (Ishibashi, 2001; Smith & Callery, 2005; Young et al., 2003) however none of these studies discussed the role of information in helping children remain engaged with their experience which emerges in this study.

The concept of remaining engaged for children and young people in this study differs from other similar concepts suggested by the literature. For example, in Ulrich's (1999) concept of positive distractions the patient can be a passive participant simply experiencing views through windows or artwork on walls. There is no assumption of physical interaction with some aspect of the environment. For participants in this study, the concept of remaining engaged requires children's active interaction with the social, physical or organisational environment of the hospital to bring about the experience of empowerment, competence and control.

### **Supporting Person-Environment Fit and Environmental Congruence**

Environmental congruence and person–environment fit are important concepts for understanding what constitutes a supportive environment for children and young people in hospital. Children's perception of environmental congruence and their experience of person-environment fit are also components in their feeling of well-being.

**Person-environment fit.** Children's experience of fit is closely linked to their capacity to meet their personal, social and physical needs from moment to moment. It is linked to whether they are able to do what they feel like doing, and the environment's capacity to support them in their endeavours to follow through on their desires, throughout their experience of hospitalisation.

Children's quest for fit encompasses their personal needs such as being able to find solace in the environment during emotionally challenging times. It is linked to their social needs such as being able to find support or to socialise when desired. It is linked to being able to seek out environmental contrast and experience a variation in their physical surrounds when desired, such as when they feel the need to escape or retreat. Finally, it is linked to being able to find facilities and organisational opportunities for entertainment and engagement.

The findings from the current study indicate that for children in hospital, achieving person-environment fit is a dynamic process that is reliant on the capacity and facilities of the environment, and the ability of the individual to choose to engage with them. Seeking person-environment fit is one of the motivating forces in the dynamic relationship that exists between children and a paediatric environment.

Children continuously strive for fit with the environment during hospitalisation. This finding reflects one of the core principles of Stokols' (1992, 1996) social ecological approach to health promotive environments, which is that people-environment interrelations are characterised by cycles of mutual influence. Participants make the link between their contact with, use of, and response to the environment, and their capacity to maintain a positive state of mind and ability to heal quickly. The dynamism in the relationship between children and young people and the hospital environment is introduced by children and young people's desire to help themselves, and find ways to cope with, and manage their experience in the environment. At times, this involves minimising the impact of the sociophysical environment on their experience.

The emphasis on a dynamic multi-faceted relationship between an individual and their environment as the core of person-environment fit and therefore individual well-being reflects another fundamental principle of Stokols' (1992, 1996) social ecological model. He argues that it is through the study of this interplay and the elements involved in it that it is possible to understand how to support an individual's well-being in any environment. Understanding this interplay and the forces which provide the dynamism in the relationship provides the basic understanding required to develop supportive environments.

Kaplan's (1983) conceptualisation of a compatible and supportive environment is very apt for describing the supportive and dynamic relationship that exists between children and young people and a paediatric setting. He conceptualises a supportive environment as one that "focuses on eliminating the barriers that... make it hard for people to help themselves. It takes seriously the concept of human choice and human purpose" (p. 323). A supportive environment is an environment that is high in compatibility in which individuals do not have complete control over important outcomes, but it supports them in their quest to attain those goals or outcomes. Person-environment fit in this conceptualisation is the experience of high compatibility between the characteristics of the environment and the capacity for individuals to exercise choice and purpose within that environment in order to meet their needs.

Kaplan's (1983) conceptualisation emphasises the importance of minimising barriers to self-help and facilitating individual choice. The findings from this study would support

the emphasis on these two considerations in relation to children and young people achieving person-environment fit in a paediatric setting. It is a question of facilitating their capacity for choice and for self-help. Children and young people actively strive to manage their own experience and help themselves, although they accept they do not have complete control over important outcomes, and it is important that the environment does not resist their efforts at self-help. As Olds (1991) states “a healthcare environment can be maximally effective when it affirms the capacity of children to heal themselves” (p. 112).

Ultimately a supportive environment, using Kaplan’s (1983) definition, is one in which choice, and the information necessary for making choices are readily available. He interprets these characteristics as ensuring high environmental legibility and minimising environmental distractions and coercions, as well as providing opportunities for reflection. All of these governing characteristics are supported by the findings from this study. Understanding children’s person-environment fit in a paediatric setting and their capacity to find the environment supportive means appreciating and minimising the potential constraints in the environment on an individual’s capacity for choice and control. It also means, as Kaplan (1983) suggests, minimising unwanted distractions, providing a legible environment, and providing opportunities for reflection and retreat.

Children’s experience of fit is also linked to their capacity to experience competence, comfort and control in the environment. These attributes have been identified previously as being crucial in patients’ experience. Ulrich’s (1991b) theory of supportive healthcare design stresses the importance of situational control, access to social support, and positive distractions within a supportive healing environment. These considerations are also supported by Olds’ (1991) in her assessment of supportive paediatric design. She identifies personal control over such things such as social contact, privacy and personal space as essential. She also recommends that children need to feel comfortable and to experience competence regularly whilst in a hospital.

These salient attributes are also supported by the current study. Children and young people appreciate the opportunities for exercising situational control, and the opportunities for participation in activities that would enable them to feel competent in their experience. They also appreciate feeling comfortable in the environment.

**Environmental congruence.** One of the dimensions of environmental comfort for children and young people in this study is their perception of environmental congruence. The perception of environmental congruence for children and young people is an important part of achieving person-environment fit. This is what Michelson (1970) would define as mental congruence, or an individual's perception that an environment is conducive to his or her personal needs, functions and lifestyle. It constitutes children's perception of the comfort of the environment and its capacity to meet their needs.

The concept of mental congruence is more relevant in this context than the concept of experiential congruence. Many of the participants had not actually had the opportunity to explore the environment and experience the appropriateness of the activities because of the limitations of their diagnosis and treatment, however, they were aware of them. These participants made judgments based on the activities that they were aware of existing in the environment and their appropriateness for kids.

For children and young people in this study the evaluation of environmental congruence was often enmeshed in the discussion concerning their perception of the child-friendliness of the environment and its appropriateness as an environment for kids. As has been discussed in the previous chapter, the perception of child-friendliness and the appropriateness of the environment for kids is linked to the friendliness of the staff, the volume of activities that are available and the welcoming aesthetics of the environment. Using these three components in their evaluation of the environment, children and young people were indirectly providing an assessment of their perception of the environment's congruence with their needs.

Bronfenbrenner (1979) argued that it is the environment as it is perceived by the individual that may count more in environmental congruence than the environment as it can be objectively described. This argument suggests that the crucial element in environmental congruence may not be the actual configuration of the environment so much as the individual's perception of the congruence of the environment. The assessment by the individual may matter more than the nature of the environment.

This study certainly indicates that an individual's perception of congruence is crucial in their feeling of comfort and therefore their feeling of fit with the environment.

Children's perception of the hospital as being 'a good place for kids,' and a child-friendly environment is important, because it is linked to their expectation of being able to fulfil their needs in the environment.

'Messages' of child-friendliness were implicit in the environment for children and young people from the building signage system, to the hospital logo, to the actual presence of so many other children, and the inferred presence of other children through the artwork on walls. Through the discussion with participants, it was clear that the environment contained many messages of welcome and appropriateness both overt and subliminal, which they recognised and interpreted as an indication of child-friendliness and a congruent environment.

The experience of person-environment fit and the perception of environmental congruence are revealed in this study to be very important for children and young people in hospital. They are linked to children's capacity to meet their needs, feel comfortable, feel competent, feel supported, and in control at least to some extent within their experience. They are also linked to children's feeling of well-being in the environment.

### **Features of a Supportive Paediatric Environment**

In summary, the findings indicate that understanding what constitutes a supportive paediatric environment revolves around three major concepts: supporting children's feeling of well-being, person-environment fit, and environmental congruence. Within each of these, there are particular considerations that should be addressed.

**Feeling of well-being.** Understanding the concept of feeling of well-being means accepting that it is a subjective, holistic assessment and response to hospitalisation, which encompasses three principal components including: children's ability to feel comfortable in the environment, their ability to maintain a positive frame of mind, and their ability to remain positively engaged in the experience. An environment that is supportive will support children's feeling of well-being by anticipating children's needs to experience these three considerations.

**Person-environment fit.** Understanding the concept of person-environment fit for children in a paediatric setting means being mindful of the need to support children's choice, needs and purposes, and their capacity for self-help. It means providing an environment that does not resist their efforts at self-help but instead facilitates their capacity to manage their own situation and meet their social, emotional and physical needs from moment to moment.

It also means accepting that the relationship between the children and young people and the context of the hospital is dynamic and is characterised by cycles of mutual influence, with children and young people continuously actively managing and negotiating their fit with the hospital context.

**Environmental congruence.** Understanding the concept of environmental congruence in this context means appreciating the impact of patients' perception of the environment's capacity to support their needs. In particular, it means appreciating the importance of children's perception of child-friendliness in the environment and the environment's appropriateness for them. The findings indicate that the key characteristics of a child-friendly paediatric setting in patients' estimation include the volume and type of activities available in the environment, the friendliness of the staff and the appeal of the environmental aesthetics.

## CHAPTER 12

### WHAT ARE THE KEY ATTRIBUTES OF THE PHYSICAL ENVIRONMENT IN A SUPPORTIVE PAEDIATRIC ENVIRONMENT AND HOW DO THEY FUNCTION?

#### **Environmental Aesthetics**

There is already consensus among commentators that the environmental aesthetics of healthcare environments is important to patients' feeling of well-being (Caspari, Erikson & Naden, 2006; Olds, 1991; Ulrich, 1991b, 1992b, 2001). The central argument is that creating aesthetically pleasing environments will contribute to patients' well-being by influencing their emotional response (Caspari, Erikson & Naden, 2006). The findings from this study would support this. The discussion concerning aesthetics will revolve around children and young people's response to the artwork, colour and brightness of the environment, which were the major dimensions of the environmental aesthetics that children and young people discussed in this study. In combination and individually, these components have the capacity to provide messages of support and welcome, child-friendliness and appropriateness. They also provide some of the tangible characteristics of the built environment, which help children and young people remain engaged, and to maintain a positive state of mind.

**Artwork.** The participants in this study reveal that the artwork around the hospital is greatly appreciated and serves a number of functions. These include providing visual variation in the environment, providing a source of entertainment and engagement, and providing a source of colour and quirkiness in the environment. Participating in creating art or craftwork was also a preferred activity for participants. Participants report participating in these activities whilst in hospital even if they would not normally do them, and finding real enjoyment in their creations.

The artwork varies constantly around the walls of the hospital and this is appreciated as a source of constantly changing sensory stimulation. Olds (1991, 2001) discussed a concept called *difference-within-sameness*. She cited natural examples as the ultimate definition of this concept - a babbling brook, wafting breezes, sunlight dancing on leaves. The concept centres on the notion of the need to experience variation in sensory stimuli to enable constant attention and engagement in an environment, even if it is

variation within sameness. This means that even if the feature does not change radically as it unfolds such as the brook itself, the visual and auditory play of the water over the stones on its way is enough to provide renewed sensory interest for the observer. The findings from this study indicate that artwork is appreciated by patients in this capacity.

Another finding from this research is that both children and young people did not like the artwork that was too simplistic or seemingly pitched at younger children and find it irritating to have in their space for long periods of time. Although this artwork is not desirable they would rather have this artwork on their walls than have nothing at all. Blumberg and Devlin (2006) in their study with adolescents found that it was important to add artwork to the environment that did not include “blatant emblems of childhood” (p. 315) such as cartoon characters, clowns, balloons and teddy bears. Other commentators have also reported a need for less childish interiors for adolescents (Liabo et al., 2002; Tivorsak et al., 2004).

One of the most important findings from this study in relation to artwork is the opportunity it provides for children to communicate with other children. Participants regularly report noticing the artwork that was completed by other children and appreciating it for its implied ‘message’ of support. They also appreciate it because this artwork is a sign that children and young people had been invited to participate in the creation of the environment. The inclusion of this artwork in the environment is construed by children and young people as a clear sign that this environment is for children and young people and it provides a feature through which children and young people identify with the environment. Having artwork in the hospital environment that has been completed by children and young people clearly gave participants a sense of ownership of the environment.

Another finding of importance is that the presence of artwork in the environment represents an overt message to children and young people that their welfare and needs matter to the organisation, or are even central to its considerations. The artwork is seen by participants as a deliberate organisational strategy to give children and young people something to look at that would brighten up their environment and make them feel happier. It is perceived as a tangible indication that the organisation has a caring attitude

to children and young people. As such, the artwork in the environment is a major part of the welcome message that children perceive in the environment.

Research with children and young people in or about healthcare settings consistently shows their appreciation for bright, colourful décor and artwork is usually a part of this assessment (Blumberg & Devlin, 2006; Hutton, 2002, 2003, 2005; Sharma & Finlay, 2003; Tivorsak et al., 2004). Beyond identifying children's preference for colour and artwork, most studies do not qualify children's preference further, and defined the roles that they are playing in children's experience.

**Colour.** There is less to say about colour independently of artwork in the findings from this study as the discussions about colour invariably centred on the volume of artwork. It is clear that children and young people appreciate variation in colour and at least some use of bright colours. It is also clear that any variation in colour that occurs around the hospital environment is noticed by children and young people.

As with artwork, the amount of colour in the environment is a key indicator in children and young people's estimation of the appropriateness of the environment for children and young people. Having colour in the environment is linked by participants to feeling happier, and as with artwork, it is construed as being a deliberate organisational strategy to make children and young people feel welcome in the environment.

Colour is also particularly appreciated by participants as one of the features in the environment that prevented the hospital looking and feeling like a hospital. Colour has the capacity to undermine the institutional feel of the environment.

The institutional feel of the hospital becomes increasingly important to participants as the time they spend in the environment increases. Any feature which serves to undermine participants' consciousness of being in hospital increases in importance with time. Adding more colour to the environment was frequently recommended by participants as a possible environmental improvement. The assumption that they were revealing is that children's environments should be full of colour. Other studies with children and young people in hospital settings provide the same indication (Blumberg & Devlin, 2006; Sharma & Finlay, 2003).

Other commentators also discuss the importance of colour in children's hospitals (Malkin, 1992; Olds, 1991) but there is limited research in relation to children's response to colour in paediatric environments (Blumberg & Devlin, 2006; Tivorsak et al., 2003). This includes children's real preferences for colour in hospital environments and the functions that colour plays in children's feeling of well-being and their perception of person-environment fit.

One study of relevance was carried out on children's colour-emotion associations. Boyatzis and Varghese (1994) conducted a study with 60 children aged between 4 to 7 years into children's emotional responses to nine different colours. The study found that across the colours used in the study children's emotional associations were predominantly positive, with nearly three quarters of the responses citing the positive feelings of excitement, happiness and strength. They also found that bright colours invoked more positive responses than dark colours (Boyatzis & Varghese, 1994).

Although this study was conducted with younger participants, there are two possible implications from these findings that are relevant to the current study. The first concerns the finding that overall the presence of colour invokes positive, strong and self-affirming emotional response. The second relevant finding is that if bright colours are positively associated with feeling strong and happy this may be why children in hospital prefer to have contact with bright colour in this environment. As well as contributing to patient's feeling of person-environment fit as discussed earlier, the implication is that the presence of colour has the capacity to actively contribute to children's feeling of well-being by providing support for children's positive state of mind and positive emotional response.

**Brightness.** This is another concept, which emerged in this study, but the findings reveal that there is limited consensus amongst participants as to what constitutes brightness. It is clearly a concept that is important to participants and, like colour, it is discussed in a way, which indicates that brightness is a fundamental component of children's environments in children and young people's estimations. However, the findings reveal that brightness in the environment could be a term used to refer to the amount of light, the amount of colour, the presence of artwork, the presence of plants,

and the attitude of people, in particular the staff. Children clearly have a preference for a bright environment, even if that means different things to each child.

Overall, the findings reveal that bright environments are well lit, full of visual interest and colour, have plants in them, and adults who are supportive, and whose attitude is positive. It is also clear that these are preferred environments for children and young people.

Some of these findings in relation to bright environments are corroborated by other studies in healthcare settings (Blumberg & Devlin, 2006; Liabo et al., 2002; Sharma & Findlay, 2003). However, like artwork and colour, brightness is a dimension of the paediatric environment that has not been the focus of research and warrants further exploration.

### **Spatial Variety**

Spatial variety is the term being used to discuss variation in spatial qualities and functions within a hospital environment in patients' experience. Spatial variety includes discussion on the importance of having non-medical spaces in the hospital, and of having access to outdoor areas.

**Having different places to go to.** Participants appreciate the variation in areas, functions, atmospheres and spatial qualities that occur within the hospital. This reflects the role that this variation plays in children's experience. Children and young people report using this environmental variation to help them remain interested and engaged with the environment, to support their different emotional needs and moods, and to find ways to support their desire to have different types of experiences in the environment.

The variation that is appreciated occurs on a number of levels that the built environment can influence. Aesthetic variation and its importance have already been discussed. Another form of variation that is appreciated lies in the type of areas that are included in the design. The opportunity to go to places within the hospital that are in contrast to ward areas is utilised and appreciated by all participants who are able to do this. These areas often include the recreational and entertainment areas, the food outlets and the shops. They varied from the rest of the hospital aesthetically, and in their primary

function in that they were not associated with the medical function of the hospital. They also provided experiences that were familiar and comfortable for participants which allowed them to 'feel normal' and which provided direct links to their life outside the hospital.

Providing experiences that are familiar and comfortable is discussed in the literature in relation to providing home-like qualities in the environment (Olds, 1991; Tivorsak et al., 2004). Making something more like home is linked to the softness of décor, the scale of furniture and the aesthetic qualities of the space. These aspects of the environment were not points raised by participants in this study. Carney et al. (2003) discuss the desire for familiarity and links with home life in relation to the need for continuity of care and of familiar experience. In their study they found that children appreciated having access to games and activities that could provide a link to their home life.

This finding is shared by the current study although it is extended considerably as it is not simply replicating familiar activities that children enjoy, it is replicating whole patterns of behaviour and experience such as going to a café for lunch with their family, going shopping, or having a picnic in the gardens with friends or family. In this study, children's enjoyment of these activities is linked to their familiarity but also to their capacity to let them experience control in their experience. These activities are usually self-directed and encompass the need for active engagement and interaction with the environment. They often form part of the children's and their family's self-management and coping strategies as has been discussed earlier.

Non-medical spaces within hospital environments are discussed in the literature as desirable but not essential. From the findings in the current study, it is possible to argue that they are essential to children's feeling of well-being during hospitalisation. Participants report using the variation in spaces and their functions and activities to help regulate their mood and manage their emotional response to being in hospital. Garden and entertainment areas are some of the most preferred places in the environment because they have the capacity to provide relief from the experience of hospitalisation, which helps to prevent participants from becoming emotionally overwhelmed by their own situation.

There is considerable discussion on the value of having a wide range of activities available in the environment and for the need to provide optimal levels of stimulation and distraction for children and young people in hospital (Acton et al. 1997; Blumberg & Devlin, 2006; Hutton, 2002, 2003; Lindheim, Glaser & Coffin, 1972; Olds, 1991; Tivorsak et al., 2004) as well as the need to provide opportunities for control, time management and activity choice during hospitalisation (Rivlin & Wolfe, 1985). However this does not translate into a discussion concerning the value of non-medical spaces within a hospital environment.

Blumberg and Devlin, (2006) move toward this discussion in their study in that they ask their adolescent participants to prioritise from a list, the types of additional facilities that they would prefer in a hospital environment. This is useful but it needs to be accompanied by a discussion on the merits of including these kinds of facilities in the environment in relation to children's overall experience of hospitalisation and their capacity to manage it.

Participants identify using preferred non-medical places in their efforts to manage their own emotional response and changes in mood. This reflects the work of Korpela and others (Korpela, 1989, 1992; Korpela, Kytta & Hartig, 2002; Korpela, Hartig, Kaiser & Fuhrer, 2001) into young people's use of favourite places in emotional self-regulation. In Korpela's (2002) definition of the concept of environmental regulation, he holds that "the physical environment itself can become an essential part of the process of regulating the experience of self and emotions" (p. 367). In this study environmental use and place preference is linked consistently with children's coping strategies and emotional response management. Participants often discussed using their preferred areas within the environment to help regulate their mood.

**Having contact with nature and access to outdoor environments.** Outdoor areas are some of the most preferred in the environment and the most regularly recommended as places to find peace and privacy, to escape and retreat to, and to regulate self. This finding is also supported by other research results that indicate that natural settings are often preferred places for emotional self-regulation (Korpela, 1989, 1992; Korpela et al., 2001; Owens, 1988). In this study, children and young people report using outdoor areas when they need to get away from the ward for a while, or they need some time on

their own, or time with their family. Private spaces in the Hospital are difficult to find and outdoor areas provided some of the best.

One of the major reasons, as perceived by children and young people, that having access to these areas with their different spatial qualities is so important is for the restorative experience that is inherent in having contact with nature. Children and young people in this study describe their contact with nature in restorative terms. They use their contact with nature to 'feel better' to 'feel more normal'. The findings reveal that they appreciate the colours, the softness of the green spaces and their contrast to the qualities of the built environment. They also appreciate the beauty of these spaces and their capacity to nourish their spirit, and provide a sense of peace and freedom.

Ulrich has argued that prolonged affective response to the environmental aesthetics of natural settings has the capacity to bring about restoration in patients (Ulrich et al., 1991, 1999). He has argued that these characteristics offer stress restoration and buffering or enhanced coping, which in turn improves patients' health outcomes. The design of this study has no capacity to measure health outcomes, but it is reasonable to argue, based on the findings, that children's contact with nature enhances their capacity to cope with their situation because of the way they ascribe value to this experience and the possibility of having this experience. Participants describe their regret at losing access to outdoor areas because of their illness or treatment program. Having access to the outdoors is a greatly valued opportunity. Being able to go to natural or green areas is linked by participants to feeling healthier and more normal.

Another role of outdoor spaces is in providing real environmental contrast. Common reasons given for the importance of being able to go outdoors for the contrast in environmental qualities such as being able to experience the fresh air, sunlight and contact with nature. Many studies confirm the desirability of having passive or active interaction with nature and outdoor environments for the benefits to health (Kaplan, 1992; Morris, 2003) and in particular for patients in hospital (Gesler, 1992; Sherman et al., 2005a; Ulrich & Parsons, 1992). Whilst the benefits were not measured in this study it is clear from the findings that children and young people place great value on having this access and the importance of it in their feeling of well-being in hospital.

**Adaptability and Flexibility**

The potential for adaptability and flexibility is a frequent recommendation for children's environments (Kritchevsky, Prescott, & Walling, 1977; Olds, 1979; Prescott, 1987). Mostly this recommendation is associated with the need to provide developmentally appropriate experiences and activities for a cross-section of age groups of children that may use the particular environment in question. In the context of play, learning or neighbourhood environments, providing for adaptability and flexibility constitute a way of introducing graded and varied challenges.

In the context of healing environments, there is less emphasis on the developmental benefit of the environment and a greater emphasis on the need to support healing and comfort. However, the need for adaptability and flexibility is still apparent. The findings from this study indicate that the need is linked to the length of time patients are in the environment and what their experience of hospital consists of as a result of their illness.

Children and young people who spend a lot of time in hospital as well as those who are in isolation as a result of their treatment, experienced the greater need for environmental adaptability and flexibility than the other patients in this study. In both cases, these patients are frustrated at the sameness of their experience and the lack of possible variation in their surroundings. The flexibility that these patients seek encompasses their need for greater variation in treatment routines, greater change in the available activities and facilities and greater possibility of change to their surroundings.

**Personalisation.** One of the most widely appreciated points of environmental flexibility and adaptability that patients experienced was the opportunity to personalise their bed area. The importance of being able to personalise bed spaces cannot be underestimated. This capability enables patients to reflect a little of themselves to the outside world. It has the capacity to surround them with familiar things of value, and it has the capacity to allow patients to take control of a small piece of the environment and mould it to suit their needs. This final capacity becomes increasingly important if patients have to spend a long time in hospital as they can alter their displays in response to their changing needs.

Participants who had spent a long time in hospital report enjoying being able to personalise their bed area and being able to change it as they wanted to. They report that it is important to help them feel comfortable in the environment and to stay engaged with the hospital environment. They also report its importance increases with time as homesickness and restlessness with being in hospital increase. This simple point of flexibility and adaptability in the environment was one of the most valuable ways children and young people could use to manage their time in hospital, cope with their separation from home, and breakdown the strangeness of the experience of being in hospital.

Breaking down the strangeness of being in hospital is contingent on reducing the divide between new patient and unfamiliar hospital environment. Children's ability to personalise their bed area was used to instigate and facilitate a feeling of person-environment fit and comfort in the environment. As most participants reported spending the majority of their time in hospital on their beds, being able to personalise this area is very important to them.

The importance of being able to personalise bed areas in hospital is not extensively discussed in the literature. Blumberg and Devlin (2006) found that being able to bring in personal belongings and posters to personalise the bed area, was important for the adolescent age group. This was linked to establishing their identity and their level of comfort in the environment. Being able to personalise the bed area was more important to adolescents than the appearance of the ward room and its appropriateness for age because it provided an opportunity for self-expression and manipulation of the environment.

Other commentators have stated the importance of providing the capacity in the built environment for patients to be able to bring in personal belongings by providing picture boards, lockable storage, and shelves (Acton et al., 1997; Shepley, Fournier & McDougal, 1998). However, these recommendations are not linked to a discussion about the role of personalisation or the importance of being able to bring in personal belongings in children's experience of hospitalisation.

**Key Features of the Physical Environment**

The features of a supportive physical environment identified from this study include the aesthetics, spatial variety and the capacity for adaptability and flexibility within the environment.

**Environmental aesthetics.** The three aesthetic components identified as being particularly important to children and young people in this study include artwork, colour and brightness. In combination these three components contribute greatly to children's estimation of the appropriateness of the environment for them and the child-friendliness of the environment. They also have the capacity to help children, young people maintain a positive frame of mind, and to remain positively engaged during experience of hospitalisation.

**Spatial variety.** Similarly to the role of the environmental aesthetics, being able to experience difference in the types of spaces, their functions, qualities and atmospheres within the hospital environment is essential for helping children maintain a positive frame of mind and to remain positively engaged. Providing non-medical activities and spaces within the hospital environment as well as providing access to outdoor areas and contact with nature, is also an essential support for children and young people's emotional self-regulation, and self-restoration during hospitalisation.

**Flexibility and adaptability.** The capacity to support these characteristics in the environment becomes increasingly important to children and young people who have to spend long periods in the hospital environment and for those who have to spend lengths of time in isolation. One of the most appreciated ways of including flexibility is allowing patients to personalise their bed areas. Providing patients with the capacity to alter their immediate environment provides patients with the capacity to experience control, express their identity and reveal their interests, alter the environment aesthetically and to personalise it with familiar and valued objects. The value for patients of being able to personalise their bed space lies in their capacity to feel more comfortable in the environment and less removed from their lives outside of hospital. It also reduces the strangeness of the experience of hospitalisation. Based on the findings from this study, any opportunity to increase the capacity for patients to manipulate their environment in a hospital design would be appreciated by children and young people.

## CHAPTER 13

### WHAT ARE THE ADVANTAGES OF PARTICIPATORY RESEARCH WITH CHILDREN AND YOUNG PEOPLE TO HEALTHCARE DESIGN?

#### **Children and Young People's Insight Challenges Assumptions**

**Children as passive recipients of care.** A dominant representation of patients in healthcare literature is one of a disempowered, passive recipient of care, at the mercy of a stressful, overbearing environment that affords them very little self-determination. This applies equally in the literature on adults' and children's experience. For example Ulrich's (1991a) theory of supportive healthcare design is based on the premise that patients are continually stressed by their environment and illness and that this should be the starting point for understanding patient experience.

The findings from this study argue for a very different conceptualisation of children and young people as patients in hospital. The dominant representation to emerge from this study is one of a very active, involved patient who values autonomy and agency and exercising control. It is a patient who enjoys negotiating relationships within the environment, seeking engagement with the environment, and actively managing their time in hospital for themselves, in as far as it is possible for them to do so.

These two representations are almost opposites and the significance of this lies in the potential impact of either conceptualisation on a design brief. An environment designed for passive, stressed patients conceptualised as victims of their circumstance is likely to be very different from an environment created for active, motivated patients who expect to engage with the environment and exercise self-management.

Participants in this study did not view themselves as victims or passive recipients of care, and they did not discuss being continually stressed by their diagnosis or their environment. There were incidents where they did not feel they had sufficient control over the situation, and times when they were stressed by their treatments or by pain or sickness, but this did not translate into an overall feeling of disempowerment within the whole experience. The influence of being bored and the restlessness that this could create could be described as a low level of continual stress. However, as with incidents

where patients experienced a lack of situational control, experiencing boredom did not translate into an overall feeling of being disempowered in the experience, or a feeling of being at the mercy of a stressful environment.

Instead, participants described and focused on the active strategies they constantly employed to help themselves cope and remain engaged with the environment and the experience. Most of these strategies are self-initiated and self-directed, involving all the social, physical and organisational resources children and young people could identify within the environment as being available to them. Appreciating patients' desire to manage their own experience in this way is critical as the potential for self-management needs to be supported by the resources and facilities provided in the designed environment. If not well anticipated in the designed environment then patient's potential self-management strategies may not be well supported, undermining children and young people's feeling of well-being within the hospital environment.

Understanding the holistic experience of patients in a healthcare setting has the potential to lead to a much more comprehensive notion of what constitutes supportive paediatric design. It is likely that reducing patients' stress is only one aspect of supporting patients' well-being in hospital. To focus on stress reduction within paediatric design is unlikely to lead to environments that actively support children's feeling of well-being.

As Canter (2001) and Stokols (1992, 1996) argue, supporting well-being is a much greater task than simply removing problems. Cantor (2001) argues that "there may be many indirect routes from the physical environment to our well-being and there will certainly be many non-environmental influences on our well-being, so there will never be a simple one-to-one relationship between a building and health" (p. 54). He argues that trying to support individual well-being by identifying and eliminating problems is too simplistic.

This argument is borne out by the findings from this study. Whilst children and young people could identify problems, they did not focus on the need to remove problems as being essential to their feeling of well-being in hospital. Instead, they focused on the need to sustain positive engagement, maintain a positive state of mind, feel comfortable in the environment, and on how these things could be facilitated by the environment.

Using a poor conceptualisation of who patients are and what is important to them without reference to their experience and expert knowledge has a number of potential ramifications. As well as those discussed, a passive conceptualisation of children as patients does not encourage professional groups to actively engage with children and young people and allow their experience to inform and shape healthcare environments and policies that will strive to meet their needs. When children and young people's potential input is not recognised for the contribution it can provide then this becomes a point at which children and young people are disempowered. Children and young people are socially disempowered, and at the mercy of adults' assumptions if their potential to contribute is not valued, recognised or harnessed.

The tenets of the new sociology of childhood are borne out of this realisation. This movement rejects the historical approach to children's well-being which sanctions adults' structuring of children's lives and deciding how they should be lived (Mayall, 2000). Denying the status of children as social agents denies them a fundamental right and leaves adults making decisions about children's lives from an inadequate premise of knowledge about children and their lives (Prout & James, 1990; Qvortrup, 1994).

Fundamental assumptions about *who patients are* and what the nature of their experience is like will be operating in the background of any healthcare design project. It is vital that these assumptions are informed and based on evidence from the user groups themselves as they have the capacity to make a significant impact on the final environment designed. In relation to children and young people, the potential variation in assumptions made by adults and the reality of children's experience can be great. If adults assume they have greater knowledge of childhood than children do themselves, assumptions such as the 'passive patient' will persist and lead to paediatric environments which constrain children's experience and fail to support them adequately.

**The notion of patient-centred care.** The notion of what might constitute patient-centred care that emerges from this study is a model of care that respects children's competence, their desire for inclusion and involvement in healthcare management and decision-making, and their desire for organisational support for self-help and self-

management. It is one that supports the notion of children as social agents who wish to exercise agency and control in their experience and in their environment.

Patient-centered care and family-centred care are the current models of healthcare discussed in the literature (Lindheim et al., 1972; Martin et al., 1990; Martin et al., 1998; Smith, Coleman & Bradshaw, 2002). Central to these models is a premise of respect for patients, and the need to provide comfort and social support for patients and their families throughout their experience of healthcare (Beatrice et al., 1998). In response to the evolution of these models the physical healthcare environment has become more humanised and more conscious of patient well-being and patient experience (Verderber & Fine, 2000). These changes are discussed in the literature as evidence of the empowerment of the patient and their experience within healthcare design and practice (Malkin, 1992).

In reality, most of these changes to both healthcare practice and healthcare design have not been made in response to research into patients' experience, especially in the case of children and young people. There is very little empirical evidence on children's experience of hospitalisation and whilst modern children's hospitals certainly reflect a much more patient-conscious orientation than the institutions built in the past, they still represent adults' interpretation of what children and young people need and like in their environments in large part.

Evidence-based practice and evidence-based design are the modern orientations in healthcare contexts but we cannot claim to be doing either in relation to children and young people because there is so little evidence available in relation to their experience (Morison et al., 2000).

In a study conducted by young people into young people's ability to assess quality of care, two main reasons were given for why children and young people should be asked to evaluate their care: firstly because they are the ones experiencing the care and secondly, surrounding adults are not necessarily there all the time (Moules, 2004). The supportive quote reads "my parents would not know exactly what had happened even if I told them" (p. 31). Parents' or adults' interpretation of children's experience should not be accepted as a direct account of children's experience, nor should it be accepted as

a suitable replacement for children's own accounts when children and young people are able to give their own accounts.

Notions of patient-centred care have ramifications for both the experience of hospitalisation and the nature of the built environment proposed in support of models of care. As with the conceptualisation of who the patient is, notions of patient-centered care are also problematic for children and young people if they are based on adult assumptions about what constitutes patient-centred care for children and young people with little reference to the views of children and young people themselves.

### **Children and Young People's Views Ground Adult Understanding**

**They should ask me, it's happening to me.** In this study participants clearly expected to be consulted and to be heard by surrounding adults during their hospitalisation. Adolescents in particular were very conscious of their treatment from staff, which revealed or failed to reveal their respect for them as individuals' who are competent in their own lives. Adolescents were very sensitive to the assumptions that they were 'just stupid kids' when they perceived this in the behaviour of medical staff. These participants knew they were authorities on their own experience and they expected this to command respect from surrounding adults. Likewise, younger participants also resented adults overriding their perspective on their experience. Participants had a strong sense of self and a strong sense of the respect that this should command from surrounding adults.

Ignoring children as experts in their experience undermines the soundness of research that claims to reflect children's experience, and it undermines the usefulness of the results of such research in children's lives. It also denies the researcher the opportunity to identify his or her own biases and assumptions in relation to children and childhood, which will also impact on the research.

If this study had not been participatory and had not involved children and young people in the development of the methods and subject areas of focus, the questions used would not have included many of the most informative. The researcher would also have had to make assumptions about which areas in the environment were important in children's experience and what were the key questions to ask about the experience. The

participatory developmental stages ensured that this was not necessary and that the questions used were grounded in children's experience and reflected salient attributes of it. These developmental phases also ensured that the researcher's assumptions about these things were revealed and the inaccuracies in them identified.

A specific example concerns the researcher's initial assumption ahead of the study that children's response to their own medical situation would also affect their response to the hospital environment. From the first pilot study in the Hospital which involved the walking interviews with children and young people this assumption was identified as being incorrect. Children and young people consistently managed to maintain separate assessments of both their own situation and their response to the hospital environment and these could be quite different from each other. Invariably participants would report becoming restless and resenting their own situation but not as a consequence, resenting or disliking the hospital environment. Instead, they had the capacity to go on valuing attributes of the physical environment independently of their own situation.

This example illustrates the importance of seeking children's views and challenging the assumptions made by adults about children's experience. In this instance, the impact of the discovery that the researcher's assumption was incorrect had real implications for understanding the independence yet interconnectedness of the domains of children's experience during hospitalisation. Accepting that children and young people can distinguish in their overall response between their own medical situation and the hospital environment empowers the environment in children's experience. It should also increase the importance of the environment in healthcare and design professionals' estimation. It provides them with a mandate to increase the focus on the importance of the physical environment in children's experience of hospitalisation for its capacity to counteract the influence of children's medical experience.

Participation by children and young people as a routine part of the design or research process seems obvious when creating environments where the ambition is to meet children and young people's needs. However, it is not routinely practised (Horelli, 2006). Logistically consultation with children can be time consuming, costly and difficult. Design teams in particular may not feel confident in carrying the consultation process out, nor convinced that it has the capacity to add to their understanding of their

design brief. If, in response to these constraints, children are excluded from consultative processes then the potential of a children's environment to meet the needs of children is undermined. Morison et al. (2000) argue that "it is difficult to achieve a valid understanding of a child's wishes, because of the biases and expectations that adults bring to their evaluation of the situation" (p. 115). Without evidence from children and young people themselves, adults are condemned to creating layer upon layer of unsubstantiated assumption about what constitutes a 'good environment for kids'.

Participatory research with children and young people has the capacity to provide real insight into the experience of hospitalisation from those actually experiencing it. It has the capacity to ground both paediatric design and paediatric care in real experience and remove the need for layers of assumption by adults about children's experience. The strength of participatory research with children and young people is that it provides key insight into their lived experience which is not a perspective that surrounding adults can provide. Adults' projections of their interpretation of what constitutes a supportive environment for children and young people are not what we should accept in paediatric healthcare design as a substitute for children and young people's own insight.

Adults as designers and shapers of children's experience need to recognise and acknowledge children's competence and capacity to contribute, because children's evidence has the capacity to inform paediatric healthcare practice, policy and design. Children and young people's competence and capacity to contribute to research and design needs to be consistently recognised. We need to engage with children and young people as active shapers and managers of their own lives because it will lead to healthcare environments and services that have a greater capacity to meet their needs.

**The importance of completing research in the context of the experience.** The value of participatory research in providing insight into children's lives needs recognition in both healthcare and healthcare design research. The value of participatory research with children and young people in the actual contexts of their experience is an extension of this concept, which is equally important. Accessing children and young people as participants, managing recruitment and ethical constraints in a hospital setting has been identified as very difficult, costly and time-consuming (Blumberg & Devlin, 2006; Coyne, 1998). These constraints are very real obstructions to the completion of

participatory research with children and young people in healthcare settings, but it should not act as a deterrent for researchers.

Blumberg and Devlin (2006) in their study on design issues for adolescents in hospital, used a sample of 100 school students, 30% of whom had been in hospital overnight, 5% had been hospitalised for 1 to 2 weeks and 1% had been hospitalised for 3 to 4 weeks. One of their findings was that there was no perceptible difference in answers between children who had been in hospital overnight and those who had not. However they recommended further research into the experience of adolescents who had had extended stays in hospital and even into the experience of those with overnight stays in hospital. This recommendation indicates their recognition of the importance of research being conducted in the actual context of the experience being researched.

Ideally, we should not be designing paediatric healthcare settings that do not reflect evidence from children and young people's lived experience of hospital environments. It is only through this kind of research with children and young people who can respond from an insiders perspective that we can be sure that we have identified the specific considerations which are formative in patient experience. Imagining what might be the important things in the experience of hospitalisation does not provide a substitute for research conducted with patients who have actually experienced hospitalisation.

A further consideration for why conducting research with children and young people in the context of their experience is important concerns understanding not only *what* is important but *why* it is important. Currently there is a great demand for guidance and recommendations in relation to healthcare design. Many commentators interpret this as the need to identify specific attributes within healthcare environments that should be regularly replicated or avoided in future paediatric design (Blumberg & Devlin, 2006; de Vos, 2006; Hutton, 2002, 2003, 2005; Ulrich, 1995, 2001; Ulrich & Zimring, 2004). The perceived problem with providing a list of desired environmental attributes which children and young people prefer and a list which identifies attributes to avoid, is that the potential to design a supportive paediatric environment as a result is limited unless each attribute is coupled with an understanding of why it is important and what roles it plays in children and young people's experience of hospitalisation.

Understanding why environmental features and attributes are important in patient experience and what roles they may play improves the chances that the design solution will support patient needs. Knowing more about patients' lived experience of hospital environments has the capacity to provide greater flexibility and to strengthen the possibilities of person-environment fit for patients.

The participatory nature of the current study has revealed attributes and environmental considerations, which children and young people identify as being important in their experience. It has also revealed why these attributes are important and what functions they fulfil in patients' experience. Research like this has the capacity to enrich the operating framework for designers, health professionals and policy makers working in paediatric settings by providing a conceptual framework that supports their capacity to make informed decisions.

A specific example concerns participants' preference for single or shared wardrooms. Currently there is an increasing trend in paediatric hospital design to support the design of wards that consist entirely of single rooms. This is driven largely by a medical agenda to increase infection control, although this is not well substantiated in research at present (Dowdeswell, Erskine and Heasman, 2004). In this study, half of the sample preferred single rooms and half preferred shared rooms. Sharing was preferred by participants because it provided company and prevented them from being alone and feeling lonely. Shared rooms consisting of two people were considered the optimum. Single rooms were preferred because they gave the participant control over the social contact they would have with other patients and because they gave them more privacy with their families. The findings in relation to children and young people's preferences for single or shared rooms are corroborated by findings from other studies (Blumberg & Devlin, 2006; Miller et al., 1998).

In light of the current trend for hospitals consisting entirely of single rooms, the experience of a modern paediatric hospital for many of the participants in this study would be without the social support and contact that they need, and it may even be plagued by new fears of being alone. If children's views on this subject and children's holistic needs were allowed to influence the final design preference and solution adopted, a very different design trend may be advocated.

**The Strengths of Participatory Research for Healthcare Design**

Participatory research reveals children and young people's competence in their own lives. It also reveals the unique perspective they offer on their own experience. Through participatory research children and young people show that they are active shapers and managers of their own experience, even under difficult circumstances such as prolonged visits to hospital. They have an authority and a perspective on their experience that adults cannot have, and which designers, researchers and policy makers can engage with for the benefit of healthcare practices and services, and paediatric design.

**Challenge adults' assumptions.** In particular, the strengths of participatory research with children and young people for healthcare design lie in its capacity to challenge adult assumptions about children's lives and challenge adult's depictions of them. This in turn will challenge the way they conceive of accommodating children and young people within any design.

**Ground adults' understanding.** Participatory research also has the capacity to ground adult understanding in the reality of children's experience rather than the imagined reality of children's experience. This also identifies the importance of completing research with children and young people in the contexts in which their experience is taking place.

## CHAPTER 14

### STRENGTHS, LIMITATIONS AND FURTHER RESEARCH

#### **Strengths**

The aims for this study were ambitious, but it is reasonable to suggest that the study makes useful contributions to them all. The depth and quality of children's data has enabled preliminary definitions of what constitutes a supportive paediatric hospital environment and what comprises children's feeling of well-being in a paediatric setting to be proposed. Components within the physical environment have also been identified for their role and function in a supportive paediatric environment, and in children's feeling of well-being in a paediatric setting.

The findings also support the proposition that participatory research with children and young people has the capacity to provide unique insight into children and young people's experience. The study illustrates the opportunity and benefit to knowledge of seeking children's response to their own lives. The potential for further participatory research is identified, and recommendations are made for supportive paediatric hospital design.

#### **Limitations**

Completing research in a healthcare environment is a challenge. There were a number of methodological considerations that may have affected the results of this study. Many of these were introduced by the nature of the context. Others were introduced by the research design.

Conducting interviews with children and young people at their bedsides meant that there was constant interruption and little privacy at times. Finding alternative places to interview participants that were not medical spaces and had some privacy in the hospital environment was also very difficult. Using the small interview rooms on the wards which some patients also visited to receive information about their diagnosis was not ideal. It meant that these rooms may have become difficult places to spend time for some participants, however these were often the only option for privacy. The implication of this is that children and young people may not have been as comfortable or relaxed in these interviews as they might have been in another space.

The unpredictable nature of patients' time in hospital also made it difficult to carry out member-checking exercises with the participants following each interview and this process was discontinued approximately a third of the way into the main study interviews. The impact of this was that the researcher's interpretation of the remaining interviews was unchecked by the participants themselves. The alternative member-checking exercise used at the end of data analysis with a group of patients whose profile was representative of the initial sample group was a useful and informative step but it cannot be said to be the same and serve the same function as a more traditional member-checking exercise.

It is unfortunate that a greater number of younger children did not decide to participate. It is not possible, however, to say how this may have affected the results of the study. The initial aim of the study was to explore the experience of patients aged 7-18 years but in the end the majority of participants were aged 11-17 years.

Deciding to allow children and young people to set the parameters of the physical environment that would be discussed in this study meant that there was a risk that not all types of area in the Hospital may be included. In the end no clinical or medical area was included and the information regarding children and young people's experience of these areas and their response to them is limited.

### **Recommendations for Further Research**

There are several recommendations for further research. The preliminary proposals of what constitutes a supportive paediatric environment and what are the main components of children's feeling of well-being in a paediatric setting are both worthy of further exploration and evaluation in larger, possibly multi-site studies. Through larger studies it would be possible to evaluate the transferability of these concepts as defined in this study, and to add additional qualification to both proposals.

There is also an opportunity for further research to evaluate the relevance of these preliminary definitions of a supportive environment and of what constitutes children's feeling of well-being based on age, gender, cultural background and diagnosis. Variation based on some of these variables, in particular age, gender and diagnosis, was apparent in the findings from this study and warrants further exploration.

It would also be possible based on the findings from this study to develop a preliminary indicator framework for measuring children and young peoples' feeling of well-being in a paediatric setting. The findings from this study resulted in a preliminary hierarchy of domains, themes and dimensions that could be used as the basis for the development of a well-being indicators framework for either a patient satisfaction measure or a well-being measure.

The salient components of the physical environment identified in this study and their roles and functions in children's experience are also worthy of further evaluation and qualification. This includes the conceptualisation of what constitutes child-friendliness in a paediatric hospital environment. It also includes a greater specification of the characteristics of environmental aesthetics, variation, adaptability and flexibility within a paediatric environment which children and young people would find supportive and why. Many of the findings from this study are not sufficiently specific to greatly contribute to designers' understanding of how these concepts should be translated into the built environment. Further research into the attributes identified in this study could produce further layers of useful specification for designers.

## CHAPTER 15

### CONCLUSIONS AND RECOMMENDATIONS

This chapter will offer a synthesis of some of the findings and preceding discussion. The focus of this summary will be on identifying the major theoretical propositions and the design recommendations for a supportive paediatric hospital environment emerging from the study.

#### Theoretical Propositions

**Proposition 1: Defining a supportive paediatric environment.** There are four theoretical propositions that have resulted from this study. The first major proposition that emerged from this study concerns what constitutes a supportive paediatric environment. A preliminary definition of a supportive environment includes:

- An environment that supports children's feeling of well-being by addressing their need to feel comfortable in the environment, maintain a positive frame of mind, and remain positively engaged.
- An environment that facilitates children's goodness of fit by supporting individual choice, control and self-help, and by minimising unwanted distractions.
- An environment that provides children and young people with the perception of environmental congruence by maximising the opportunities to include features which indicate child-friendliness. These include maximising the volume of age-appropriate activities in the environment, providing a bright and colourful environment, and a welcoming and friendly social environment.

**Proposition 2: Defining what constitutes children's feeling of well-being.** The first proposition encompasses two other theoretical propositions. The first of these includes a preliminary definition of what constitutes children's feeling of well-being. This study reveals that this concept is a subjective and fluctuating self-assessment that encompasses three principal components including:

- Children's capacity to feel comfortable in the environment where comfort is understood to be comprised of physical, social and emotional considerations.

- Children's capacity to maintain a positive frame of mind that encompasses their capacity to minimise the impact of difficulty and boredom, and maximise the opportunity of having positive and entertaining experiences.
- Children's capacity to remain positively engaged which encompasses children's active involvement and participation in their experience of hospitalisation, enabling them to exert control, and to experience competence and empowerment.

**Proposition 3: Defining a child-friendly paediatric environment.** The second proposition encompassed in the definition of the nature of a supportive paediatric environment is the concept of a child-friendly environment. This is an environment that children and young people perceived as being 'good for kids' which means that it is perceived as welcoming, comfortable and appropriate for children and young people. It contains three principal features.

- Age-appropriate, entertaining and engaging activities (a large volume and selection of things to do)
- Bright, colourful aesthetics including artwork (providing variation, interest and colour, and 'messages' of welcome and support)
- Welcoming, friendly and a positive response from the hospital community (part of the need for a supportive social environment)

**Proposition 4: Conceptualising children as active shapers and managers of their experience in hospital.** The final proposition that has emerged from this study concerns the conceptualisation of children and young people as active shapers, managers and negotiators of their experience whilst in hospital. This proposition is in-keeping with the sociological conceptualisation of children as social agents in their own lives (Prout & James, 1990). This proposition encompasses children's preference for inclusion and participation in all aspects of their experience and their expectation of active self-management as far as possible. This proposition also has methodological implications in that it suggests participatory methodologies as an ideal way of acknowledging and understanding children's role in their experience.

## **Design Recommendations**

There are three major areas of design recommendations to result from this study. These include environmental aesthetics, spatial variety and the need for adaptability and flexibility in the environment.

### **Design recommendation 1: Understanding the roles of environmental aesthetics.**

The environmental aesthetic features that were discussed in this study included artwork, colour and brightness. Through these three aesthetic elements, children and young people perceive messages of welcome, comfort, appropriateness and fun. In combination, these three elements help children and young people to sustain a positive frame of mind and to remain positively engaged, both of which directly contribute to their feeling of well-being. The key features in relation to each of the three elements include:

- **Artwork:** Art should be age-appropriate and without simplistic images associated with young children. It should include artwork completed by other children and young people as this artwork in particular conveyed messages of support and welcome and the importance of children's welfare to the organisation.
- **Colour:** The environment should include a large amount of colour (preferably bright colour) and this should vary around the environment.
- **Brightness:** Brightness is a nebulous concept that represents a composite assessment of a range of environmental features that potentially involves many different aspects of the environment including the need for a lot of colour, light and plants in the environment. Anything in the environment can contribute to the assessment of brightness ranging from the social attitudes of the hospital community to the colour of carpet and furniture, and the size and placement of windows and skylights.

### **Design recommendation 2: Recognising the importance of spatial variety and function.**

Spatial variety encompasses the need for non-medical places and spaces offering a range of different activities, atmospheres and spatial qualities, including outdoor and natural areas. This spatial variation provides a key role in enabling patients to meet their needs for environmental contrast, emotional self-regulation and self-

restoration and to exercise control and self-management. Specifically these recommendations include:

- Providing facilities which enable children and young people to carry out normal routines with their friends and family, such as cafes, shops, common room areas, play areas and age-appropriate areas for socialising (particularly for adolescents).
- Providing access to outdoor areas and natural environments for contrast and to enable patients to escape and to experience a restorative environment. Natural places are preferred areas and play a key role in patients' emotional self-regulation and self-restoration as well as providing greatly appreciated environmental contrast with the indoor environment of the hospital.

**Design recommendation 3: Recognising the value of flexibility and adaptability in paediatric design.** Providing flexible and adaptable environments or environmental attributes means providing patients with the capacity to alter their immediate environment. This translates into providing patients with the capacity to experience control, express their identity and reveal their interests, alter the environment aesthetically, and to personalise it with familiar and valued objects. Being able to personalise their bed area was the best representation of this in this study. The value in being able to do this for patients lies in their capacity to feel more comfortable in the environment and less removed from their lives outside of hospital. It also reduces the strangeness of the environment and the experience of hospitalisation. Any opportunity to increase the capacity for patients to manipulate their environment in a hospital design would be appreciated by children and young people.

### **Final Comments**

In discussing the journey of this research, it is hoped that others will be encouraged to carry out further exploration of children and young people's experience of healthcare settings. Completing research in a healthcare context is difficult but in this instance, the generous participation of children and young people has provided rich insight into their experience of a paediatric hospital setting. Gaining children and young people's insight into their experience can only enrich our understanding, and our capacity to provide hospital environments that support their needs.

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## APPENDIX A

## Participant information and consent forms and parents information and consent forms for Pilot Study 1

## Participant Information Sheet

**PhD Research Project**  
Participant Information Sheet: Pilot Study 1**Hi!**

My name is Kate and I am inviting you to take part in an exercise that is part of my research project. This sheet contains information which will help you decide whether you would like to take part.

**How can I help?**

You are being asked to take me on a tour around your home or backyard or parts of your neighbourhood, showing me the places that you would normally go to and the places that are important to you so that we can talk about them. Anything you tell me will not be told to anyone else.

**What will I be asked to do?**

As we walk around the neighbourhood you will simply be asked to talk to me about the places we visit. You will be asked to carry a walkman and wear a microphone so that your conversation with me can be recorded. This is so that I can listen to what you have said later on. The walk will take about half an hour or so to complete.

**Who can I talk to about it?**

You can ask me *any* questions you like. Just remember you don't have to do this and no one minds if you decide not to, and if you change your mind during the walk you can pull out at any time. Keep this sheet in case you want to call me.

My phone number: Kate Bishop 0407 454 261

## Participant consent form: Pilot Study 1



The University of Sydney

Faculty of Architecture

SYDNEY NSW 2006 AUSTRALIA

College of Sciences and Technology

*Environment, Behaviour & Society Research Group*

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**Consent Form – Participants  
For Pilot Study 1 (neighbourhood walk)**

**Project Title:** From their perspectives: Children and young people’s experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney. Telephone: (02) 9351 8765 or 0407 454 261

Margaret Wallen Senior Occupational Therapist-Research,  
The Children’s Hospital at Westmead. Telephone: 9845 0000

Professor Gary Moore, Dean, Faculty of Architecture, University of Sydney  
Assoc. Professor David Evans, Faculty of Education and Social work, University of Sydney

By giving my consent I understand:

1. What the exercise is all about and what I will be doing in it.
2. That I don’t have to participate if I don’t want to and that I can pull out at any time.
3. That any information I give today will not be reported with my name or any other personal information that would identify me.
4. That I have read the information sheet and had time to talk about it with my family and friends.
5. That I can ask the researcher any questions I have about the study at any time.

Name of Participant \_\_\_\_\_

Verbal consent given: YES NO OR

Signature of Participant \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_ (Please Print)

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

Researcher’s name: Kate Bishop

Researcher’s Signature \_\_\_\_\_ Date: \_\_\_\_\_

## Parent Information Sheet: Pilot Study 1



The University of Sydney

SYDNEY NSW 2006 AUSTRALIA

*Environment, Behaviour & Society Research Group*

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### Research Information Sheet – For Parents or Guardians For Pilot Study 1 (home environment walk)

**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney. Telephone: (02) 9351 8765 or 0407 454 261

Professor Gary Moore, Dean, Faculty of Architecture, University of Sydney  
Assoc. Professor David Evans, Faculty of Education and Social work, University of Sydney

Margaret Wallen Senior Occupational Therapist-Research,  
The Children's Hospital at Westmead. Telephone: 9845 0000

I invite you to consider giving consent for your child to participate in a research exercise that will be conducted under the guidance of the Occupational Therapy Department at The Children's Hospital Westmead and as part of doctoral research being carried out by Kate Bishop, Faculty of Architecture, University of Sydney.

#### The Purpose of the Research

We need to understand what designers need to know in order to design physical environments which support the health, development and well-being of children with special needs. The aim of this particular study is to understand the experience of children and young people in a hospital environment, so that this can improve healthcare design in the future. One of the best ways to do this is to ask the children themselves what is important to them in their interaction with the physical environment.

The findings from this study will be used to complete a doctoral degree and to make recommendations which could contribute to the development of guidelines for designers of hospital and healthcare facilities which take into consideration the needs and wants from the physical environment, as expressed by the children and young people themselves.

#### The Purpose of the pilot study

The aim behind this pilot study is to begin to develop language concerning the environment and children's interaction with it which can be used in the interviews with participants in the main study. Using language and terminology which is relevant and appropriate to each age group is important for the success of the interviews.

The researcher proposes to take a few children spanning the age range of the participants in the main study on a walk through the neighbourhood, visiting the places they would normally visit and places that are important to them. The researcher will introduce subjects for conversation such as: What would you do here? How would you describe this place to a friend? What are the things you like about this place? What are the things you don't like about this place? These conversations will be recorded on walkmans which each child will be given for the exercise, and later analysed by the researcher.

**Risk to the participants**

There are no foreseeable risks to participants.

**Personal Information and confidentiality**

Your child's name, age, gender will be known by the researcher. However, no published material will contain information which allows an individual to be identified. All data collected in this study will be kept in locked storage by the researcher for five years and will then be destroyed.

**Other Information**

Participation in this exercise is voluntary.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with Kate Bishop or with Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee which has approved this project.

This information sheet is for you to keep. You will also be given you a copy of the signed consent form if you choose to let your child participate in this project.

## Parent/ guardian consent form: Pilot Study 1



The University of Sydney

Faculty of Architecture

SYDNEY NSW 2006 AUSTRALIA

College of Sciences and Technology

*Environment, Behaviour & Society Research Group*

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<http://www.arch.usyd.edu.au/hwfa/research>

### Consent Form – For Parents and Guardians For Pilot Study 1 (home environment walk)

**Research Title:** From their perspectives: Children and young people's experience of a paediatric Hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney. Telephone: (02) 9351 8765 or 0407 454 261

Professor Gary Moore, Dean, Faculty of Architecture, University of Sydney  
Assoc. Professor David Evans, Faculty of Education and Social Work, University of Sydney

Margaret Wallen, Senior Occupational Therapist-Research, The Children's Hospital at Westmead. Telephone: 9845 0000

In signing this form I understand:

1. The nature of the exercises and the nature of my child's participation in the exercise.
2. Participation in this project is voluntary.
3. That this research has been approved by both the Ethics Committee at The Children's Hospital, Westmead, and the University of Sydney Human Ethics Committee.
4. That any information obtained through this exercise, will not contain any personal information concerning the participant which enables them to be identified.
5. I understand that any person with concerns about the conduct of this exercise can contact Kate Bishop or Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee at The Children's Hospital, at any time to discuss them.

I have read and understand the information sheet and this consent form and give my consent for my child to participate in this research study.

Name of Child \_\_\_\_\_ (Please print)

Name of Parent or Guardian \_\_\_\_\_ (Please print)

Signature of Parent or Guardian \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_ (Please Print)

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX B

## Participant information and consent forms and parents information and consent forms for Pilot Study 2A

## Participant Information Sheet

**Research Project: The Children's Hospital Westmead  
Participant Information Sheet: Pilot Study 2, Part A**

**Hi!**

My name is Kate and I am inviting you to take part in an exercise that is part of my research project. This sheet contains information which will help you decide whether you would like to take part.

**The Research Project: What's it all about?**

I want to know how kids feel about the hospital environment and what they would like designers to know when they are designing hospitals for kids in the future.

**How can I help?**

You are being asked to take me on a tour around the hospital, showing me the places that you would normally go to and the places that are important to you so that we can talk about them and take photographs of them. Anything you tell me will not be told to anyone else.

**What will I be asked to do?**

As we walk around the hospital you will simply be asked to talk to me about the places we visit. You will be asked to put on a walkman and microphone so that your conversation with me can be recorded. This is so that I can listen to what you have said later on.

You will also be asked to take photographs of places that are important to you with a disposable camera that will be given to you. These things will be given back to me at the end of the walk. The walk will take about an hour to complete.

**Who can I talk to about it?**

Talk about it with your family or friends. You can ask me *any* questions you like about the project. Just remember you don't have to do this and no one minds if you decide not to, and if you change your mind during the walk you can pull out at any time. Keep this sheet in case you want to call me. My phone number: Kate Bishop 0407 454 261






**Participant Consent Form: Pilot Study 2A**



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ABN 53 188 579 090

**Consent Form – Participants**  
**For Pilot Study 2, Part A. (involving patients)**

**Project Title:** From our perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD student, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney  
Phone: (02) 9351 8765 or 0407 454 261  
  
Margaret Wallen, Senior Occupational Therapist – Research  
The Children's Hospital at Westmead  
Phone: (02) 9845 6038  
  
Professor Gary Moore, Dean, Faculty of Architecture,  
University of Sydney

By giving my consent I understand:

- 6. What the exercise is all about and what I will be doing in it.
- 7. That I don't have to participate if I don't want to and that I can pull out at any time.
- 8. That whatever I decide to do won't affect the care I get in hospital.
- 9. That any information I give today will not be reported with my name or any other personal information that would identify me.
- 10. That I have read the information sheet and had time to talk about it with my family and friends.
- 11. That I can ask the researcher any questions I have about the study at any time.

Name of Participant \_\_\_\_\_

Verbal consent given:      YES                      NO                      OR

Signature of Participant \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_ (Please Print)

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

## Parent/Guardian Information Sheet: Pilot Study 2A

the  
children's  
hospital at Westmead

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ABN 53 188 579 090

### Research Information Sheet – For Parents or Guardians For Pilot Study 2, Part A. (involving patients)

**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney  
Telephone: (02) 9351 8765 or 0407 454 261

Margaret Wallen Margaret Wallen Senior Occupational Therapist-Research, The Children's Hospital at Westmead  
Phone: (02) 9845 6038

Professor Gary Moore, Dean, Faculty of Architecture, University of Sydney

I invite you to consider giving consent for your child to participate in research that will be conducted under the guidance of the Occupational Therapy Department at The Children's Hospital Westmead and as part of doctoral research being carried out by Kate Bishop, Faculty of Architecture, University of Sydney.

### The Purpose of the Research

We need to understand what designers need to know in order to design physical environments which support the health, development and well-being of children with special needs. The aim of this particular study is to understand the experience of children and young people in a hospital environment, so that this can improve healthcare design in the future. One of the best ways to do this is to ask the children themselves what is important to them in their interaction with the physical environment.

The findings from this study will be used to complete a doctoral degree and to make recommendations which could contribute to the development of guidelines for designers of hospital and healthcare facilities which take into consideration the needs and wants from the physical environment, as expressed by the children and young people themselves.

### The Purpose of the Pilot Study

There are three aims behind this pilot study. The first is to develop language concerning the environment of the hospital and children's interaction with it which can be used in the interviews with participants in the main study. Using language and terminology which is relevant and appropriate to each age group is important for the success of the interviews. The second aim is to identify the areas in the Hospital that children use and

why. The third aim is to generate photographs of the Hospital environment, which are also needed for use in the interviews in the main study.

The researcher proposes to take a few children spanning the age range of the participants in the main study on a walk through the hospital environment, visiting the places they would normally visit and places that are important to them. The researcher will introduce subjects for conversation such as: What would you do here? How would you describe this place to a friend? What do you notice about this place? What are the things you like about this place? What are the things you dislike about this place? These conversations will be recorded on a walkman which each child will be given for the exercise, and later analysed by the researcher.

The participants will also be given disposable cameras and asked to photograph places of importance to them. These photographs will form the basis of a set to be used in the main study to help participants identify where they have been in the Hospital.

**Risk to the participants**

There are no foreseeable risks to participants. However a plan has been developed to respond to any medical or emotional need that arises for participants during the exercise which includes alerting relevant personnel within the hospital.

**Personal Information and confidentiality**

Your child's name, age, gender and illness will be known by the researcher. However, the confidentiality and anonymity of all participants will be preserved as each participant will be given a pseudonym which will be associated with their information throughout the study. Personal information and information from this exercise will be kept separately and no published material will contain information which allows an individual to be identified. All data collected in this study will be kept in locked storage by the researcher for five years and will then be destroyed.

**Other Information**

Participation in this exercise is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect your child's care at the hospital.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with Kate Bishop or with Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee which has approved this project.

This information sheet is for you to keep. You will also be given you a copy of the signed consent form if you choose to let your child participate in this project.

## Parent/Guardian Consent Form: Pilot Study 2A

the  
children's  
hospital at Westmead

### Consent Form – For Parents and Guardians

For Pilot Study 2, Part A. (involving patients)

**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD student, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney.  
Phone: (02) 9351 8765 or 0407 454 261

Margaret Wallen, Senior Occupational Therapist –Research  
The Children's Hospital at Westmead Phone: (02) 9845 6038

Professor Gary Moore, Dean, Faculty of Architecture,  
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ABN 53 188 579 090

In signing this form I understand:

1. The nature of the exercises and the nature of my child's participation in the exercises.
2. Participation in this project is voluntary and if I decide not to take part or decide to withdraw at any time this will not otherwise affect my child's care at the hospital.
3. That this research has been approved by both the Ethics Committee at The Children's Hospital, Westmead, and the University of Sydney Human Ethics Committee.
4. That any information obtained through this exercise, will not contain any personal information concerning the participant which enables them to be identified.
5. I understand that any person with concerns about the conduct of this exercise can contact Kate Bishop or Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee at The Children's Hospital, at any time to discuss them.

I have read and understand the information sheet and this consent form and give my consent for my child to participate in this research study.

Name of Child \_\_\_\_\_ (Please print)

Name of Parent or Guardian \_\_\_\_\_ (Please print)

Signature of Parent or Guardian \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_ (Please print)

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX C

## List of direct questions used in Pilot Study 2B

Domains	Subject areas (broad & specific)	Possible questions for main study interview
Personal	Personal control <ul style="list-style-type: none"> <li>Situational control over physical environment</li> <li>Situational control over social environment</li> </ul>	1. Do you think you have enough freedom to do things as you want to here?
	Personal Respect <ul style="list-style-type: none"> <li>For patient privacy</li> <li>Confidentiality</li> </ul>	2. How about your privacy, do you feel they respect that?
	Effect of illness <ul style="list-style-type: none"> <li>Influential on psychological and physiological health and feeling of wellness</li> <li>The worry of treatments and procedures</li> </ul>	3. Do you have good days and bad days? What makes it a bad day? Does the way you feel change what you think of the Hospital? 4. What about your medical treatments? Do they worry you?
	Personal safety <ul style="list-style-type: none"> <li>Whether they feel safe in hospital environment</li> </ul>	5. Do you feel safe in the hospital?
	Response to environment <ul style="list-style-type: none"> <li>Like/dislike environment</li> </ul>	6. Do you like the Hospital environment? What do you like/dislike about it? 7. Do you think this is a good hospital for kids? Why?
	Reflection on Experience <ul style="list-style-type: none"> <li>Reflection on experience</li> </ul>	8. What do you find the hardest thing about being in hospital? 9. What would be the thing that you would most like to change?
	Emotional self-regulation <ul style="list-style-type: none"> <li>Coping emotionally</li> <li>Keeping busy (to avoid boredom &amp; avoid introspection)</li> </ul>	10. When things start to get too much for you, how do you handle that? 11. Do you like to keep busy? Why?
Organisational	Organisational rules and restrictions <ul style="list-style-type: none"> <li>Patients' consciousness of them</li> <li>Freedom to move around and use the environment</li> </ul>	12. Are there rules and restrictions you have to follow here? How do you feel about those?
	Access to information <ul style="list-style-type: none"> <li>Being kept informed</li> </ul>	13. Do the doctors and nurses tell you what's going on? Is it important to you to know what's going on?
	Being consulted and being heard <ul style="list-style-type: none"> <li>Participating in their own healthcare management</li> </ul>	14. Do you feel the doctors and nurses listen to you when you want to tell them things?
Social	Social support <ul style="list-style-type: none"> <li>From family</li> <li>Friends (outside)</li> <li>Friends (inside)</li> <li>Staff (nursing and others)</li> </ul>	15. When your family comes to see you, what kind of things do you like to do with them? 16. How important is it making friends in the hospital? What kind of things do you do with them?
	Social interaction <ul style="list-style-type: none"> <li>With family</li> <li>Friends outside</li> <li>Friends inside</li> <li>Staff</li> </ul>	17. Do you have contact with your friends outside the hospital? Is this important to you? 18. Do you talk with the hospital staff? Who would you normally talk to? 19. Who would you normally turn to when you need someone to talk to?
	Age-appropriate activities <ul style="list-style-type: none"> <li>Social</li> </ul>	20. Do you think they have enough activities and entertainment for kids you age here? What would you change?

## List of direct questions used in Pilot Study 2B (continued).

Physical	Provide age-appropriate spaces	<ul style="list-style-type: none"> <li>Particularly in the case of adolescents</li> </ul>	21.
	Provide for comfort and welcome (sensitivity to the environment)	<ul style="list-style-type: none"> <li>Through furnishings, colour schemes</li> <li>Through providing optimal levels of stimulation</li> </ul>	22. How would you describe this Hospital environment to a friend? 23. What do you think you notice when you go around the Hospital?
	Access to outdoors & nature	<ul style="list-style-type: none"> <li>Access to sunlight and fresh air and gardens</li> </ul>	24. Is being able to go out into the gardens important to you? Why?
	Design configuration	<ul style="list-style-type: none"> <li>Needing a variety of spaces</li> <li>Shared vs. single rooms</li> <li>A place to retreat to</li> </ul>	25. Do you think it is good to have different places to go to in the Hospital? Why? 26. Would you rather share a room or be on your own? Why? 27. When you want to be by yourself, where do you go?
	Reduce noise	<ul style="list-style-type: none"> <li>Reduce background noise</li> <li>Reduce environmentally induced noise (due to poor materials, design configurations – multi-bed rooms, and communication systems)</li> </ul>	28. Is the Hospital noisy? Does noise bother you?
	Make the environment aesthetically pleasing	<ul style="list-style-type: none"> <li>Contact with artwork</li> <li>Contact with music</li> <li>Contact with comedy and entertainment</li> <li>Through colour scheme, floor coverings, furniture and curtains (Influential in patient satisfaction with quality of care)</li> </ul>	29. Do you notice the pictures and sculptures around the Hospital? What do you think about having them? 30. Do you notice colour? Do you notice brightness? What makes a place bright?
	Reduce spatial disorientation	<ul style="list-style-type: none"> <li>Clear wayfinding (4 levels: organisational, local &amp; external building cues, global structure)</li> </ul>	31. How do you find your way around? Is it easy or hard?
	Personalisation	<ul style="list-style-type: none"> <li>Personalising bed space</li> </ul>	32. What do you think about having your own things around your bed?
Time	Reduce length of stay	<ul style="list-style-type: none"> <li>Understanding the effect of time</li> <li>Minimising the impact of time</li> </ul>	33. When you're in here for a long time, does that change the way you feel about being in hospital?

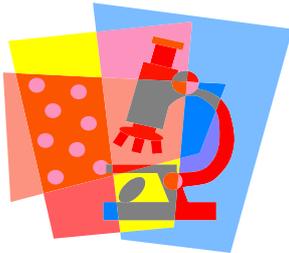
*Note.* Subject areas in black text in columns two and three are those indicated by the literature (from a combination of research with children and adults).

*Note.* Subject areas in red text are additions resulting from the findings of Pilot Studies 2A and 2B.

## APPENDIX D

## Participant information and consent forms and parents information and consent forms for the main study

## Participant Information Sheet for participants aged 7-11 years

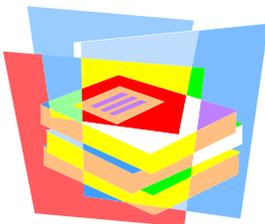
Research Project: The Children's Hospital Westmead  
Participant Information Sheet**Hi!**

My name is Kate and you are being asked if you would like to take part in my research project. This sheet will give you information that will help you decide whether you would like to take part.

**What's it all about?**

I want to know how kids themselves feel about the hospital and what they would like designers to know when they are designing hospitals for kids in the future.

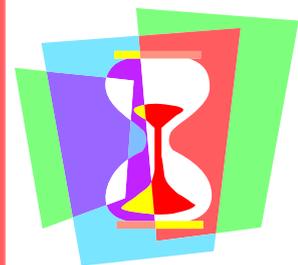
In this project I am asking kids what they think about the hospital environment. Things like what they like or don't like about the hospital? Where they have been in and around it? What they did in each place?

**How can I help?**

You can help by telling me all about your time in hospital. Whatever you tell me will not be told to anyone else.

**What will I be asked to do?**

If you decide to take part I will ask you to talk with me for half an hour. We will start by looking at some photos of the hospital and you can tell me if you have been to the places in them so that I can make a map of where you have been in the hospital. After that I will ask you a few more questions about your time in hospital and finally, I will also ask you to complete a small game. Your answers will be recorded on a tape recorder so that I can listen to them again later. The best part is that there are no wrong answers!

**Who can I talk to about it?**

Take some time and talk about it with your family or friends. You can ask me *any* questions you like about the project. Just remember you don't have to do this and no one minds if you decide not to, and if you change your mind during the interview you can pull out at any time. Keep this sheet in case you want to call me. My phone number: [Kate Bishop 0407 454 261](tel:0407454261)

## Participant Information Sheet for participants aged 12-19 years

### Research Project: The Children's Hospital Westmead Participant Information Sheet



Hi, my name is Kate and you are being asked if you would like to take part in my research project.

This sheet will give you information which will help you decide whether you would like to participate.

#### What's it all about?

I want to know how children and young people themselves feel about the hospital environment, so that this can influence how designers think about designing paediatric hospitals in the future.

In this project I am asking participants questions about the hospital environment. Including subjects such as what they like or don't like about the hospital? Where they have been in and around it and why they went there? What did they do in each place?

Your identity and everything you tell me will be kept totally confidential.

#### What will I be asked to do?

If you decide to take part I will ask you to talk with me for up to an hour. We will start by sorting through some photos of the hospital. You will be asked to say which areas you have been to so that I can make a map of where you have been in the hospital. After that I will ask you a few more questions about your time in hospital and finally, I will ask you to complete a sorting task. Your answers will be recorded on a tape recorder so that I can listen to them again later. There are no wrong answers. I am just seeking your opinion on the hospital environment.

#### Who can I talk to about it?

Take some time and talk about it with your family or friends. You can ask me *any* questions you like about the project. Just remember your participation is voluntary and no one minds if you decide not to participate, and if you change your mind during the interview you can pull out at any time. Keep this sheet in case you want to call me. My phone number: Kate Bishop 0407 454 261



**Participant Consent Form: Main study**

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and Hainsworth Street  
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ABN 53 188 579 090

**Consent Form – Participants  
For the Main Study**

**Project Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD student, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney.  
Phone: (02) 9351 8765 or 0407 454 261

Margaret Wallen, Senior Occupational Therapist-Research,  
The Children's Hospital at Westmead, Tel: 9845 0000

Professor Gary Moore, Dean, Faculty of Architecture,  
University of Sydney.

By giving my consent I understand:

1. What the study is all about and what I will be doing in it.
2. That I don't have to participate if I don't want to and that I can pull out at any time by asking my parent/guardian to notify the investigator by telephone.
3. That whatever I decide to do won't affect the care I get in hospital.
4. That any personal information such as my name and address or anything to do with my illness will not be given out to anyone or included in publications in a way that will identify me.
5. That I have read the information sheet and had time to talk about it with my family and friends.
6. That I can ask the researcher any questions I have about the study at any time.

Name of Participant \_\_\_\_\_

Verbal consent given:      YES                      NO                      OR

Signature of Participant \_\_\_\_\_

Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_ (Please Print)

Signature of Witness \_\_\_\_\_

Date: \_\_\_\_\_

## Parent/Guardian Information Sheet: Main study

the  
children's  
hospital at Westmead

### Research Information Sheet – For Parents or Guardians For Main Study

**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney.  
Telephone: (02) 9351 8765 or 0407 454 261

Margaret Wallen Margaret Wallen Senior Occupational Therapist-Research, The Children's Hospital at Westmead  
Tel: 9845 000

Professor Gary Moore, Dean, Faculty of Architecture, University of Sydney

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I invite you to consider giving consent for your child to participate in a research project that will be conducted under the guidance of the Occupation Therapy Department at The Children's Hospital Westmead and as part of doctoral research being carried out by Kate Bishop in the Faculty of Architecture, University of Sydney.

### The Purpose of the Research

We need to understand what designers need to know in order to design physical environments which support the health, development and well-being of children with special needs. The aim of this particular study is to understand the experience of children and young people in a hospital environment, so that this can improve healthcare design in the future. One of the best ways to do this is to ask the children themselves what is important to them in their interaction with the physical environment.

The findings from this study will be used to complete a doctoral degree and to make recommendations which could contribute to the development of guidelines for designers of hospital and healthcare facilities which take into consideration the needs and wants from the physical environment, as expressed by the children and young people themselves.

### Who can be involved in this study and how will they be asked to participate?

Eligible participants are children and young people aged between 7-19 years of age who speak English and have been in the hospital for at least 7 days on this visit.

They will be asked to participate in a semi-structured interview which may last approximately 30 minutes. There are no right or wrong answers. The aim is simply to seek children and young people's views on the Hospital environment.

Within each interview children will be asked to work through a series of photographs of the hospital environment, acknowledging each area they have visited and saying why they went there. They will then be asked a few questions about their response to being in hospital, and their response to the Hospital environment itself. Finally they will be asked to complete a drawing task which will include making a map of the hospital.

**Risk to the participants**

There are no foreseeable risks to participants. However a plan has been developed to respond to any medical or emotional need that arises for participants during an interview which includes alerting relevant personnel within the Hospital. In the case of a severe problem the interview will be brought to a close immediately.

**Benefits to participants**

Whilst there will be no direct benefits for the children and young people participating in this study in terms of immediate environmental improvements, they will be contributing to an understanding that will have long term benefits for other children.

**Personal Information and confidentiality**

Your child's name, age, gender, and illness will be known by the investigator. However, the confidentiality and anonymity of all participants will be preserved with each participant choosing a pseudonym which will be associated with their information throughout the study. Personal information and interview information will be kept separately and no published material will contain information which allows an individual to be identified. All data collected in this study will be kept in locked storage by the principal investigator (Kate Bishop) for five years and will then be destroyed.

**Other Information**

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect your child's care at the hospital.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with Kate Bishop or with Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee which has approved this project.

This information sheet is for you to keep. You will also be given you a copy of the signed consent form if you choose to let your child participate in this project.

## Parent/Guardian Consent Form: Main Study

the  
children's  
hospital at Westmead

**Consent Form – For Parents and Guardians  
For the Main study**

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**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being

**Investigators:** Kate Bishop, PhD student, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney  
Phone: (02) 9351 8765 or 0407 454 261

Margaret Wallen, Senior Occupational Therapist- Research  
The Children's Hospital at Westmead Tel: 9845 000

Professor Gary Moore, Dean, Faculty of Architecture,  
University of Sydney

In signing this form I understand:

1. The nature of the study and the nature of my child's participation in the study.
2. Participation in this project is voluntary and if I decide not to take part or decide to withdraw at any time this will not otherwise affect my child's care at the hospital.
3. That this research has been approved by both the Ethics Committee at The Children's Hospital, Westmead, and the University of Sydney Human Ethics Committee.
4. That the researcher will be given access to my child's medical records.
5. That any information obtained in this project, if published, will not contain the names and addresses or any personal information which will identify the participant.
6. I understand that any person with concerns about the conduct of this study can contact Kate Bishop or Anne O'Neill (Phone: 9845 1316), the secretary of the Ethics Committee at The Children's Hospital, at any time to discuss them.

I have read and understand the information sheet and this consent form and give my consent for my child to participate in this research study.

Name of Child \_\_\_\_\_(Please print)

Name of Parent or Guardian \_\_\_\_\_(Please print)

Signature of Parent or Guardian \_\_\_\_\_ Date: \_\_\_\_\_

Name of Witness \_\_\_\_\_(Please print)

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX E

## Participant information and consent forms and parents information and consent forms for the member-checking task

## Participant Information Sheet

Research Project: The Children's Hospital Westmead  
Participant Information Sheet: Checking tasks

**Hi**

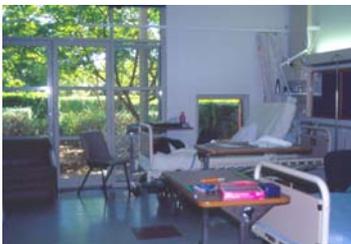
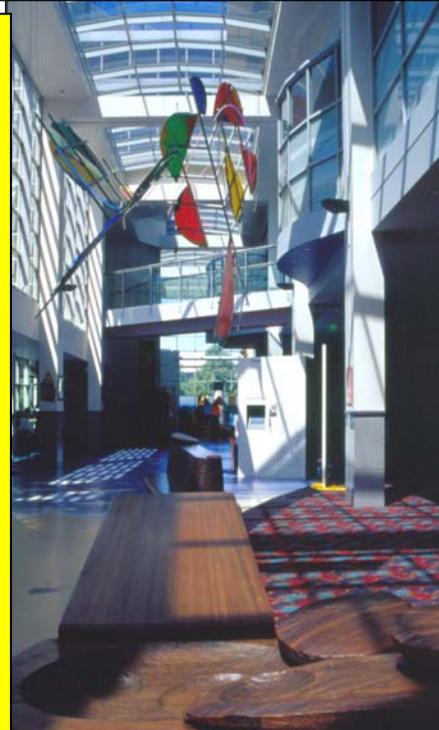
My name is Kate and I am inviting you to take part in an exercise that is part of my research project. This sheet contains information which will help you decide whether you would like to take part.

**The Research Project: What's it all about?**

I want to know how kids feel about being in hospital and the hospital environment. I am asking kids about their time here and what they would like the people who build hospitals for kids in the future to know.

**How can I help?**

I have talked with a lot of kids about being in hospital and they have identified a number of things that are important to them. I am asking you to look at the things that other kids have told me were important and to tell me what you think about these things.

**What will I be asked to do?**

I will be asking you to sort through some cards, choosing the ones that you think say important things about what it's like to be here. I will then ask you to talk a bit about each card you select. I will record what you say so that I can listen to what you have said later on.

You can tell me whatever you want and no one will know it came from you. The only time I would have to tell someone is if someone has hurt you in some way or that you might hurt someone else or yourself. If that happens I would need to talk with your nurse.

**Who can I talk to about it?**

Talk about it with your family or friends. You can ask me *any* questions you like about the project. You don't have to do this and no one minds if you decide not to. If you change you mind during the talk you can pull out at any time. Keep this sheet in case you want to call me. My phone number: Kate Bishop 0407 454 261

**Parent/Guardian Information Sheet**

the  
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ABN 53 188 579 090

**Research Information Sheet –  
For Parents or Guardians  
For checking tasks**

**Research Title:** From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:** Kate Bishop, PhD candidate, Environment-Behaviour Studies, Faculty of Architecture, University of Sydney.  
Telephone: 0407 454 261

Margaret Wallen Margaret Wallen, Senior Occupational Therapist-Research, The Children's Hospital at Westmead  
Phone: (02) 9845 6038

Professor Gary Moore, Chair of Environment-Behaviour Studies,  
Faculty of Architecture, University of Sydney

I invite you to consider giving consent for your child to participate in a research exercise that will be conducted under the guidance of the Occupational Therapy Department at The Children's Hospital Westmead and as part of doctoral research being carried out by Kate Bishop, Faculty of Architecture, University of Sydney.

**The Purpose of the Research**

We need to understand what designers need to know in order to design physical environments which support the health, development and well-being of children with special needs. The aim of this particular study is to understand the experience of children and young people in a hospital environment, so that this can improve healthcare design in the future. One of the best ways to do this is to ask the children themselves what is important to them in their interaction with the physical environment.

The findings from this study will be used to complete a doctoral degree and to make recommendations which could contribute to the development of guidelines for designers of hospital and healthcare facilities which take into consideration the needs and wants from the physical environment, as expressed by the children and young people themselves.

**The Purpose of the Exercise**

I have already spoken with a number of children and am making an interpretation of what they have said. In order to check on my interpretation I am seeking to talk with a

few more children in similar circumstances about the things that other children have already told me are important. In this way I am looking for further information that either confirms or disconfirms what other children have said.

This task will take about 20 minutes and involves sorting through cards which cover the major themes of the study. The participants will be asked to select and talk about cards which they feel are important to their experience also.

**Risk to the participants**

There are no foreseeable risks to participants. However a plan has been developed to respond to any medical or emotional need that arises for participants during the exercise which includes alerting relevant personnel within the hospital.

**Personal Information and confidentiality**

Your child's name, age, gender and illness will be known by the researcher. However, the confidentiality and anonymity of all participants will be preserved as each participant will be given a pseudonym which will be associated with their information throughout the study. Personal information and information from this exercise will be kept separately and no published material will contain information which allows an individual to be identified. All data collected in this study will be kept in locked storage by the researcher for five years and will then be destroyed.

**Other Information**

Participation in this exercise is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect your child's care at the hospital.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with Kate Bishop or with Carolyn Casey (Phone: 9845 3017), the secretary of the Ethics Committee which has approved this project.

This information sheet is for you to keep. You will also be given a copy of the signed consent form if you choose to let your child participate in this project.

**Standard Hospital Consent form for both parents and children used in Member-checking task**



**STANDARD CONSENT FORM**

**Research Title:**

From their perspectives: Children and young people's experience of a paediatric hospital environment and its relationship to their feeling of well-being.

**Investigators:**

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I have read and understand the Information Sheet, and give my consent/ for \_\_\_\_\_ to participate in this research study, which has been explained to me by Kate Bishop.

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I understand that I am free to withdraw from the study at any time and this decision will not otherwise affect my/ my child's treatment at the Hospital.

NAME OF CHILD: \_\_\_\_\_ (Please print)

NAME OF PARENT OR GUARDIAN: \_\_\_\_\_ (Please print)

SIGNATURE OF PARENT OR GUARDIAN/ CHILD: \_\_\_\_\_ Date: \_\_\_\_\_

NAME OF WITNESS: \_\_\_\_\_ (Please print)

SIGNATURE OF WITNESS: \_\_\_\_\_ Date: \_\_\_\_\_

NAME OF INTERPRETER: \_\_\_\_\_ (Please print)

SIGNATURE OF INTERPRETER: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX F

## Prompt cards used in final trustworthiness task

Theme	Card
Influence of illness	Everything depends on how I'm feeling
Boredom	It gets boring the more time you spend here
Keeping busy	It's important having lots of things to do here to keep you occupied
Family	My family is my main support
Escape	I really like to get away from the ward sometimes
Access to nature & outdoors	I really like being able to go outside
Friends and roommates	Making friends here is really important
	Having contact with my friends outside the Hospital is great
Environmental Aesthetics, welcome & comfort	Having the artwork and colour around is great and makes a big difference
Personalisation (of bed space)	It's really good to have my own things around my bed
Being for kids	This place is very welcoming for kids
Age-appropriateness	It's good for kids my age here
	They need to make some changes for kids my age here
Variety and difference	I really like having a variety of things to do and places to go here
Personal control	I can't always do things my way here but it doesn't matter
	I wish I had more say over how I have to do things here
Privacy	I wish I could have more privacy here
Room configuration	I prefer a single room
	I prefer to share a room
Food	The food isn't great
Maintenance, functionality and serviceability	I notice how clean things are and if they are well looked after
Value for money	Some things are too expensive here
Wayfinding	It's easy to find my way around
Information	I like getting information about my illness
Safety and security	I feel safe here
Improvements & recommendations	I think there could be some improvements
Not like a hospital	Sometimes it doesn't feel like a hospital
Other	Anything else you want to tell me?

*Note.* These themes are in no particular order. The actual cards used were all separate and the order of cards was changed with each participant.

## APPENDIX G

### Minor themes: Summary Description and Dimensions

Similarly to the major themes, minor themes also have a main alignment to a domain based on the evidence aligned to the theme and on the concept inherent in the theme. There are five minor themes with main alignments to three of the domains including social experience, physical environment and organisational considerations.

#### Domain: Social Experience

**Theme 1. Age-Appropriateness.** This theme encompasses participants' consciousness of age, and age-appropriateness in any aspect of the hospital experience.

**Alignment with domains.** Apart from the main alignment to the domain: social experience, this theme is aligned with three other domains also, including physical environment, organisational considerations, and personal experience.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Social experience:* The alignment with this domain is indicated by the evidence for a single dimension including *being able to socialise with peers (1)*.
- *Personal experience:* The alignment with this domain is indicated by the evidence for a single dimension including *consciousness of age (2)*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for a two dimensions including *the need for age-appropriate areas (3)* and *the need for age-appropriate aesthetics (4)*.
- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a two dimensions including *the need for age appropriate activities (5)* and *the need for age-appropriate treatment from staff (6)*.

**Exploration of dimensions.** In total there are six dimensions identified in this theme. Each of the dimensions identified within the theme will be explored here.

*Dimension 1: Being able to socialise with peers.* Most participants prefer socialising with patients their own age but this was increasingly the case for older participants. For adolescent participants, socialising with friends is a much more common pastime.

*Dimension 2: Consciousness of age.* Age-appropriateness could be an issue for participants of any age, depending on the topic of conversation. However, most of the discussion about age-appropriateness occurred in the interviews with the adolescent participants.

*Dimension 3: The need for age-appropriate areas.* Areas such as the Starlight Room are often assessed in relation to age-appropriateness. Participants as young as 11 years said that they do not go there, as this facility does not have anything for kids their age. The ward playrooms were not used by any of the participants of this study, as most of them said they were too old. However, even those who had been in the hospital as much younger children had not used these spaces.

The spaces that exist for adolescents to socialise such as the Wade Ward common room are greatly appreciated, along with the activities that are available there. However many of the adolescent participants request more places to for their age group to socialise.

*Dimension 4: The need for age-appropriate aesthetics.* Younger participants commented on how appropriate things like the curtains and the murals and the colourful signs were for kids. Older participants often considered the same things to be too child like. Older participants were especially intolerant of the inappropriateness of the aesthetics in areas that were designated areas for adolescents. For example, the curtains in the adolescent ward have cartoon characters on them.

*Dimension 5: The need for age appropriate activities.* Many participants feel that the array of activities available is comprehensive for children and limited for adolescents. Many compensate for this by bringing in their own entertainments. More age-appropriate activities is a frequent recommendation from adolescent participants. They felt that the entertainments available, the movies and the activities such as the computer games in the Starlight Room are aimed at younger children.

*Dimension 6: The need for age-appropriate treatment from staff.* Adolescent participants resent being spoken to and treated as if they are children. They remark on the way staff deliver information to them as though they were younger kids, either not giving them enough information, talking down to them, or talking with their parents instead.

## **Domain: Physical Environment**

**Theme 1. Wayfinding and orientation.** This theme is concerned with participants' response to finding their way around the Hospital environment, and the methods that they used.

**Alignment with domains.** Apart from the main alignment to the domain: physical environment, this theme is aligned with three other domains also, including social experience, personal experience and time.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including *attributes of the environment providing wayfinding cues (1)*.
- *Personal experience:* The alignment with this domain is indicated by the evidence for a single dimension including *children's response to wayfinding (2)*.
- *Social experience:* The alignment with this domain is indicated by the evidence for a single dimension including *social wayfinding strategies (3)*.
- *Time:* The alignment with this domain is indicated by the evidence for a single dimension including *the influence of time on wayfinding (4)*.

**Exploration of dimensions.** In total there are four dimensions identified in this theme. Each of the dimensions identified within the theme will be explored here.

*Dimension 1: Attributes of the environment providing wayfinding cues.* Most participants use the signs. The signs themselves are a source of interest for younger participants who like them because of their bright colours and their themes which include stylised animals. These participants use the distinctiveness of the signs as landmarks to guide them rather than the text on the face of them.

Some participants also use the variation in the corridor artwork to help them orientate themselves in the building and navigate their way around it.

*Dimension 2: Children's response to wayfinding.* Most participants report that finding their way around the Hospital is easy and has never troubled them. Many are happy to use their journeys as a way of exploring the environment and like to rely on their memory to relocate places rather than using other systems. Although a couple of the participants report getting lost from time to time, none of the participants find the task of navigating the building intimidating, whether on their own or with others.

*Dimension 3: Social wayfinding strategies.* Younger participants report leaving wayfinding up to their parents. Some participants regularly rely on instructions from staff or from other patients to provide wayfinding and directional information.

*Dimension 4: The influence of time on wayfinding.* The longer the time spent in the environment the more familiar participants report becoming with its layout. However, they report that this did not necessarily lead to fewer errors in their navigation of the building as they often rely on their memory rather than any other orientation support to navigate the building.

**Domain: Organisational Considerations** (The themes below are in no particular order)

**Theme 1. Maintenance, functionality and serviceability.** This theme concerns children and young people's response to the management of facilities and their maintenance, serviceability and functionality in relation to their purpose.

**Alignment with domains.** Apart from the main alignment to the domain: organisational considerations, this theme is aligned with two other domains also, personal experience and physical environment.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a single dimension including *the implications for organisational procedures (1)*.
- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including *the areas and attributes that are the focus of participants' comments (2)*.

**Exploration of dimensions.** In total there are two dimensions identified in this theme. Each of the dimensions identified within the theme will be explored here.

*Dimension 1: The implications for organisational procedures.* Beyond the recommendations for greater attention to cleanliness in some areas, the management and provision of facilities, activities and areas also features regularly in the discussion. Participants were clearly conscious of how serviceable many of the areas were, whether things were in disrepair or not, and whether facilities functioned well or not, in light of their purpose. In particular, recommendations are made for an improvement in the speed of repairing broken facilities.

Cleanliness is a key consideration for children and young people. It is used occasionally in reference to the indoor areas as an indicator that this is a good hospital environment, in that it is suitably clean. Conversely it is also used regularly to criticise areas outdoors. Clearly there is an expectation amongst the participants that the hospital should be very clean and very hygienic. Anything less is viewed as very unsavoury and unsafe. Improved cleanliness is a frequent recommendation in relation to outdoor areas.

*Dimension 2: The areas and attributes that are the focus of participants' comments.* In particular, the cleanliness of outdoor areas including features such as the fountains which are "dirty" and the grassy areas which were covered in cigarette butts attract comment.

Facilities in disrepair also greatly disappoint participants, especially if the disrepair inhibits their use of the area. For example the Wade Ward common room has a limited range of facilities, several of which such as a pool table and TV console could not be used at the time of this research. Children reveal their attention to the detail of the environment and its impression on them in relation to these issues. Invariably participants are able to say exactly which bits are broken or unclean in each area, working entirely from their memory.

Participants also comment when they consider that an area or facilities set up for a specific purpose works well. When making overall comments about their response to an area they often assessed it in light of its purpose. They appreciated the functionality of specific spaces such as the bedrest area on the Wade Ward and the serviceability of other facilities such as the pinboards, power points and telephones around their bed spaces.

When participants were asked how places could be improved many of the suggestions were practical changes related to better functioning. For example, there were requests for more lockable areas, more pinboards, more car parking, and a non-smoking area in the Children's Garden.

**Theme 2. Personal safety and security.** This theme is concerned with participant's feeling of safety and security in the hospital.

**Alignment with domains.** Apart from the main alignment to the domain: organisational considerations, this theme is aligned with two other domains also, personal experience and physical environment.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Organisational considerations:* The alignment with this domain is indicated by the evidence for a single dimension including *a reliance of hospital security systems (1)*
- *Personal Experience:* The alignment with this domain is indicated by the evidence for a single dimension including *feeling safe and feeling their belongings were safe (2)*
- *Physical environment:* The alignment with this domain is indicated by the evidence for a single dimension including *physical indicators of a safe environment (3)*.

**Exploration of dimensions.** In total there are three dimensions identified in this theme. Each of the dimensions identified within the theme will be explored here.

*Dimension 1: A reliance of hospital security systems.* There is a reliance on the hospital security systems to keep patients safe. Participants are aware of hospital security and the combination of measures, such as personnel and cameras, in place for their safety and they use these to justify how safe they feel.

Participants also report feeling safe because of the constant vigilance of the nursing staff.

*Dimension 2: Feeling safe and feeling their belongings were safe.* Most participants report feeling safe in the hospital and that they are not worried about their safety in the hospital. They are more worried about theft of personal belongings rather than threats to themselves.

Many participants had stories about personal theft from both staff members and other patients which worried them.

*Dimension 3: Physical indicators of a safe environment.* The visible security measures participants can see in the environment such as the security grill surrounding verandahs and the security cameras installed in the hospital, provide visual indicators of a safe environment for participants.

**Theme 3. Improvements and recommendations.** This theme is concerned with all the improvements and recommendations made by participants.

**Alignment with domains.** Apart from the main alignment to the domain: organisational considerations, this theme is aligned with two other domains also, social experience and physical environment.

**Dimensions within the theme that indicate alignment with the domains.** These include:

- *Organisational considerations:* The alignment with this domain is indicated by the evidence for three dimensions including *changes to activities and facilities (1)* and *changes to rules and restrictions (2)* and *a greater attention to cleanliness of outdoor areas and repair of broken facilities (3)* and *a greater variation in the menu (4)*.

- *Social experience:* The alignment with this domain is indicated by the evidence for a single dimension including *attention to age-appropriateness for adolescents* (5).
- *Physical environment:* The alignment with this domain is indicated by the evidence for three dimensions including *attention to physical comfort for patients and their families in wardrooms* (6) and *an increase in gardens and flowering plants in the environment* (7) and *an increase in the amount of colour* (8).

**Exploration of dimensions.** In total there are eight dimensions identified in this theme. Each of the dimensions identified within the theme will be explored here.

*Dimension 1: Changes to activities and facilities.* Participants recommend a greater volume of activities and facilities for adolescents, and for patients in isolation.

*Dimension 2: Changes to rules and restrictions.* Adolescent patients request more leniency in rules regarding visiting hours for friends' visits.

*Dimension 3: Greater attention to cleanliness of outdoor areas and repair of broken facilities.* Participants request greater attention be given to the cleanliness of outdoor areas, particularly water features such as fountains as it undermines the welcome of these areas for patients. They also request that broken outdoor facilities be repaired in quicker timeframes.

*Dimension 4: Greater variation in the menu.* Participants request more variety in the food menu.

*Dimension 5: Attention to age-appropriateness for adolescents.* A recommendation for more age-appropriate activities, rules, and treatment from staff are recommendations made by adolescent participants.

*Dimension 6: Attention to physical comfort for patients and their families in wardrooms.* Participants desired a greater control over ambient light and noise in the environment. It also includes provision for more comfortable beds in particular for both patients and the family member sleeping beside them.

*Dimension 7: Increase the number of gardens and flowering plants in environment.* Participants' suggested improvements often include the recommendation for more plants and more gardens around the hospital.

*Dimension 8: An increase in the amount of colour:* More colour and more artwork in some areas around the hospital is also a frequent recommendation.

## APPENDIX H

Table outlining domains, major themes, their dimensions and sub-dimensions

Domain	Theme	Dimensions	Sub-dimensions
1. Personal Experience	1. Influence of patients' diagnosis and treatment program	1. Influence of a patient's feeling of wellness on their response to the Hospital.	
		2. Influence of a patient's diagnosis on how interested they are in socialising.	
		3. Influence of a patient's diagnosis on their consciousness of the physical environment.	
		4. The influence of a patient's diagnosis on their interest in using resources within the environment.	
		5. Relationship between a patient's diagnosis, the amount and number of times they have to spend in hospital and their response to the hospital	
	2. Coping and coping strategies.	1. Personal efforts to maintain a positive outlook	
		2. Personal coping strategies	<ul style="list-style-type: none"> <li>• Keeping busy</li> </ul>
		3. Social coping strategies	<ul style="list-style-type: none"> <li>• Seeking support</li> <li>• Contact with friends outside hospital</li> <li>• Contact with family</li> <li>• Socialising with friends made in hospital</li> </ul>
		4. The physical environment as part of coping strategies.	<ul style="list-style-type: none"> <li>• Personalising bed area</li> <li>• Escaping ward environment</li> <li>• Having a variety of areas and types of places to go to in environment</li> </ul>
		5. The role of information in helping children prepare and cope	
		6. The influence of time on the effectiveness and need for coping strategies.	

**Table (continued). outlining domains, major themes, their dimensions and sub-dimensions**

Domain	Theme	Dimensions	Sub-dimensions
<b>1. Personal Experience</b>	3. Personal control and privacy	1. The individual's need and desire for privacy and control	• Dignity and respect
		2. Control, privacy, roommates and their families	
		3. Greater control over environmental attributes including light and noise	
		4. Wardroom configuration	• Single versus shared rooms
		5. Capacity to participate in their own healthcare management	• Being consulted, being heard • Being kept informed
		6. Influence of time on patients' desire for privacy and control	
<b>2. Social Experience</b>	4. The roles and experience of family	1. Family as the central source of support	
		2. Socialising with family	
		3. Needing places to socialise with family	
		4. Family comfort in the environment	
		5. Family as buffer between children and organisation	
		6. The impact of cost and inconvenience on families	
		7. Familiarity versus homesickness	
		8. Missing Family	
	5. Friends and roommates	1. Friends as source of support	• friends from home • friends made in hospital
		2. Socialising with friends	• friends from home • friends made in hospital
		3. Roommates for company	
		4. Needing places to socialise with friends	
		5. Availability of age-appropriate social activities.	
		6. The influence of time on the need for friends and company	
<b>3. Physical Environment</b>	6. Environmental aesthetics, welcome and comfort	1. Artwork	
		2. Colour	
		3. Brightness	
		4. The influence of time on the response to environmental aesthetics	

**Table (continued). outlining domains, major themes, their dimensions and sub-dimensions**

Domain	Theme	Dimensions	Sub-dimensions
	7. Access to nature and outdoors	1. The need for environmental contrast	
		2. The need for contact with nature	
		3. Accessing familiar social outdoor activities	
		4. Having access to outdoor activities	
		5. The need for contact with nature and outdoors across time	
<b>4. Organisational Considerations</b>	8. Indications of a child-friendly organisation	1. A culture of child-friendliness	
		2. The volume and type of activities and facilities	
		3. The importance of not looking like a hospital	
		4. Kids supporting kids through the environment	
		5. Sensitivity to the welcome from staff	
<b>5. Time</b>	9. Variety and difference	1. The impact of boredom and sameness	
		2. The importance of environmental variation	<ul style="list-style-type: none"> <li>• Variation in aesthetics</li> <li>• Variation in areas, their functions and opportunities</li> <li>• Variation in spatial qualities</li> </ul>
		3. The need for a variation in daily hospital routines	<ul style="list-style-type: none"> <li>• Variation in treatment programs</li> <li>• Variation in activities</li> <li>• Variation in food</li> </ul>