University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

Supportive play environment for children living with life-threatening and life-limiting conditions: a mixed-methods study in Kuwait and the United Kingdom

by

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Thesis for the degree of Doctor of Philosophy

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Abstract

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Play is every child’s right and of primary importance for their well-being. Living with a life-threatening and life-limiting condition (LTC/LLC) challenges the children’s modes of play. The aim of this research was to explore the nature of these children’s play in two cultures and investigate the social and physical environmental factors related to their play participation at inpatient healthcare facilities (children’s hospital ward and hospice).

A parallel mixed-methods study design was employed. Q methodology and observational data were collected from children with LTC/LLC (n=42) between the ages of 5 and 11 and from their caregivers (n=39) in two countries, Kuwait and the UK. The data were analysed using factor analysis and content analysis. Then the findings of both datasets were integrated.

The findings showed that children prioritised being with others. However, this was very limited often due to isolation precautions. This gives rise to their engagement in more sedentary solitary play. The available play resources were challenges for the children to use due to their physical and cognitive impairments which limited possible play options and autonomous play. Occasionally, play was done for them rather than the child engaging in play. The findings of the study did not indicate significant cultural differences in the collected data.

This research contributes to the area of children’s play and living with LTC/LLC. It enables understanding some of the children’s play needs that can be incorporated within the inpatient healthcare environments to support children’s participation in play. Suggestions are made to create opportunities for social play and encounter for the children’s impairments respecting their different play modes. Future research should explore these children’s play patterns, develop mediums to understand their playfulness experience and evaluate the impact outcome of play environment adaptation on children’s well-being.

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Research Thesis: Declaration of Authorship

Print name:	**Zainab A Jasem**
Title of thesis:	**Supportive play environment for children living with life-threatening and life-limiting conditions: a mixed-methods study in Kuwait and the United Kingdom**

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
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Definitions and Abbreviations

Active/motor play	Gross bodily movements, play with motion, physical play (e.g., running, jumping, playing sports and rough-and-tumble)
Caregiver	Refers to the primary person taking care of the child (e.g., parents, grandparents and paid caregiver)
Children with complex needs	A group of participants who were in need of a lot of additional support, and intensive ongoing care on a daily basis because of their physical disabilities and cognitive impairment. These children were mainly characterised by lower intellectual and linguistics abilities considering their ages
Communication/ language play	Play using words and gestures (e.g., jokes, singing and storytelling)
Concourse	Raw material of Q methodology of issues surrounding the topic collected from conversation, TV, literature, questionnaires and not restricted to words, but including collections of paintings, pieces of art, photographs and even musical selections
Constructive play	Creation, making and building (e.g., arts and crafts, building blocks and puzzles)
Co-operative play	Child plays and interact with others
DBS	Disclosure and Barring Service
Eigenvalue	The amount of variation within the dataset explained by a factor
ERGO	Electronic Research Governance Online
Explorative and manipulative play	Exploration of object/environment and simple manipulation of objects (e.g., listening to the sound of the ringing bells and exploring glass peddles and coloured stones)
Factor array	Converted z-scores of Q set items into original values used in the sorting process (i.e. +4 and -4)
Factor extraction	Process of deciding the number of factors to retain in order to explore the phenomenon
Factor rotation	Applied to get as much Q sorts (participants) as possible close to the axes, where each axis represents a factor
Games with rules	Games with pre-set rules, require some level of understanding (e.g., Connect Four and Monopoly)
HRA	Health Research Authority
Hospice	An organisation that provides palliative care services, specialist respite care, end-of-life and bereavement support
ICF	International Classification of Functioning, Disability and Health

Legal guardian	Person who has a legal right and parental responsibility for the child (i.e. it was not always the caregiver for the population in this study)
LTC/LLC	Life-threatening and life-limiting conditions
Meaning unit	Words, sentences and photos that carry meaning to describe a feature of the phenomenon
NHS	National Health Service
NRES	National Research Ethics Service
Parallel play	Child plays alongside other playmate nearby but with no interaction
Participants	Both children and caregivers
PCA	Principal component analysis
PEO	The Person-Environment-Occupation Model of occupational performance
Play with electronic devices	Play using technology devices (e.g., playing on tablet, watching TV and playing videogames)
PPC	Paediatric palliative care
Pretend play	Use of objects and/or actions for imitation, role play, imaginative and make-believe play (e.g., play house, fantasy figures and playing with cars)
Q matrix	An enlarged diagram on which the cards of the Q methodology are arranged in the participant's order of preference
Q set/sample	The study's sample in Q methodology. Statements that need to be arranged by the participants related to a specific topic
Q sort	Each participant arrangement of the Q set on the Q matrix
Q sorting	Process of rank-order statements (Q set) of the Q methodology, related to a specific topic, along a continuum, i.e. from mostly agree to mostly disagree or from most important to most unimportant
QoL	Quality of life
Solitary play	Child plays alone by themselves
Unit of analysis	An independent element to be kept in mind during the content analysis process as a context
Variance	Average of the spread of the data
UK	United Kingdom
UoS	University of Southampton

Chapter 1 Introduction

In this thesis, a doctoral research study on a supportive play environment for children living with life-threatening and life-limiting conditions (LTC/LLC) is presented. This chapter is an introduction to the research topic and the main research focus: play and environment. This is followed by illustrating the general purpose of this research and describing the philosophical framework behind this work. An overview of the thesis structure is also reported.

1.1 Introduction to the research topic

Occupations, as defined by the occupational therapy profession, are the purposive activities that occupy one's time, bringing meaning and adding value to life (Strong et al. 1999; Clark and Lawlor 2009). Considering children, play is their primary childhood occupation; a central domain of their lives (Parham 2008; Ray-Kaeser and Lynch 2017; Moore and Lynch 2018) and for which a strong positive relationship exists between participation in occupation, play, and children's health and well-being (Law 2002; Hocking 2009; Gerlach et al. 2014; Law and King 2014; Moore and Lynch 2018).

Evidence confirms that children living with LTC/LLC experience play disruption (Boucher et al. 2014; Amery 2016). For some of these children there might be curative treatment, but which may still fail, while for others there is a lack of any reasonable hope of a cure, and the likelihood of death is before adulthood (McNamara-Goodger and Feudtner 2012; Shaw et al. 2015). Examples of LTC/LLC are cancer, cardiovascular diseases, congenital anomalies, immune disorders, organ failures, neurological disorders and others (Fraser et al. 2012; World Health Organisation 2014).

Less attention is usually paid to the needs of play for these vulnerable children, and this is in spite of the fact that the role and value of play increases for children living with such illnesses (see 1.2.1 for the benefits of play) (Burkhardt et al. 2011; Boucher et al. 2014; Amery 2016). Glasper and Haggarty (2010) and Glasper et al. (2014) highlighted that children living with LTC/LLC are, first and foremost, children who have the needs of any child to play. Despite children's prognoses or medical conditions, they remain children, and have the right to act and live as children, however long that may be (United Nations 2006; World Health Organisation 2007; Boucher et al. 2014).

Interdisciplinary contribution is required to enhance this field to support children's play given that it is a multidimensional concept (Reilly 1974). However, each discipline contributes from its own perspective and interests. Play occupation, as part of children's everyday lives, was the focus of this research and viewed through an occupational therapy lens given the researcher's own professional background as an occupational therapist. The environment was adopted as a potential medium for enhancing children's engagement in play. The importance of focusing on the environment emerged from the literature review (presented in Chapter 3) and the research approach which this study was built on (see 1.4 The positionality of the research section later in this chapter).

1.2 Focus of the research

1.2.1 Play

Understanding play

Play used to be considered as a one of the clearly recognised occupations when looking at the classifications of occupations across the occupational therapy theories (Turpin and Iwama 2011). This recognition is due to the centrality of play in the lives of human beings. Accordingly, it has attracted the attention of individual researchers and theorists from a variety of cultural and professional backgrounds (Rubin et al. 1983). As a consequence, this resulted in difficulty in finding a unified definition to explain what play is (Rubin et al. 1983; Hughes 2010; Burghardt 2011). According to Tanta and Knox (2015), children's play (and the different types of children's play) can be understood by distinguishing the essential features of play from other behaviours typically found in children. For the purpose of this study, play was referred to as the child's behaviour of engaging in a freely chosen activity that carries subjective experience of joy and fun. Therefore, this definition was employed by considering four features: 1) *intrinsic motivation*: play for its own sake focusing on the action and meaning, rather than the outcome or product of it; 2) *active engagement*: the child is engaging in play physically, psychologically, or both – which might be high or low intensity of engagement (e.g., watching others playing) – including the affective domain (i.e. feeling included); 3) *non-obligatory*: where play is self-directed and controlled by the child who has the choice over what to take part in, even when it was led by others; and 4) *pleasurable*: the child enjoys the experience (Reilly 1974; Rubin et al. 1983; Wood and Attfield 2005; Parham 2008; Hughes 2010; Burghardt 2011; Gray 2011; Lynch and Moore 2016). These features differentiate play from other activities which might seem similar to play such as work and leisure. Work is, however, externally motivated and not always freely chosen (Hughes 2010), and leisure takes place in residual time only despite, on occasion, being used interchangeably with play (Sellar and Stanley 2010; Lynch and Moore 2016).

The form of children's play changes as they grow: play serves different purposes for different groups (Tanta and Knox 2015). During the middle childhood ages (which is the focus of this study;

see Chapter 4 – 4.2 Research settings and participants), children prefer spending time with their peers and are particularly interested in physical play, electronic games, dramatic play, collecting and trading, and arts and crafts (Rubin et al. 1983; Parham 2008; Hughes 2010). There is a universal trend of children spending fewer hours outdoors and in active play, while also having more adult supervision, than children of previous generations (Gray 2011; Gleave and Cole-Hamilton 2012; Murray 2018). In addition, there has been a global increase in children's screen time and use of electronic devices (Alazemi 2015; Dashti and Yateem 2018; Torjesen 2019). This applies to children in both Kuwait and the UK (the focus of this study; see Chapter 2 Chapter 4–4.2 Research settings and participants).

Another way to understand play is by looking at its function. Piaget (1951), whose work is considered seminal in the field of children's play, states that play is an end in and of itself, serves functional pleasure, and has a developmental trajectory from the early days of a child's life. Smith (2010), in line with Piaget (1951), acknowledged play's crucial position within the evolutionary approach where play is central to skill acquisition. A child can gain rich life experience through play; it is a fundamental building block for the different dimensions of a child's life (Parham 2008). Throughout play, physical development can be achieved because play is closely related to active physical participation (e.g., building gross and fine motor skills and coordination) (Wood and Attfield 2005; Smith 2010). A child's participation in play can also provide a safe atmosphere in which to develop social skills (e.g., learning role taking and sharing) and facilitates their emotional development (e.g., self-control, managing conflicting feelings and being sensitive to others) (Rubin et al. 1983; Gray 2011). Cognitive growth, including planning, attention skills and language development, can all be linked to play skills as well (Isenberg and Quisenberry 2002; Rigby and Huggins 2003). Thus, through play, children can gain and integrate the different skills and develop a sense of mastery over their own bodies as well as their surroundings (Hollenbeck 2005). This is in addition to play contributing to children living their childhood. Considering the LTC/LLC, play is integral to the parallel planning of care for children experiencing such conditions (further discussed in Chapter 2 – 2.1 Children with life-threatening and life-limiting conditions). Such children can benefit from the process of engagement (i.e. interaction with peers allows children to fully experience their childhood) and from participation (i.e. developing later-life skills) (Sturgess 2003; Mandich and Rodger 2006; Lynch and Moore 2016). Hollenbeck (2005) elaborated that occupational therapists consider play as occupation; in other words, they consider an improvement in a child's engagement in play as an outcome of therapy. They believe that play is also a means of developing other life skills. It helps to distract from uncomfortable symptoms and acts for some children as a coping strategy (Glasper and Haggarty 2010; Nabors et al. 2013; Potasz et al. 2013; Al-Yateem and Rossiter 2016; Capurso and Pazzagli 2016). Play also addresses their spiritual needs and psychological well-being (Boucher et al. 2014). Additionally, Ito et al. (2015) found that, for children with cancer, play and opportunities to play freely were essential elements leading to a good death. A possible way for making these play opportunities available to children living with LTC/LLC is by considering the environment in which children can play. It is worth noting that play in this study is being studied as play occupation for the sake of itself by focusing on the process of play, rather than on its outcome or as a medium to achieve other goals.

As with any occupation, play is subjective. Its meaning refers to the quality of the experience, as suggested by Tanta and Knox (2015). Participation in similar play activities may carry different meanings for different children. Furthermore, according to James et al. (1998), the meaning that children assign to play differs from the meaning that adults assign to it. When adults talk about the benefits of play, they are likely to refer to the educational benefits. This is due to the shift in societies towards a more academically oriented approach, with increased time and weight being given to schooling and education (Gray 2011; Milteer et al. 2012; Jasem and Delport 2019).

Available evidence suggests differences in cultural values and attitudes towards play. Parmar et al. (2004) conducted a study about children’s play, which included Asian and Euro-American parents. They found that Asian parents placed a greater emphasis on the physical contributions of their children during play, while the Euro-American parents were more concerned about their children’s social development. Another study by Ivrendi et al. (2019) investigated the perceptions of play in Turkish and Norwegian cultures. The results of the study indicate that there is a preference for Lego bricks in Turkey, whereas fixed play equipment and dramatic play materials are preferred in Norway.

Professional groups concerned with children’s play

As mentioned previously, different professions have different viewpoints on play. For instance, nurses/ doctors can use play for distraction. The different healthcare professionals therefore differ in their way of handling children and addressing play in inpatient healthcare settings such as children’s hospitals and hospices (the research fields addressed in this study, further discussed in Chapter 4 – 4.2 Research settings and participants). In particular to play focused professions, play specialists (in the UK) and child life specialists (in Kuwait) are among the professionals who deal with children in hospital and hospice settings who were found in the settings where the data for this study were collected.

According to the Healthcare Play Specialist Education Trust (2019) and the National Association of Health Play Specialists (2018), the role of the play specialist is to organise daily play activities in a playroom or at a child’s bedside. The activities assist the children in reaching their developmental goals and in regaining lost skills. They also prepare children for hospital procedures and help them to deal with pain, fear and anxiety.

In the UK, staff were first found to play with children during late 1950s, at St. Bartholomew's Hospital and St. Thomas' Hospital in London (National Association of Health Play Specialists 2019). The importance of this role with children was recognised, over time, and courses were established to train people in this new profession (National Association of Health Play Specialists 2019).

It has been documented that a 'child life specialist' in the United States is the equivalent of 'play specialist' in the UK (Hubbuck 2009). The Association of Child Life Professionals (2018) reports that child life specialists work with children in difficult and traumatic situations within healthcare settings. They provide psychological interventions, like preparing children for procedures and helping them to deal with fear and anxiety, often through therapeutic play.

In North America, the child life speciality profession was founded in 1920's (Association of Child Life Professionals (2018b). In Kuwait, the profession was introduced in 2003 providing psychological support to children, in addition to providing attractively decorated wards for children's treatment and rest (Kuwait Association for the Care of Children in Hospital; Burns-Nader and Hernandez-Reif 2016). For the purpose of this study, the term 'play specialist' is being used to represent *play specialists* in the UK and the *child life specialists* in Kuwait.

Occupational therapists on the other hand have a special interest in children's play, which is one of their occupations; play is an end goal to achieve and be used as an aim of intervention (Lynch and Moore 2016). Despite the special interest that occupational therapists have in children's play, occupational therapy training and practice places less focus on play as an occupation for children; this appears to be a global phenomenon (Lynch et al. 2018; MItchell et al. 2018). The researcher can confirm this from personal experience, as she practised in Kuwait, where play is rarely the focus in occupational therapy and is more used as a medium. Similarly, in the UK, this is documented by Howard (2002) as the norm.

In Kuwait, no occupational therapists were employed by the establishment where the data were collected for this study. Most of country's occupational therapists are found in physical rehabilitation settings or, in the case of those working with children, at schools for children with special needs. In the UK, on the other hand, occupational therapists are employed by the hospital where data were collected. However, they were not employed by the hospice that was involved in this current research project.

It worth mentioning here that the unique contribution of studying children's play from an occupational therapy perspective is its view to play as children's occupation, part of everyday children's routine and the professional expertise in considering the environment to enable individual's occupational performance that will contribute to enhancing their health and well-being.

1.2.2 Environment

The environment can be understood as the context that affords occupational possibilities impacting occupational performance (Kielhofner 2008; Turpin and Iwama 2011). There is a great deal of attention given to the environment in particular within occupational therapy models of practice. This has been acknowledged since the early history of occupational therapy (Law 2002; Turpin and Iwama 2011). This importance came from its link to the individuals' occupational performance that resulted from the inter-relationship of individuals and their environments (see Chapter 2 – 2.3 A supportive play environment section) (Law 1991; Law et al. 1996; Breines 2004; Kielhofner 2008). It is recognised within the occupational therapy field that changing the environmental conditions is a possible way of carrying out an intervention, rather than only focusing on changing the patient to foster their participation and getting an adaptive response (Law et al. 1996).

This study focused on two types of the environments; the social and the physical environments. For the purpose of this research, these two aspects of the environment are used as:

- <u>The social environment</u>: the availability of people, their relationships, and the norms and expectations within that group (Turpin and Iwama 2011; American Occupational Therapy Association 2014).
- <u>The physical environment</u>: the natural and constructed surroundings including buildings, design feature of spaces and objects, or geographical features and their properties (Law et al. 1996; Kielhofner 2008; Turpin and Iwama 2011; American Occupational Therapy Association 2014).

In their playfulness approach Skard and Bundy (2008) highlighted four elements to be considered when measuring the environmental supportiveness for children's play, this to include: caregivers, playmates, playthings and play space; all of which constitute the social and physical environments considered in this research. It is noteworthy that the cultural aspect of the environment infuses and influences both the social and physical aspects of that environment (Kielhofner 2008), which was taken into account by applying the research in two different countries, Kuwait and the UK (2.4 The culture) and in particular, by studying these concepts in the contexts of a children's hospital ward and a children's hospice (4.2.1 Research settings).

1.3 The purpose of this research

The focus of this research was to find possible ways to support children with LTC/LLC in their participation in play considering the environment to address the gap in the literature (see Chapter 3 for further details).

1.4 The positionality of the research

The experience of an occupational participation – in this study, play – is unique in each situation because of the dynamic relationship between person and environment (as explained in 1.2 Focus of the research section) (Law et al. 1996). As a consequence, this contributes to the subjectivity of the experience (Estelle 2013; Lamb 2015). This concept, the unique subjective experience, within occupational therapy was influenced by pragmatism (Cutchin and Dickie 2012); a philosophical concept based on the belief of the existence of multiple realities and rejecting traditional dualism (Dewey 1916; Rorty 1982, 1999; Johnson and Onwuegbuzie 2004). Pragmatism influences the development of the occupational therapy profession alongside with other health and social sciences (Creek 2014). Breines (1987) suggests this link with pragmatism was advocated by Adolph Meyer, one of the founders of the occupational therapy profession. He was a friend and colleague to John Dewey and William James, the most famous pragmatists at that time (Breines 1987; Cutchin and Dickie 2012; Creek 2014; Lamb 2015).

Pragmatism was employed for this research as an appropriate foundational framework because of its recognition to the epistemological relativism (further discussed in 4.1.1 Mixed methodology) (Tashakkori and Teddlie 1998). Classic pragmatists were anti-Plato concept of reasons and common sense where truth can be achieved by science and inquiry (Rorty 1999). They, however, illustrated that knowledge cannot represent reality; inquiries help in taking a more diversity of individuals' point of views to get a better understanding of the world (Rorty 1999). Such aspects were crucial to consider when undertaking a research project that targets children living in different areas and communities. This invariably means that the populations will differ in their beliefs over many different aspects, not least what is considered relevant to them and their play in particular. This therefore makes pragmatism a responsive approach in accounting for these differences. Pragmatism also assists researchers to escape from the concrete demands which people usually carry from their communities when collecting and analysing the data. This is particularly important because of the fact that most practice today is based on evidence-based practice and publications where the majority was produced by white, middle-class, western, English-speaking people who may have little in common values and priorities of people in other parts of the world (Connell 2007; Hammell 2019).

Another reason for choosing pragmatism over other frameworks is the belief that knowledge in this study is built on the assumption that reality is multiple, complex, constructed and stratified (Robson 2002; Johnson and Onwuegbuzie 2004). There is a trend pushing professions, including occupational therapy, to more scientific rationales to demonstrate the effectiveness of their intervention (Leland et al. 2015). It is, however, difficult to evaluate the engagement in occupation for health based on objective measures solely because of the subjectivity attached to understanding aspects related to the reality. In a paper by the World Federation of Occupational Therapists et al. (2017) where the research priorities in occupational therapy were identified, the contributors highlighted the need to account for person-centred qualitative outcomes when evaluating the effectiveness of occupational therapy interventions. This is due to the profession, its philosophical core concepts (e.g., client-centredness) and the nature of its end goals (e.g., improving patients' quality of life (QoL) and their life satisfaction level) (World Federation of Occupational Therapists 2010). Hence, using a pragmatism framework allowed the choice of the most appropriate methods that can assist in answering the research question (Chapter 4).

Pragmatism, as a concept, also had an influence on the utilised research design by its influence on the research paradigms; the paradigm war between the positivists, who believe in the concept of objective reality, and the interpretivists/constructivists who on the other hand deny this concept; mainly by highlighting relativism and the critical role and influence of the researcher in such constructions (Robson 2002; Lichtman 2014). Pragmatism evolved rejecting the rigid adoption of the forced choice between either one of these paradigms (Teddlie and Tashakkori 2009). It does, however, advocate the use of multiple methods of data collection that are most appropriate to answering the research question which might require deductive and inductive reasoning logic (Teddlie and Tashakkori 2009; Turnbull and Lathlean 2015; Creswell and Plano Clark 2018). Therefore, the mixed-methods research design emerged as a product of the pragmatic paradigm (Tashakkori and Teddlie 1998; Teddlie and Tashakkori 2009) and was used in this study.

To understand children's play and answer the research question appropriately (defined in 3.8 Research question), it was important to have the children's voice. Undertaking research *with* children, rather than *on* children, has a huge impact in discovering their perspectives, as well as eliciting a deeper understanding of their world (Christensen and James 2008b; Randall 2012b; Ellingsen et al. 2014). It is a fact that it is not always easy to perform research with children, particularly when requiring them to put their perspectives and viewpoints into words. This proviso is especially relevant when considering children with LTC/LLC. The relative lack of research that focus on the play of children with LTC/LLC (as found from reviewing the literature in Chapter 3) might be related to the methodological challenges that present. In order to overcome this barrier, the significance of the inclusion of children was considered during the very initial phases of planning this study. The researcher took the responsibility to adapt and use approaches that were suitable for children's participation. Accordingly, Q methodology and observation (Figure 1-1) were used in order to answer the research question (detailed in Chapter 4). It is noteworthy to highlight that besides considering children's perspectives, their caregivers were also included in this study, and they also provided useful insights into children's everyday play. In this study the term 'caregiver' was used, and not parents, as it refers to the primary person taking care of the child, including the grandparents, for instance, in addition to parents.

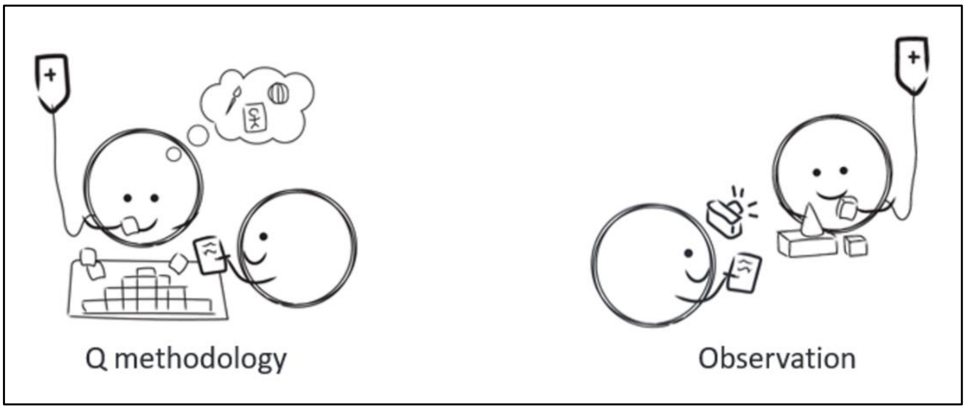


Figure 1-1 The used research methods

1.5 Overview of the thesis

This study is a mixed-methods research study, presented in this thesis in the traditional format, comprising introduction, background, literature review, methodological and methods frameworks, ethical considerations, findings and discussion. Subsequently, reflexivity and conclusions are presented. Appendix A represents an overview of some of the thesis' main aspects.

1.6 Summary of the chapter

In this chapter, the importance of play as a childhood occupation and its association to children's health and well-being was discussed. Given that children living with LTC/LLC experience disruption in their play, the environment is a possible intervention medium to enhance their participation in play. The established relationship between children's participation in play and their environment is well documented in the occupational therapy literature and supported by the pragmatism approach. This approach was adopted as a foundational framework for this research since knowledge in this study is believed to be subjective, multiple, complex and constructed. For this reason, it was crucial to have the children's voice, besides that of their caregivers, in eliciting deeper understanding of their world. This study was undertaken and subsequently presented in this thesis following the traditional format.

Chapter 2 Background

This chapter builds upon the concerns, interests and motivations towards the play environment for children living with LTC/LLC established in Chapter 1. A background of the research area is set in this chapter to cover issues related to children living with LTC/LLC, building on the significance of considering their play and the environment. Occupational science literature is also recognised in the thoughtful consideration of children's occupational right to play. This is in addition to the role of the culture and its link to illnesses as well as to children's play.

2.1 Children with life-threatening and life-limiting conditions

The number of children living with LTC/LLC worldwide is estimated at more than 21 million (Connor et al. 2017). Fraser et al. (2012) investigated the prevalence of LTC/LLC in England and found that these conditions across patients aged 0-19 years showed an annual increase which was estimated to have doubled between 2000/2001 and 2009/2010.

LTC/LLC are mainly characterised with shortened lifespan, where the likelihood of death is before reaching adulthood (i.e. before their 18th birthday) (McNamara-Goodger and Feudtner 2012). For the children with the first type, life-threatening conditions, there might be curative treatment which however may also fail (e.g., organ failures of heart), whereas the life-limiting, also called life-shortening conditions, are lacking any hope for curative treatment (e.g., severe cerebral palsy) (McNamara-Goodger and Feudtner 2012; International children's palliative care network 2015; Shaw et al. 2015).

These health conditions are characterised with prognostic uncertainty. The Spectrum of Children's Palliative Care Needs (Shaw et al. 2015) is an approach that helps identify needs of children who have LTC/LLC using Hain and Devins (2011) directory. It is a standardised comprehensive framework which is based on five prognostic colour-coded categories (Figure 2-1): a) green: children living with a potentially fatal condition, but for whom survival into adulthood can be expected; b) yellow: children living with a significant health need or a disability, whose risk of dying is expected before adulthood; c) amber: children with increasing instability or progressive deterioration where death is expected in a few months to years; d) red: children experiencing critical illnesses where survival is not expected beyond the next few weeks; and e) purple: children who die (Shaw et al. 2015).

Children who are likely to have palliative care needs

Diagnoses are likely to fit into one or more of the categories of children requiring palliative care, published by ACT (now Together for Short Lives) www.togetherforshortlives.org.uk

Children who are diagnosed or recognised to have a potentially life shortening (fatal) condition before their 18th birthday.

Survival into adulthood is likely.

Would you be surprised if this child died as a result of this condition or problem?

Children whose death before adulthood (18th birthday) is not unexpected.

May live for many years.
Care needs may be similar to other children who have complex chronic conditions.

Would you be surprised if this child died before adulthood (their 18th birthday)?

Children who have increasing instability or progressive deterioration.

Death is not unexpected in months to years.

Would you be surprised if this child died within the next few months to years?

Children who are critically ill.

Survival is not expected beyond the next few weeks.

Would you be surprised if this child was alive in a few weeks time?

Children who die.

Children who are not expected to have palliative care needs

Children living with significant health needs and/or disability, but whose risk of dying is comparable to that of the general population.

Children who recover and whose risk of dying is comparable to that of the general population.

Figure 2-1 The Spectrum of Children’s Palliative Care Needs (Shaw et al. 2012) used with permission

Despite the advancement in healthcare, children continue to have large unmet needs (Downing et al. 2016). Paediatric palliative care (PPC) is an advanced interdisciplinary care planning approach to address those needs and is directed towards maintaining the QoL for children with LTC/LLC and their families (McNamara-Goodger and Feudtner 2012; Teitelbaum et al. 2013; National Institute for Health and Care Excellence 2016; World Health Organisation 2019b). This is through addressing their complex issues by adopting the biopsychosocial approach considering the child’s mind, body and spirit (Tester 2006; McNamara-Goodger and Feudtner 2012; Baker et al. 2015). PPC can be received throughout the course of illness, i.e. from the diagnosis, regardless whether or not a child receives treatment directed at the disease or at the end-of-life phase (McNamara-Goodger and Feudtner 2012; International children's palliative care network 2015) as clearly illustrated in Figure 2-2. It can be delivered in different settings – for example, home, hospital and hospice setting.

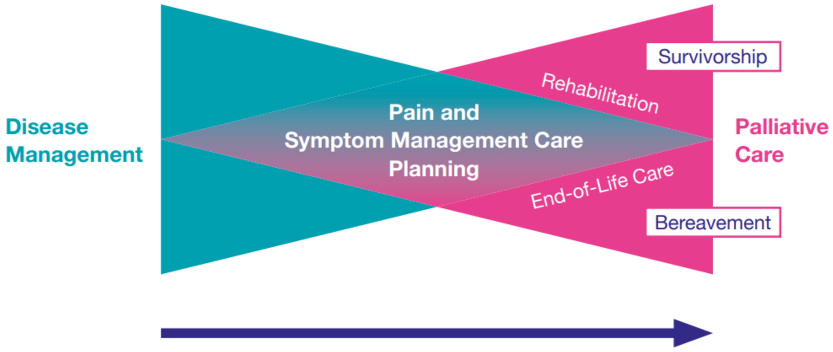


Figure 2-2 Palliative care throughout course of illness (Hawley 2014) used with permission

Thus, regardless of the stage of the child’s illness or setting of care provision, PPC aims to meet the children’s and their families’ needs by embracing their physical, emotional and social elements targeting aspects that are often inadequately addressed by medical care, including children’s needs to play (Tester 2006; McNamara-Goodger and Feudtner 2012; Boucher et al. 2014; Baker et al. 2015; International children's palliative care network 2015; World Health Organisation 2019b). These children often experience loss or impairment that affects their participation in play (Burkhardt et al. 2011; Boucher et al. 2014; Amery 2016). This could be as a result of the conditions themselves, instruments used (e.g., technology-dependent children and the limitations placed on their play from using these devices) and, on some occasions, the precautions required by the condition (e.g., the need of being isolated) (Burkhardt et al. 2011; Keesing and Rosenwax 2011).

These conditions are characterised by uncertainty which makes play more valuable and important in the parallel care planning (Burkhardt et al. 2011; Boucher et al. 2014; Amery 2016). Where children are expected to die before reaching their adulthood – there is still a chance for them to become adults (Brook and Hain 2008; McNamara-Goodger and Feudtner 2012; Shaw et al. 2015; Amery 2016). This therefore suggests giving special consideration to the need for parallel planning: preparing the child for the worst, but hoping for the best; notably, to include play in this planning. In other words, play is an important aspect to be considered for the children who may live until adulthood to develop later life skills, and on the other hand, for the children who are not expected to live longer. For those with shorter lives, the importance of play is drawn from the evidence on the highly positive influence of play on children’s well-being and living their childhood (Law 2002; Hocking 2009; Gerlach et al. 2014; Law and King 2014; Moore and Lynch 2018).

Wilcock (1999) framework of doing, being and becoming is a helpful approach for understanding the importance of living childhood and the parallel planning. ‘Being’ a child and living childhood depends on what the individual is ‘doing’ today which shapes their lives tomorrow (Lyons et al. 2002; Mandich and Rodger 2006). By engaging in doing, children can learn skills, develop their self-identity and build their roles (Mandich and Rodger 2006), whereas ‘becoming’, although it depends on the present, doing and being, maintains the notion of potential growth through participation (Wilcock 1999; Lyons et al. 2002). Therefore, play is an effective tool that carries benefits from the process of engagement (i.e. doing and being so that children can live their childhood) and the purpose/outcome from participation (i.e. becoming adults and enhancing later life skills) (Sturgess 2003; Mandich and Rodger 2006; Lynch and Moore 2016). In particular, Mandich and Rodger (2006) elaborated on the critical significance of focusing on ‘being’ for children with LTC/LLC and their being truly themselves for the aim of developing their inner well-being. Nevertheless, the importance of focusing on living childhood in the parallel planning is based on the fact that childhood is essential to be viewed as a stage by itself for the children to live (James et al. 1998). Children themselves may prefer to view the world contemporaneously and not as distant from their current concerns which is in contrast to the adult’s lens that is usually future-oriented (James et al. 1998; Mayall 2002).

2.2 Occupational science

Knowledge with regards to occupation is produced by occupational science; a discipline that is concerned with humans as occupational beings (Molineux and Whiteford 2011; Pierce 2014). It investigates the centrality of occupation in human life and its relation to health (Clark and Lawlor 2009; Molineux and Whiteford 2011). Despite the fact that most of the occupational scientists are occupational therapists, it has been grown out of occupational therapy (Molineux and Whiteford 2011). However, occupational science has nurtured the occupational therapy practice by its generation of knowledge about occupations – in particular, the relationship between occupation and health and well-being (Molineux and Whiteford 2011; Frank 2012). This accordingly has fortified the occupational therapy application of the theories into real world practice and supported its emphasis on occupation-based practice (Clark and Lawlor 2009; Pierce 2014). Therefore, before moving into the discussion on the play and environment, it is noteworthy to explore children’s right to play from an occupational science lens. It is important to re-emphasise that play in this research is being studied as play occupation for the sake of itself.

Occupational science explicates restrictions to participation in occupation. Thus, postulating on the right of each individual to have an opportunity for participating in occupations that meet their needs, this concept is referred to as occupational justice (Molineux and Whiteford 2011; Durocher et al. 2014). The inability to engage in typical childhood occupations can result in occupational injustice (Mandich and Rodger 2006). Considering play as the children’s occupation, several factors may contribute to limiting full potential of participation. As mentioned earlier, children with LTC/LLC experience play ‘*deprivation’*, which indicates that other external circumstances reduce their opportunities of playing compared to their ‘healthy’ peers (Townsend and Wilcock 2004; Durocher et al. 2014). This could be due to the design of the playground equipment for instance, which precludes a child with limited mobility skills. As a consequence, this may lead to ‘occupation *marginalisation*’ (Mandich and Rodger 2006) where the opportunities for playing generally, or engage in specific types of play, are not available to them (Townsend and Wilcock 2004; Durocher et al. 2014). When these opportunities are being restricted based on age, gender or disability, the result can be ‘occupational *apartheid’* (Townsend and Wilcock 2004). Thus, ‘occupational *imbalance*’ in a child’s life is evident when they spend excessive time being restricted to specific activity or play type. This may also lead to ‘occupational *alienation*’: being isolated and disconnected from their occupations and peers (Townsend and Wilcock 2004). All of these will negatively influence children’s occupational identity as well as health (Townsend and Wilcock 2004; Mandich and Rodger 2006).

Attaining occupational rights can be achieved by empowering participation in meaningful occupation. According to the World Federation of Occupational Therapists (2014), every individual has the right to occupational opportunities that require them to take part in occupations which carry meaning for them and contribute positively to their own well-being. Occupational therapy addresses play performance issues in a systematic manner (Law et al. 1996) by considering the complex, transactional relationship of the child and the context where play occurs to achieve optimal performance engaging in playful experience (Rigby and Huggins 2003).

2.3 A supportive play environment

The successful performance of an occupation is dependent on the integration of the skills of an individual, the demands of an occupation, and the supports and challenges of the context (Strong et al. 1999). Given that children with LTC/LLC experience deprivation in their play occupation, the environment is a possible way to enhance their participation in play (Rigby and Huggins 2003; World Health Organisation 2019a). The selection of the environment resulted from the reviewed literature (Chapter 3) and the researcher’s background as an occupational therapist targeting environmental intervention. This is for the aim of getting a supportive play environment which is an environment that matches the children’s abilities and facilitates the occupational demands improving the occupational performance (explained further later in this section). For the purpose of this research, which aims to understand the features of a supportive play environment, the Person-Environment-Occupation Model of occupational performance (PEO) (Law et al. 1996) was adopted.

The PEO clearly summed up the occupational therapy profession's foundation of emphasising increasing the fit between person, environment and occupation (Turpin and Iwama 2011). This framework is a transactive approach in which its components are interdependent and occupational performance is the outcome of the dynamic interaction between them (Figure 2-3) (Law et al. 1996; Turpin and Iwama 2011). The closer the overlap between the elements, the greater the degree of harmony is achieved (Law et al. 1996; Strong et al. 1999). This idea is clearly evident in flow theory proposed by Csikszentmihalyi (1988) which was one of the theories that this model, the PEO model, was built on (Law et al. 1996; Strong et al. 1999). The flow theory is based on providing the right opportunities to have a positive engagement experience that can be achieved by matching an individual's abilities with the environmental demands (Csikszentmihalyi 1988). This good fit, as a consequence, has a direct influence on improving QoL and the well-being of an individual due to the ability to participate in valued meaningful occupations. Accordingly, the PEO is one of the overarching occupational therapy models which enables using theory to guide environmental intervention practice (Stewart and Law 2003).

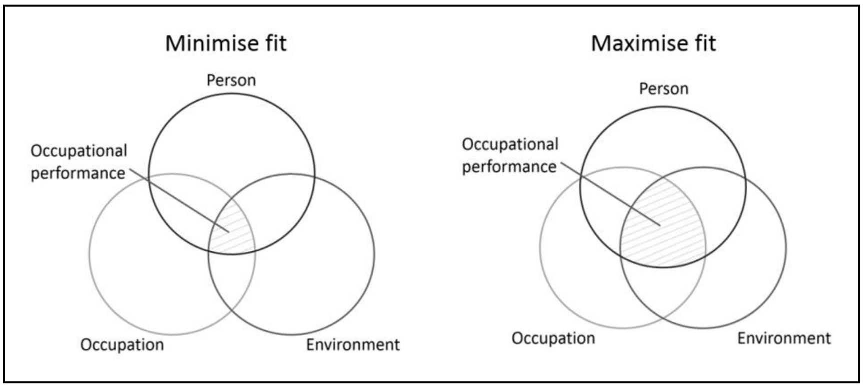


Figure 2-3 Changes to occupational performance as a consequence of variations in person, environment and occupational fit adapted from Law et al. (1996)

Nevertheless, the PEO model is compatible with the comprehensive rehabilitation model of the International Classification of Functioning, Disability and Health (ICF), by the World Health Organisation (2019a) – see Figure 2-4. It introduces the concept of including personal and environmental factors, which is in contrast to most of the provided health services that primarily focus on disability and impairment (Law and Baum 2005). After gaining permission from the World Health Organisation, Brown and Chien (2010) reproduced the fit between the ICF and PEO models by merging the figures of these two models, to illustrate the compatibility between the two models (see Figure 2-5).

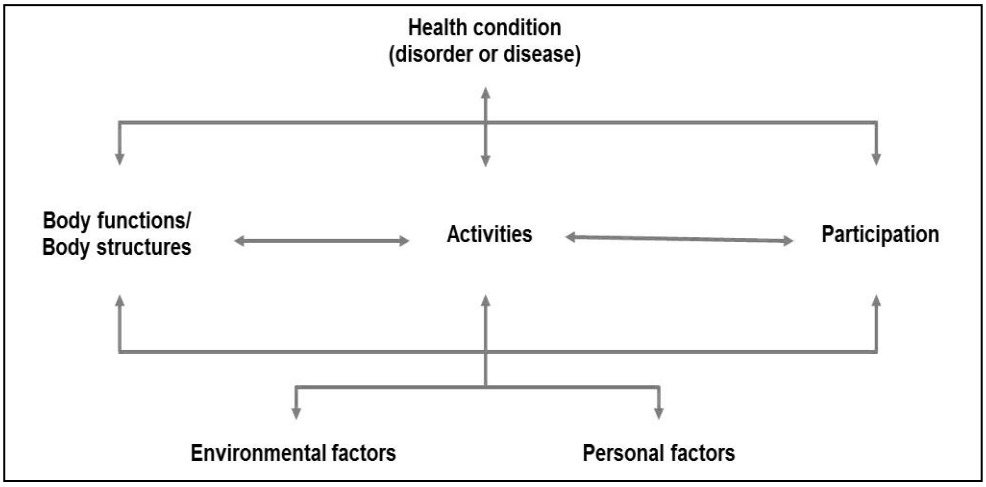


Figure 2-4 The ICF Model: Interaction between ICF components (World Health Organisation 2019a) used with permission

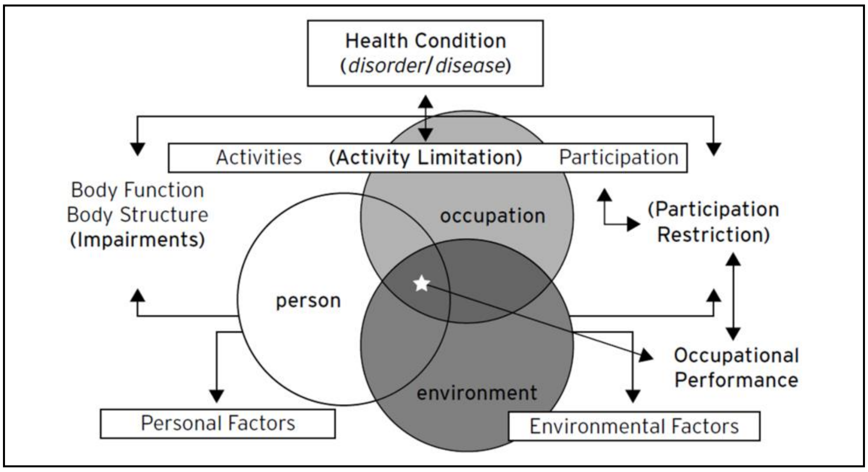


Figure 2-5 Conceptual interaction between PEO model and the ICF (Brown and Chien 2010) used with permission

The PEO model was considered in this research as an assistant tool for understanding the possibilities of enhancing environmental resources and reducing barriers within the social and physical aspects of the environment (defined in 1.2.2 Environment) (Strong et al. 1999; Rigby and Huggins 2003; Turpin and Iwama 2011). This was for the purpose of discovering possibilities to assist in maximising occupational engagement of children with LTC/LLC in play. This model is independent of culture, age, life stage, country and setting; thus, has been used with children with various health conditions and ranging severities (Strong et al. 1999; Stewart and Law 2003). Additionally, its use in this study facilitated investigating the two different cultures, Kuwait and the UK. Therefore, in this study, a *supportive play environment* is referred to as an environment that increases the fit between the play and the child; in which it matches the children's abilities and facilitates the occupational demands resulting in maximising the fit, and thus improving the occupational performance.

2.4 The culture

This study considered two societies – Kuwait and the UK – to broaden the understanding of the studied phenomenon. The researcher had ample access to these two societies, being from Kuwait and currently studying in the UK. Kuwait is a Middle Eastern Arab country whose predominant religion is Islam. There, the concept of PPC is considered newly-established. Fadhil et al. (2017) elucidate that palliative care is largely unaddressed within the Eastern Mediterranean Region. The UK however, a northern developed, predominately Christian country, recognised the first specialist PPC in the 1980s (McNamara-Goodger and Feudtner 2012). Each country was purposefully selected to capture some of the diversity of sociocultural elements impacting play for children with LTC/LLC.

In this section, two concepts are considered with regards to the culture: the cultural influence on illness and the cultural influence on play. This is because it is crucial to study the different cultures specifically before implementing or transferring concepts across cultures. al-Awamer and Downar (2014) compared clinicians with palliative care experiences in both Western and Middle Eastern countries. The results confirmed that some cultural, legal and religious aspects within the Middle Eastern countries are not considered within the western palliative care model (e.g., the preferences of not using specific terms such as cancer and the strong impact of religion on medical decisions such as the use of specific opioids for pain control). In addition, countries are becoming multicultural, that is, it is important to understand these differences as they continue to become more ethnically and culturally diverse. Bülow et al. (2008) claim that many regions across the world are no longer homogeneous in terms of their faiths; in Kuwait, for example, more than half of its population are non-Kuwaitis (69.6%) having different faiths and beliefs (The Public Authority for Civil Information 2018). Thus, cultural competence are particularly important for the delivery and receiving of healthcare (Brown and Sourkes 2006; Bülow et al. 2008). The cultural beliefs, values, and experiences shape each patient’s definition of illness and death (Martin and Barkley 2016) which is essential to bear in mind when considering the prognostic uncertainty nature of the children’s conditions where clinicians, children and their caregivers cannot know how long these children will live. Therefore, the comparison that was utilised in this study, consequently, can allow better implications from the findings regarding the environment of children’s play.

2.4.1 Illness and death in different cultures

The meanings of illness and death, within a clinical care environment, have cultural connotations (al-Awamer and Downar 2014; Martin and Barkley 2016). Faith, education and traditions are different cultural factors that could shape individuals' acceptance of, decisions about and actions towards an illness (e.g., treatment seeking or place of death) (Brown and Sourkes 2006; Silbermann et al. 2012; Håkanson et al. 2017).

Considering religious influence, Islam and Christianity are discussed as the main two faiths within Kuwait and the UK. One of Islam's teachings is that each individual will face death which cannot happen except by God's permission. Diseases, consequently, can be a cause leading to death which is already inevitable (Sachedina 2005; Mendieta and Buckingham 2017). Within Islam, pain and illnesses are recognised as a form of test and trials of faith (Sachedina 2005; Silbermann et al. 2012; Mendieta and Buckingham 2017). It has been advised in Islam by Imam Al-Hassan Al-Mujtaba 'Work for life as if you will never die, and work for your hereafter as if you will die tomorrow' (Al-Majlisi 1983). Accordingly, Islamic teaching encourages Muslims to seek treatment when they fall sick (Clarfield et al. 2003; Silbermann et al. 2012). Refusal of treatment leading to death or asking someone for help to die are never allowed in Islamic laws (Sachedina 2005; Bülow et al. 2008). Christianity holds much in common with Islam with tests and trials, and respect for medical ethics, especially beneficence and non-maleficence as every individual has intrinsic worth and dignity (Clarfield et al. 2003; Bülow et al. 2008). However, it differs in some significant aspects (Clarfield et al. 2003). While in Christianity patients have the ultimate right to decide at the end of critical terminal stages, in Islam, despite autonomy being respected, it is secondary to the patient's healthcare team's decision and the religious leader (Clarfield et al. 2003; Bülow et al. 2008). In their review on palliative care in Islamic countries, Mendieta and Buckingham (2017) assert that stopping treatment cannot be easily accepted by Muslims. They have a strong faith in waiting for a miracle. Relatives, in addition, usually have unrealistically high expectations from the medical care team (Mendieta and Buckingham 2017).

Nevertheless, some factors are well studied in specific communities while others are not. An example of this is the place of death. Bluebond-Langner et al. (2013) found in their systemic review that home is the preferred place of death for children and young people; however, the reviewed studies were conducted within western countries only, including the UK, Germany, France, Australia, the United States and Canada. Mendieta and Buckingham (2017), on the other hand, discussed in their review on palliative care in context of Islam and highlighted that some Muslims believed that dying must not occur in hospitals as it will interfere with some customs of Islamic teachings: for instance, of visiting the sick patient.

This does not suggest, however, that there is uniforms regime within the one religion or the Middle Eastern countries for example (Bülow et al. 2008; Baddarni 2010; Silbermann et al. 2012). There are always different factors influencing the patient's culture within the same region including psychological, educational and socioeconomic statuses. Despite acknowledging these differences, it is a fact that the healthcare environments are designed to be used by all; this therefore emphasises the importance of having an environment that suits the different needs (See Chapter 1 – 1.4 The positionality of the research).

2.4.2 Play in different cultures

Play is not an isolated event; rather, it is about the interaction with the sociocultural context (Larson 1995; Ray-Kaeser and Lynch 2017). Researchers acknowledged the proposed variations across and within cultures regarding the universal play dimensions (Rubin et al. 1983; Haight et al. 1999; Hughes 2010). Across human societies, family structural arrangements, cultural beliefs and practices have influence on the expression of play, the determination of play partners, the setting in which play occurs and time allowed for play (Rubin et al. 1983; Parham 2008; Hughes 2010; Roopnarine 2011). As a result, the adoption of the comparison design between cultures was a vital approach employed to focus on when studying children's play. This is particularly the case because play is a concept that is under-studied across the different cultures regarding children with LTC/LLC despite the fact that it is one of the most common elements of childhood across cultures (Smith 2010; Roopnarine 2011).

In spite of the acknowledged cultural differences, play in middle childhood (the age of the studied population, see Chapter 4 – 4.2 Research settings and participants) is characterised with specific common features which are worth mentioning. During this age, peer groups are prominent, as children enjoy being together in addition to having play interest in physical play, electronic games, dramatic play, collecting and trading, and arts and crafts activities (Rubin et al. 1983; Parham 2008; Hughes 2010). Available evidence, though, suggests a universal trend towards less active and outdoor play, and an increase in adults' direction and supervision compared to previous generations (Gray 2011; Gleave and Cole-Hamilton 2012; Murray 2018). Pynn et al. (2019) suggest that this shift could be a result of the perception towards ideal good parenting that contradicts the notion of active free play. It appears that many of the recent published papers on children's play generally in Kuwait are regarding their use of electronic devices (Alazemi 2015; Dashti and Yateem 2018) while in the UK it is more about their physical activities (Brockman et al. 2011; Jago et al. 2017); however, both express similar concerns which is the reduction of traditional play. Therefore, it is important to highlight here that this is the case with normally developing children;

hence, the situation is apparently more complicated with children with LTC/LLC, which will be explored further in the next chapter (Chapter 3).

2.5 Summary of the chapter

LTC/LLC are characterised with shortened lifespan and prognostic uncertainty. This makes play more valuable and important for the children to be included in their parallel planning of care to live their childhood. More specifically this is achieved by focusing on the play for its own sake as children's occupation. Enabling play preserves the children's occupational rights for their participation in valued occupation that can contribute to their health and well-being. A supportive play environment is a proposed strategy for enhancing children's play that matches the children's needs and abilities with the environmental demands. Investigating this concept in two different countries – Kuwait and the UK – can advance the understanding of the studied phenomenon and enhance the implications of its findings. However, it is crucial to acknowledge cultural differences given their association with the perceptions of illnesses and nature of play in the different communities. The LTC/LLC and its relation to children's play in particular is explored in the next chapter.

Chapter 3 Literature review

This chapter reviews empirical studies discussing the play of children with LTC/LLC. The chapter begins with a description of the methodology used in this review as well as the employed data sources and search strategy. There follows a discussion of the selected papers, the thematic analyse and synthesis of the studies. The chapter concludes with the review's gaps and a statement of the emergent research question and objectives of the study.

3.1 Review methodology

A scoping review was utilised in this literature search since very little is known about play of children living with LTC/LLC. This scoping review assisted in mapping the available literature broadly and comprehensively (Arksey and O'Malley 2005; Armstrong et al. 2011; Norman and Griffiths 2014). As a consequence, it facilitated identifying the research gaps in order to build a more precise research question for this thesis (Davis et al. 2009; Norman and Griffiths 2014). Aveyard (2014) and Peters et al. (2015) have been referred to as guidance to conduct and report this scoping review to increase the robustness of its findings.

3.2 Review method

Given that children with LTC/LLC experience disruption in play, in order to understand the phenomenon, the review was based on the following question: 'What is known from the existing literature about the everyday children's play who are between the ages 5-11 living with LTC/LLC at any setting (home, hospital or hospice) and in any country?' Accordingly, this question guided the decisions on sources for inclusion in the review and the selection criteria which are detailed in the next sections (Peters et al. 2015). The review was conducted using a stated protocol to promote the reliability of the findings (Cronin et al. 2008; Aveyard 2014; Peters et al. 2015).

3.2.1 Data sources and search strategy

To extract relevant literature, a comprehensive search was conducted drawing on different sources of data from a range of professional contexts including health, palliative care, social services, sociology studies and design and architecture-related topics of the environment. This included multiple searches in electronic databases (AMED, CINAHL, PsychINFO, Medline, Embase, Web of Science, Scopus, ASSIA and Cochrane Library) (Table 3-1). In addition, the search also included Grey literature, manual searches of relevant journals (see Appendix B) and reference lists to ensure the topic was covered from a variety of sources (Cronin et al. 2008; Thomas and Harden 2008). The search was limited to papers published between 1990 and March 2019. Although it can be considered a long time period, this was selected due to the limited number of available studies. The researcher only searched Arabic and English written literature to limit the chance of mistranslation from other languages in which the researcher is not fluent.

Table 3-1 The accessed electronic databases

Database	The scope/rationale for choosing	Applied limits
Embase	Embase (1980-2019) covers human medicine and related biomedical research.	Language: Arabic and English Date: 1990 to March week 3 2019
CINAHL	Cumulative Index of Nursing and Allied Health Literature Plus. It covers journals related to nursing and health-related publications.	
Medline	Medical Literature On-Line which is a service of the National Library of Medicine and additional life science journals.	
PsycINFO	Psychology Information that covers international literature in psychology and related fields.	
AMED	Allied and Complementary Medicine Database contains records for articles relevant to alternative treatments including complementary medicine, occupational therapy, hospice care and palliative care.	
Web of Science	Provides peer-reviewed scholarly journal articles in the sciences, social sciences, arts and humanities.	
ASSIA	Applied Social Sciences Index and Abstracts which covers research in the field of social science.	
Scopus	Scopus provides research output in the fields of social sciences, and arts and humanities.	
Cochrane Library	Systematic reviews of literature on medicine, nursing and allied health professions.	

The main search terms (see Table 3-2) ‘children’, ‘play’, and ‘LTC/LLC’ were selected from the overall research topic. The search was not limited to include the play environment; hence, to understand the concept of play and how it relates to children with LTC/LLC generally and account for any other related factors. A thesaurus was also used as a guide for terms to locate any relevant articles (Creswell 2014). Boolean operators (OR and AND) and search symbols (see Appendix C) were used in combination with different keywords and subject headings (also called MeSH, Medical Subject Heading) to ensure that as many related topics as possible were covered (see Table 3-2). An experienced librarian reviewed the search strategies and the search terms used, as did the researcher's academic supervisors.

Table 3-2 Search terms used

Children		Play		LTC/LLC	
OR		OR		OR	
child* pediatric* paediatric* "Pediatrics" "Chronically Ill Children"	AND	play* game* toy* recreation* entertainment* disrtact* "Play and Playthings" "Play Therapy" "Childhood Play Behavior" "Childrens Recreational Games" "Recreation"	AND	"life limit*" "life-limit*" "life short*" "life-short*" "life threat*" "life-threat*" "chronic ill*" "chronic condition*" "chronic diseas*" "chronic diagnos*" "terminal ill*" "terminal condition*"	"terminal diagnos*" "terminal diseas*" "sever disabilit*" "Terminally Ill Patients" "Terminal Cancer" "Chronic Illness" hospice* "palliative care*" "end of life" "end-of-life" "terminal care"

3.2.2 Selection criteria

The following Table 3-3 summarises the inclusion and exclusion criteria of the reviewed studies. To be included in the review, studies must have discussed the everyday play of children with LTC/LLC. The authors needed to be clear in their results regarding the sample group. The included studies had to have mentioned either life-threatening or life-limiting conditions, palliative or end-of-life care, or long-term complex health conditions. The reviewed studied also needed to have included children between 5 and 11 years. This is because the middle childhood ages were the focus in this thesis (detailed in the next chapter; see 4.2.2 Participants' selection criteria). The criteria were not restricted to place of play (e.g., home or healthcare setting) or country of publication. Despite acknowledging the potential cultural influence on play, this is an under-researched field and therefore studies were included irrespective of country of origin.

Non-research literature (anecdotal views or opinions) was excluded because they only described the authors' expectations or their anticipation of the way things might happen rather than their reality. In addition, studies examining the effectiveness of play, such as play with therapeutic intent (e.g., sand play) or play as distraction (e.g., in a hospital's waiting area or emergency department) were excluded. Research papers focusing on staff or parents' satisfaction regarding the service/facility were also excluded. This was due to the aim of reviewing the children's play.

Table 3-3 Inclusion and exclusion of the literature review criteria

Inclusion criteria	Rationale
• Arabic and English written papers	• To limit the chance of mistranslation from other languages.
• Publications between the years 1990 to March 2019	• To ensure the reviewed information is valid. Although it can be considered a long time period, this was included due to the limitation of available studies.
• Publications in all countries	• Despite acknowledging the potential cultural influence on play, the fact is that this is an under-researched field and the main interest at this stage is exploring the play of children with LTC/LLC.
• Studies discussed the daily play of children with LTC/LLC	• The review's aim is to explore the daily play in children's lives.
• Studies discussing play of children covering the ages 5-11 years	• Play in middle childhood ages was the focus in this thesis.
• Children's play at home or within the hospital or hospice setting	• To understand their play generally.
Exclusion criteria	**Rationale**
• Non-research literature (anecdotal views or opinions)	• They only described the authors' expectations or anticipated the way things happen rather than their actual reality.
• Topics about play as distraction (e.g., in a hospital's waiting area or emergency department) or play as therapy	• Benefits of therapeutic play are already well established.
• Studies focusing on staff or parents' satisfaction regarding the service/facility	• The focus of the review is children's play.

3.3 Research outcome

A vast number of papers were identified (see Appendix D), perhaps because of the broad search terms used; however, it was important to review all the relevant possibilities. To determine the relevance of a paper, the titles and abstracts were initially screened, and then the full papers were reviewed to decide whether each met the eligibility criteria (Table 3-3).

3.3.1 Study selection

After removal of duplicates, a total of 4,884 studies of potential interest were retrieved from the literature search. The records were thereafter screened by title and abstract resulting in 323 papers which were fully reviewed against the inclusion and exclusion criteria. The excluded studies were mostly because they were non-empirical research, studied play's therapeutic effectiveness, evaluated therapeutic camping programmes on children's conditions, or targeted other age groups, i.e. adolescents only. This process generated 16 relevant papers for inclusion in this review (see Figure 3-1).

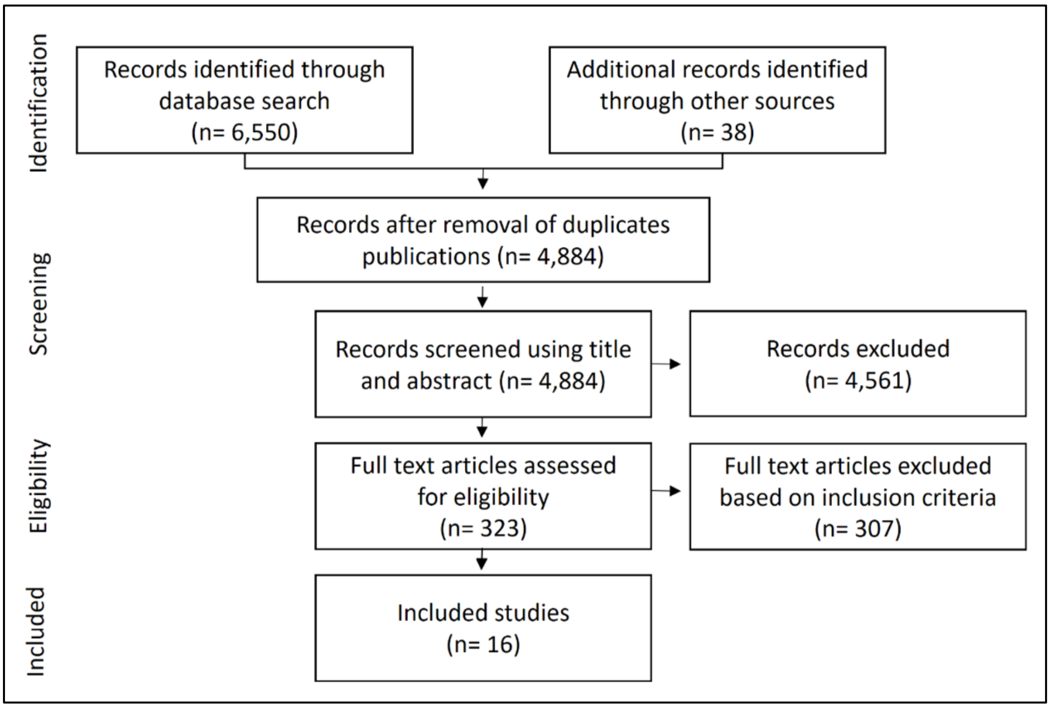


Figure 3-1 PRISMA flowchart of study retrieval and selection process

3.3.2 Data extraction and appraisal

A critical appraisal skills programme (CASP) and the Joanna Briggs Institute Critical Appraisal Tools were employed to appraise the evidence and assess the quality of the reviewed papers (Cronin et al. 2008; Thomas and Harden 2008; Joanna Briggs Institute 2017b, a; Critical Appraisal Skills Programme 2018). The appraisal guides were selected based on study design; i.e. qualitative guidance was used, and where the study was mixed in design, it was used along with a quantitative guide. Each of the relevant papers was read and logged into a summary table (see Table 3-4) detailing the key characteristics of the studies as follows: purpose, design, sample, main findings and key strengths and weaknesses points. The reviewed papers' quality was also assessed and highlighted to identify the quality of reviewed studies. During this process it was evident that common themes were emerged.

Table 3-4 Summary of the selected studies' characteristics and findings

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Rabiee et al. (2005) UK	Identify priorities of children with disabilities and their families regarding outcomes of social care and support service	Qualitative semi-structured interviews with parents and children (whenever the child was not able to participate, other informants, who knows the child well, participated). Visual and non-verbal techniques used with children who does not use speech for communication	Purposive sampling of 50 families (26 families who had a child (0-18 years old) with complex health care needs and 24 who had a child (3-18 years old) who does not use speech for communication	The families and some of the children have the desire for the child to live life as non-disabled child: having interest, future and independence. Children mostly enjoyed talking about friendships. The access to leisure opportunities is significantly influenced by the child's health and wellness. However, the available options for social and leisure activities are limited.	Strength: appropriate method used, especially addressing those with limited communication skills Weakness: the final sample is not clear and the results are not well presented	Average

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Aldiss et al. (2009) UK	Identify the views and experience of children with cancer about the hospital care	Use of play and puppet as an approach to collect data during the interviews	Purposive sampling of 10 children (4-5 years old) diagnosed with cancer	Children draw the focus on having volume of and accessibility to toys, playroom and activities as the most important features of a hospital. They mentioned very little about the illness and treatment. Missing parents and friends during hospitalisation was also highlighted.	Strength: clear sample and sampling method Weakness: limited literature review and vague gap in the literature	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Gibson et al. (2010) UK	Investigate experience and views of children and young people receiving cancer care to present a model of communication and information sharing	Qualitative exploratory study utilising three participatory-based techniques according to the participant's age group (play and puppet, drawing and writing techniques and interviews)	Purposive sampling of 38 participants diagnosed with cancer (10 young children between 4-5 years, 17 older children between 6-12 years and 11 young people between 13-19 years)	Playrooms and toys are the primarily reason for satisfaction with hospitals among children. However, they were concerned about the limited play opportunities (e.g., toys, areas, playmates) and the influence of their condition on their play. Children's preferences for communication and information regarding their condition are affected by their age.	Strength: the findings clearly state and segregate the perspectives of the three age groups Weakness: limited literature review regarding the studied concepts	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Kirk and Pritchard (2012) UK	Investigate parents' and young people's perspectives of hospice support	Mixed method approach using postal surveys followed by in-depth qualitative interviews	108 questionnaires (49.8% response rate) from families who have children (2-30 years old) who had used the hospice in the previous two years. Also in-depth interviews with 12 parents (of children aged 6-20 years old) and 7 young people (9-22 years old) who were purposefully sampled from the postal survey	The participants expressed high levels of satisfaction with the quality of care in the hospice. Parents acknowledged the clinical and family-focused care while the young people enjoyed the opportunity to meet friends. The need for more age-appropriate activities and facilities was highlighted.	Strength: the use of a mixed method and piloting the questionnaires used. Weakness: the analysis process was not illustrated precisely.	Average

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Angstrom-Brannstrom (2013) Sweden	Describe a child's experience of being cared for until death focusing on the comfort and discomfort factors	Fields notes from observations, the child's drawings and his comments on them and interviews with him, his mother and a caring nurse	9-year-old boy diagnosed with cancer, his mother and a caring nurse	Comfort of a dying child can be enhanced by having the family close and experiencing normal daily activity (e.g., drawing and playing). Being home facilitates engaging in everyday activities.	Strength: use of more than one method in collecting data which enhanced credibility Weakness: single case study which limits transferability	Average

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Lambert et al. (2014a) Ireland	Investigate children's perspectives of ideal hospital social spaces	Exploratory design utilising participatory art-based approach using semi-structured interviews and group workshops that incorporated drawings and arts and crafts	Purposive sampling of 55 children (5-8 years old) in 3 randomly selected hospitals with various health conditions and severities including chronic cases and haematological, oncological, metabolic and respiratory conditions	The need for readily available, freely/independently accessible and integrated leisure activities for creating positive hospital experience and social connectivity.	Strength: despite the fact that interviews were not audio recorded, immediate electronic field notes were typed following the interviews Weakness: lack of the sample enough details	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Lambert et al. (2014b) Ireland	Explore children's perspectives of ideal physical design features of hospital built environment	Exploratory design utilising participatory art-based approach using semi-structured interviews and group workshops that incorporated drawings and arts and crafts	Purposive sampling of 55 children (5-8 years old) in 3 randomly selected hospitals with various health conditions and severities including chronic cases and haematological, oncological, metabolic, and respiratory conditions	The children valued colourful, creative interior environment. They highlighted the need for easy access to open spaces or garden that allow free movement activities and need for age- and gender-appropriate play options. They also highlighted the need for adaptive facilities and activities for those with restricted movement.	Strength: clear description of the participants and more than half of the sample had previous hospitalisation experience Weakness: it lacks direct quotes to guide the reader to the particular findings	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Riet et al. (2014) Thailand	Identify nurses' experience regarding the healing environment, garden, to support sick children	Qualitative study using narrative inquiry utilising three focus group interviews	8 nurses (2 head nurses, 3 ward nurses and 3 nurse administrators) working in two children's wards that includes terminally ill patient	The garden as a non-clinical environment supports the sick children as well as their families: happiness, relaxation, distraction and social interaction. It also has positive benefits for children as a space to play and in a safe environment, where they learn to cope with their prognosis and participate in educational activities during their hospital stay.	Strength: the reflexivity was addressed Weakness: children's stories regarding their experience were studied from nurses' perspectives	Average

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Silva and Cabral (2014) Brazil	Investigate the impact of cancer on the dimensions of children's play	Qualitative design in accordance to creative and sensitive method using lifeline and speaker map	22 relatives of seven children (school age) receiving outpatient cancer treatment	The illness itself and its treatment act as barriers to children's play, especially affecting their active play, and leave the child weakened with limited ability for physical mobility. However, the participants believed that play is a significant part of normal childhood which children need to participate in.	Strength: clear analysis process Weakness: lack of the sample's details who were not only parents of children, rather other relatives	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Graham et al. (2015) UK	Explore parents' perspectives regarding the experience of their children with severe cerebral palsy in terms of their everyday play and the therapeutic use of play	Interpretivist qualitative study using in-depth semi-structured interviews	Convenience sampling of 7 parents of children (aged 17 months to 6 years) with severe cerebral palsy	Parents believed that children's play is an element of their daily routine. On the other hand, it places a burden on them due to the support they must offer to facilitate their children's play. Some parents perceive play and therapy as separate entities, while others feel guilty when not incorporating therapy into their children's play.	Strength: clear description of the analysis process and useful practical implications Weakness: the use of convenience sampling with participants who knew the aim of the study	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Lima and Santos (2015) Brazil	Understand the children's perspectives about the influence of play in the care process during hospitalisation	Descriptive exploratory qualitative study using photographic recording and semi-structured interviews	8 children (aged 6-12 years) who were hospitalised for cancer treatment	Children prefer activities that can be easily performed in their own beds. They mostly use electronic devices as a form of entertainment. But they also engage in watching television, using toys and drawing. The different recreational activities are highlighted to provide fun, joy, distraction and interaction.	Strength: thick description of the participations which allows transferability Weakness: sampling method was not indicated	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Mufti et al. (2015) Pakistan	Explore the lived experience of children with beta-thalassemia major	Qualitative study exploring children's experiences using two stages: stage one utilised a focus group and role play with the findings subsequently used in stage two for further exploration through individual interviews	Purposive sampling of 12 children (aged 8-12 years) diagnosed with beta-thalassemia major	Personal as well as contextual factors are shaping children's experiences including societal discrimination and self-identity. Children adopted cautious lifestyles due to their condition. As a consequence, they tend not to participate in lots of play activities, especially ones requiring active physical movement. Consequently, this adversely affected their friendships.	Strength: managing the power relationship between researcher and children Weakness: the research analysis process was not clear in how stage one guided stage two or how the second was analysed	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Verschoren et al. (2015) Belgium	Investigate children's hospital stay experience and how architecture may contribution to improve this experience	Exploratory study, employing observations in a child oncology ward with face-to-face interviews with children and their parents and focus group interview with hospital staff members	4 children (8-14 years old) who were hospitalised in oncology ward, one of their parents and 5 stuff members who work with young children on a daily basis (2 psychologist, pedagogical staff member, head nurse and oncologist)	The children need the chance to continue partaking in normal everyday life. In order to design a child-friendly hospital, there was not much concern on specific colours or theme; rather there is a need for adapted places for play and distraction and sufficient places for social interaction.	Strength: clear use of method and collected from different perspectives Weakness: obtaining ethical approval was not demonstrated	Average

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Nabors et al. (2018) USA	Explore family perspectives on coping for a child with chronic illness	Qualitative descriptive study using interviews	Convenience sample of 8 children with chronic illness (5-12 years old), 12 siblings and 17 guardians (mothers, grandmother and aunt)	Children with chronic illness missed their daily routines and feel lonely during hospitalisation. They wished to go home with their family and also pets. Siblings are the usual playmates during hospitalisation with whom they share interest and enjoyable moments.	Strength: data triangulation by interviewing children, their siblings and guardian Weakness: sampling criteria needs further clarification	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Adistie et al. (2019) Indonesia	Identify the needs of children with terminal illness from parents' and nurses' perspectives	Qualitative descriptive study using individual interviews and focus group	Purposive sampling of 11 parents of hospitalised children with terminal illness (5-20 years old) and 15 nurses with at least 3 years of experience working in a paediatric ward	One of children's psychological needs is motivation through entertainment and jokes. Children have also social needs which are to play and to be with loved ones including their family, school friends and peers.	Strength: confirmed trustworthiness through obtaining interrater reliability agreement and member checking Weakness: more explanation is needed for the presented findings	Good

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Witt et al. (2019) Germany	Investigate the impact of Leukaemia on children's play from parents' and professionals' perspectives and to identify potentials to prepare for a pretend play intervention	Qualitative study using semi-structured interviews	Convenience sample of 13 parents of children with Leukaemia (between 3- 13 years old) and 15 professionals in the field of paediatric oncology	Having Leukaemia reduced the children's ability to participate in play, in particular active play and playing with peers. This is due to the child's physical limitations, infection and delayed social skills. Children mostly engage in solitary play such as watching TV/movies, playing with tablet/smartphone or reading.	Strength: the findings were well presented and supported by participants' quotes Weakness: objectives of the study were not clearly set	Average

3.3.3 Data analysis

This review utilised thematic analysis and synthesis in deriving the main issues addressed in relation to the play of children with LTC/LLC in the existing literature. This was carried out inductively by initially generating free codes of related areas, followed by developing descriptive themes that assisted in integrating the findings from the studies through a logical flow in relation to continuity and consistency to arrive at suitable findings (Cronin et al. 2008; Thomas and Harden 2008). Samples of the codes were checked by the academic supervisors who also reviewed the analysis to ensure consistency.

3.4 Findings

A limited number of studies, 16 papers, have explored play in children with LTC/LLC; in fact, only four studies focused on play. For other studies, examining play was not the main purpose of the research. Lima and Santos (2015) explored the perspectives of children regarding the influence of play in the care process during hospitalisation, and Silva and Cabral (2014) and Graham et al. (2015) investigated the impact of children's health conditions on dimensions of their play. Witt et al. (2019), on the other hand, explored both the impact of health condition on children's play and possibilities of using play interventions. Another eight studies that explored children's experiences receiving care addressed play to some extent in their findings, despite the fact it was not the intent of the paper (Rabiee et al. 2005; Aldiss et al. 2009; Gibson et al. 2010; Kirk and Pritchard 2012; Angstrom-Brannstrom et al. 2013; Mufti et al. 2015; Adistie et al. 2019; Nabors et al. 2019). Some aspects of play were also addressed in another four studies whose main purposes were exploring the hospital environment (Lambert et al. 2014b, a; Riet et al. 2014; Verschoren et al. 2015).

With regard to the thematic analysis and synthesis used (detailed in 3.3.3 Data analysis), the findings can be classified into three main themes: continuity of play, influence of the health conditions on play and play opportunities which are discussed next. However, before presenting the findings of this review it is worth emphasising the strengths and limitations of this review.

3.4.1 Strengths and limitations of the review

In this review, a systematic approach was utilised in collecting the papers, although it is not considered a systematic review. This was due to the lack of a predefined precise research question because of the limited literature and knowledge available in this field (Green et al. 2006; Armstrong et al. 2011).

The search was also limited by not using some search terms as leisure and clowns or giggle doctors (performers who are employed to entertain children in hospital/hospice settings). This decision was because of the ambiguity and lack of clear distinction among the terms. It is a fact that there are challenges encountered in the use of interchangeable terms associated with play as leisure, leisure is in contrast to play as it takes place in residual time only (Sellar and Stanley 2010; Lynch and Moore 2016). Not using this term, leisure, might accordingly result in limiting the retrieved studies. Additionally, the decision not to use the clowns/ giggle doctors was based on the focus of the review, which is children's daily play, not therapeutic play. Nevertheless, these people are available to some children but not all. A separate study on the clowns/ giggle doctors and their role in palliative and end of life care might be warranted but this was not the aim of this study to investigate this group of staff. Furthermore, searching journal articles only written in English and Arabic might have excluded other relevant studies as only 16 studies were identified as appropriate. Fifteen of the studies were qualitative in design, except for one, which used a mixed-methods approach, and this was expected due to the nature of the studied concept. These reviewed studies helped in understand some aspects of the phenomenon (Daly et al. 2007).

Interestingly, the majority of the studies included children's voices despite the fact that children with such critical health conditions are generally under-represented in research. Children are usually excluded with studies including their carers instead, which is likely due to ethical issues, ignorance and a belief that children are less cognitively able to communicate (Scott 2008; Adistie et al. 2019). This review only included studies with children or carers representing the children, as participants were between the ages of 5 and 11 years. A number of the reviewed studies included adolescents in addition to parents of children (Kirk and Pritchard 2012; Graham et al. 2015; Adistie et al. 2019), healthcare professionals (Riet et al. 2014; Adistie et al. 2019; Witt et al. 2019) and relatives of children, e.g., parents, siblings, grandmother and aunts (Silva and Cabral 2014; Nabors et al. 2019) who may not always able to provide a complete picture of the child's actual needs or views; although, their inclusion may give a diversity of views. Some researchers studied children from birth until late adolescence (Rabiee et al. 2005; Adistie et al. 2019) and did not segregate the perspectives of the different age groups or acknowledge the type of reporter in their findings.

A quality assessment of the studies revealed that the majority were rated as either good or of average quality, which can suggest a reasonable quality overall. Almost all of the studies set a clear aim and used an appropriate design and method to answer the research question. However more thorough details regarding the methods and modes of analysis are expected, including information about the participants and the presentation of the findings. These shortcomings contributed to the average score. Thus, the process of reaching particular findings was not always clear, particularly as the reflexivity and the examination of the researcher role was not transparent in most of the studies. Despite this, a number of important implications that may help to inform future practice and research arise from this review's findings.

The findings that emerged from this review (presented in the next sections) should be considered with caution, particularly given that half of the studies were limited to patients with cancer. Additionally, children who were experiencing physical limitations were also not well covered in this review; either they were excluded or their inclusion was not made clear in the reviewed literature.

3.4.2 Continuity of play

Children and their parents hoped that the children were able to continue their normal everyday lives, of which play is an integral part (Rabiee et al. 2005; Aldiss et al. 2009; Graham et al. 2015; Verschoren et al. 2015; Nabors et al. 2019; Witt et al. 2019). It was demonstrated that children enjoy playing (Aldiss et al. 2009; Angstrom-Brannstrom et al. 2013; Graham et al. 2015; Adistie et al. 2019). Play aids in providing a sense of normality, and adds fun and happiness to their lives (Aldiss et al. 2009; Graham et al. 2015; Lima and Santos 2015; Adistie et al. 2019). Some children highlighted that they gained comfort while at home from play and everyday activities and missed many of these due to hospitalisation, such as building Lego, playing video games, colouring and reading (Gibson et al. 2010; Angstrom-Brannstrom et al. 2013; Lambert et al. 2014b; Nabors et al. 2019). Literature also reported that having the chance to play games they used at home during hospitalisation makes their stay better (Aldiss et al. 2009; Gibson et al. 2010; Lima and Santos 2015).

3.4.3 Influence of the LTC/LLC on children's play

Witt et al. (2019) found that children usually participate in sedentary play activities such as watching TV or movies, using tablets and smartphones which were also primarily solitary play. Lima and Santos (2015) further illustrated that the children mostly used electronic devices that can easily be manipulated in their own bed space as a form of entertainment. This can be seen as a result of the impact of the condition as demonstrated in the studies (Aldiss et al. 2009; Gibson et al. 2010; Silva and Cabral 2014; Graham et al. 2015; Mufti et al. 2015; Nabors et al. 2019; Witt et al. 2019). The findings reported in these studies indicated that the condition itself and its treatment restrict children's active play (e.g., riding a bike) and leave them weakened and with limited physical abilities (e.g., balancing difficulties or being attached to an infusion) to do things. This is in addition to the infection as a factor that led to isolation (Witt et al. 2019). Therefore, children had to develop a more cautious living style and follow the relevant precautions. As a consequence, they missed meeting siblings and friends and playing active games (Gibson et al. 2010; Nabors et al. 2019; Witt et al. 2019). This, therefore, limitied their play opportunities.

3.4.4 The available play opportunities for children with LTC/LLC

The very little available data in the literature on play in children with LTC/LLC revealed that available play opportunities can be considered a major reason for their limited participation in play. This includes the play equipment, spaces and playmates.

Play equipment: Despite that fact that toys were a necessary feature of the hospital for the children, participants complained about the limited availability of toys, the need for more age- and gender-appropriate activities (Aldiss et al. 2009; Gibson et al. 2010; Kirk and Pritchard 2012; Lambert et al. 2014b, a; Lima and Santos 2015) and maintenance and replacement of play tools (Riet et al. 2014). Play equipment stored in locked cabinets or high shelves was also negatively viewed by the children (Gibson et al. 2010; Kirk and Pritchard 2012).

Play spaces: In addition to the toys, the playroom was a most important feature of the hospital for a majority of the children as found by Gibson et al. (2010) and Aldiss et al. (2009). In another two studies, the participants clearly stated that the hospital was an unbearable environment (Angstrom-Brannstrom et al. 2013; Lima and Santos 2015); both studies reported that being in a hospital restricted play and took children away from their everyday routines. In addition, others were not able to use the playroom and some found it hard to only watch other children playing outside, without being able to play due to their health conditions (Gibson et al. 2010; Mufti et al. 2015).

Although, across the studies, playrooms with a wide range of activities were usually available in healthcare facilities, the specific open hours of these rooms were a cause for concern among the children (Aldiss et al. 2009; Gibson et al. 2010; Lambert et al. 2014b, a; Lima and Santos 2015; Verschoren et al. 2015). These rooms were usually closed after working hours and at weekends. Moreover, some children clarified their inability to use it or the other play areas either due to the setting's inaccessibility, their physical impairments/limitations, the need to follow precautions, or their medical intervention or isolation (Gibson et al. 2010; Lambert et al. 2014b, a; Mufti et al. 2015; Witt et al. 2019). Accordingly, children raised their concerns to have easy use of and access to play areas (Lambert et al. 2014b; Verschoren et al. 2015). Children also expressed the need for more interesting spaces (e.g., fitness room, swimming pool, and cinema) (Aldiss et al. 2009; Lambert et al. 2014b; Verschoren et al. 2015). Additionally, the bathroom was referred to as a place where enjoyable play takes place. In particular, bathing was the most common play time and the availability of bath-specific play toys was viewed positively (Lambert et al. 2014b; Graham et al. 2015).

Findings also emphasised the importance of having shared places for children to interact with each other. Some of the participants suggested that playrooms be integrated with the whole hospital or located in the centre of the facility (Lambert et al. 2014b, a) and requested relational spaces such as gardens (Lambert et al. 2014a; Riet et al. 2014; Verschoren et al. 2015). Other children mentioned the corridors and waiting areas as places where they could often get pleasant social interaction with others (Verschoren et al. 2015).

Playmates: The crucial importance of the social interaction was evident in the reviewed studies. Siblings, on one hand, were usual playmates and children missed them during hospitalisation (Angstrom-Brannstrom et al. 2013; Adistie et al. 2019; Nabors et al. 2019; Witt et al. 2019). Notably, their presence allowed the opportunity for play and laughter. The findings also highlighted that children mostly enjoyed talking about friendships, as reported by Gibson et al. (2010), Rabiee et al. (2005) and Kirk and Pritchard (2012). The latter study found that the majority of them liked school because they would get more opportunities for play due to the presence of more children. This is in line with Riet et al. (2014), who found that the garden at the hospital positively expanded the children's experience of social interaction as a place to play.

It is noteworthy to mention that Witt et al. (2019) demonstrated that most of children's play was with adults during hospitalisation. However, despite enjoying playing with parents, nurses and play specialists (Gibson et al. 2010; Graham et al. 2015), the time and energy required from the grown-ups to facilitate the child's play imposes burdens on these adults, resulting in limited opportunities. In most cases children were not able to play by participating physically and because of their limited capabilities, and this further disrupted their play with the grown-ups also (Graham et al. 2015; Mufti et al. 2015; Witt et al. 2019). Moreover, the presence of playmates was only part of the social environment where its impact was extended to include the cultural norms and support systems within the community. Mufti et al. (2015) demonstrate that children were aware about the discrimination in their community resulting from the illness they are living with. The children were also able to recognise the influence of this discrimination on losing friends. Being labelled as an unwell child in some communities means that other children will avoid making contact with that child. This negatively influenced children's self-image by viewing themselves as disabled, particularly their limited ability to move during play, which led to isolation (Gibson et al. 2010; Mufti et al. 2015).

3.5 Discussion

As drawn from the findings, the LTC/LLC may prevent children from fully experiencing their childhood by restricting their play. Often childhood activities are perceived of as ‘normal’ or as doing ‘normal’ childhood things (Glasper and Haggarty 2010). For children living with LTC/LLC, while they may aspire to such ‘normality’, achieving it may be challenging. Facilitating their access to a childhood that is, as far as possible, equitable to that of their peers in their communities (we might say ‘normal’) is a duty of healthcare professionals (Reilly 1974; Randall 2016).

Although a limited number of empirical studies have focused on this area, the 16 reviewed studies, which met the review’s eligibility criteria, identified a number of concerns regarding the play of children living with LTC/LLC. Those findings were presented in three key concepts: 1) the significance of continuity of participation in usual play and activities; 2) the influence of the health conditions on shaping children’s play; and 3) the availability of play opportunities during children’s hospitalisation. This review has enabled an insight into the play of children living with LTC/LLC, and alluded to some possible factors that assist in enhancing their participation in play.

Both the children and their caregivers acknowledged the essential role of play of aiding normality and continuity for children lives. The conditions, however, challenge and change the type of play they can take part in. This underlines the priority of understanding the types and reasons of play children were able/unable to participate in. Most of the play activities which were mentioned as affected because of hospitalisation seem to be easily carried out in a hospital setting (e.g., Lego or reading). Accordingly, more exploration is needed to discover the causal factors challenging their participation in their preferred play. The gap in this area might be because most of the studies’ focus was not directly on play, thus; there is a paucity of literature understanding the challenges to these children’s play experience and the opportunities available to them. This lack may indicate a predominance of the medical approach and the future-oriented perspectives of adults besides the lack of awareness of the major significant role of play in both being and becoming. Additionally, children who were experiencing physical limitations were not well covered in this review. This, as a consequence, underlines a crucial gap regarding the issues relating to children with more complex conditions.

Other aspects influencing children’s participation in play were the limited play materials generally, and the need for more age- and gender-appropriate toys in particular. However, this has not been elaborated on in the reviewed literature with clear examples and descriptions. Lambert et al. (2014a), for instance, gave very vague examples regarding the gender-appropriate play, claiming that girls play different things to boys on computers. Another example was on the age-appropriate toys where the study reported the available toys were only suitable for younger children. Drawing conclusions in reference to these general results highlights a huge gap in understanding children's actual needs and the exact meaning and interpretation of these needs. It is important to segregate the different participants' views in the findings, which was not always clear. It is noteworthy that the play needs of children vary considerably in terms of preferences and developmental play needs (Corsaro 2015).

On the other hand, the play spaces, as perceived by children, were not limited to playrooms; but were wherever they can enjoy themselves and have fun. The concept of the built environment's (i.e. physical environment) influence – indoor or outdoor – was not a focus among the studies of this particular population. This subsequently illustrates the need to investigate further the impact that the built environment has on play. This is particularly true given that some children were shown to experience difficulties when using the play areas, although it was not clear if the areas had been designed in a way that children with various abilities could enjoy and use them, nor what the factors limiting the use of these indoor and outdoor spaces were. Consequently, many emphasised that children's restriction in using the play areas affects their social play. This, on the other hand, can be evidence that the direct influence of the condition on play indirectly influences children's relationships with their playmates.

The social context and support is understood as the relationships between individuals and groups. Evidence generally highlights their essential role in providing a more nourishing social environment (Law 1991; Dunn et al. 1994; Law et al. 1996; Wilson et al. 2010; Nabors and Liddle 2017; Adistie et al. 2019). Despite this, what has been published in regard to this research population is very limited. This therefore restricts the possibilities of implementations of the findings, given that none of the reviewed studies was across cultures. However, the physical and social environments influence in relation to the children's play became clear. It is on this observation that the research question of this thesis was identified and the decision to focus on the environment was reached.

3.6 Summary of the review

The utilisation of a scoping review was essential in synthesising and summarising research evidence relating to play in children living with LTC/LLC. This is in order to broadly map this under-studied area as only limited literature is available. Following a systematic database literature search and selection process based on inclusion and exclusion criteria, a total of 16 studies were reviewed. These studies demonstrated that the play among children living with LTC/LLC is being influenced by their health conditions and the limited play opportunities. Social and physical environmental factors were evident as related to acting as enablers or hindrances to children's participation in play. However, these studies mentioned very little regarding children's preferences and the types of play that they were not able to engage in or the difficulties behind not using specific play areas. This is because of the lack of studies that focused on play. In addition, there was over-representation of patients with cancer with less consideration of those with more complex health conditions. This therefore limits the studies' generalisability, in addition to the earlier noted point that none was cross-cultural. As a consequence, there is an urgent need for the immediate attention of professionals to find alternative ways to enhance children's participation in play and thus enable best possible QoL whether that life is short, or extends into adulthood.

The discussed studies logically led to the purpose of this study through an identification of the gaps in the literature and forming a more precise research question as a result of the scoping review. Therefore, and in contrast to the aim of previous studies, this research adopted a unique angle to view play thoroughly. The social and physical environmental factors are to be studied in-depth as a way to facilitate children's participation in play.

3.7 Aim of the study

The aim of this study is to explore the different social and physical environmental factors that contribute to a supportive play environment for children with LTC/LLC while receiving inpatient healthcare services in Kuwait and the UK.

3.8 Research question

This research proposed to answer to the overall research question: 'What are the social and physical environmental factors that contribute to a supportive play environment for children with LTC/LLC within inpatient healthcare facilities?'

In order to answer this question, the following questions were explored:

- What are the characteristics of everyday play for children with LTC/LLC at the inpatient healthcare facilities?
- What are the social and physical environmental factors associated with their play?
- What are the differences in children's play and the environmental factor across different healthcare facilities; children's hospital ward and children's hospice?
- What are the differences between the children's play and the environmental factor across two communities, Kuwait and the UK?

3.9 Objectives of the study

Exploring the features of a supportive play environment for children living with LTC/LLC in this study was based on investigating children's play and the social and physical environmental factors. The study's objectives were to explore:

1. The children's play characteristics (e.g., children's play behaviours and areas of play) to understand the associated environmental factors.
2. The social and physical environmental factors associated with the participation of children with LTC/LLC in play, while such children are receiving inpatient healthcare services.
3. The differences between the children's hospice and hospital ward in terms of the present environmental factors and their association with children's play.
4. The cultural influence in each context of Kuwait and the UK on the environmental factors and the cross-cultural aspects between them.

Chapter 4 Methodology and methods

In this chapter, the methodology and methods used in the study are set out. The first part discussed the mixed methodology employed and the methodology of the used methods. This is followed by reporting the utilised data collection approaches alongside exploration of the sampling, recruitment, analysis and trustworthiness of the data. The chapter closes with explaining the process of integrating the two datasets.

4.1 Research methodology

4.1.1 Mixed methodology

This research adopted a parallel mixed-methods approach (Tashakkori and Teddlie 1998; Bryman 2016). The selection of this design was based on the research question set out in the previous chapter, to fill some of the identified gaps related to children's play and living with LTC/LLC, in addition to the researcher's philosophical stance (Teddlie and Tashakkori 2009; Turnbull and Lathlean 2015; Creswell and Plano Clark 2018). The latter was influenced by the pragmatism concept and the researcher's background in occupational therapy (discussed in Chapter 1) which shaped her way of understanding the worldview. Creswell and Plano Clark (2018) highlight two important aspects in this regard, which are ontology and epistemology. Ontology is a philosophical concept concerned with the nature of reality and the existing knowledge (Lichtman 2014; Neuman 2014). It includes the basic assumptions about what the reality is (Neuman 2014; Creswell and Plano Clark 2018). Epistemology is another area of philosophy that focuses on the creation of knowledge and the knowing that defines practice (Mitchell 2013; Neuman 2014; Creswell and Plano Clark 2018). The researcher acknowledges the different individuals' experiences and beliefs; in that the creation of knowledge could be substantiated by personal experience or by logic and reason, with all opinions being equal to consider (Mitchell 2013). As Rorty (1982) highlighted, in pragmatism, the idea of bivalence of all statements/beliefs is denied. The researcher recognises the existence of multiple realities and the multiple potential solutions to overcome a deficit or limitation in occupational participation. She also believes in the critical role of the context – i.e. environment – of performance in getting adaptive response. This concept was formulated and shaped from the interaction between the person, environment and occupation (see PEO model in Chapter 2 – 2.3 A supportive play environment) and that beliefs are expected to have meaning and predictable connections within their own context (Rorty 1999). Therefore, the researcher was directed to the generation of meaningful knowledge of children's real-life experiences. This is in addition to the significance of undertaking research *with* children and giving them the voice to elicit deeper understanding of their world (Christensen and James 2008b). Nevertheless, it was crucial to take into consideration the critical role and influence of the researcher in the construction of the knowledge (Robson 2002; Lichtman 2014).

The parallel mixed-methods design was adopted combining qualitative and quantitative data to answer the research question (Tashakkori and Teddlie 1998; Bryman 2016). The rich data yielded from the qualitative interpretivism approach were used alongside a statistical quantitative analysis (Tashakkori and Teddlie 1998; Lichtman 2014). Such integration can be a main advantage of mixed-methods research design (Teddlie and Tashakkori 2009; Robson and McCartan 2016). This, therefore, offset the deficits present in one paradigm by the complementary strengths of the other design (Creswell and Plano Clark 2018). The use of mixed-method design was the first considered form of triangulation – the use of multiple resources of data – which is called methodological triangulation (Figure 4-1) (Robson 2002; Teddlie and Tashakkori 2009; O'Cathain et al. 2010; Flick 2014). Consequently, it allowed more complete and comprehensive understanding of the studied phenomenon, thereby enhancing confidence in the conclusions (Flick 2014; Neuman 2014). Worthy of note is that the mixed-methods in this study was utilised with an inductive theoretical thrust in exploring this area as the study predominantly involves a qualitative approach (QUAL + quan) because of the exploratory nature of the research in investigating an under-represented topic (Collins et al. 2008; Teddlie and Tashakkori 2009; Creswell 2014). Data were collected in one phase, simultaneously using Q methodology (Figure 4-2), an integrated mixed method, and qualitative observational methodology (both methods are detailed later in this chapter). The data were collected initially from Kuwait between February and May 2018 and then from the UK between August and November 2018.

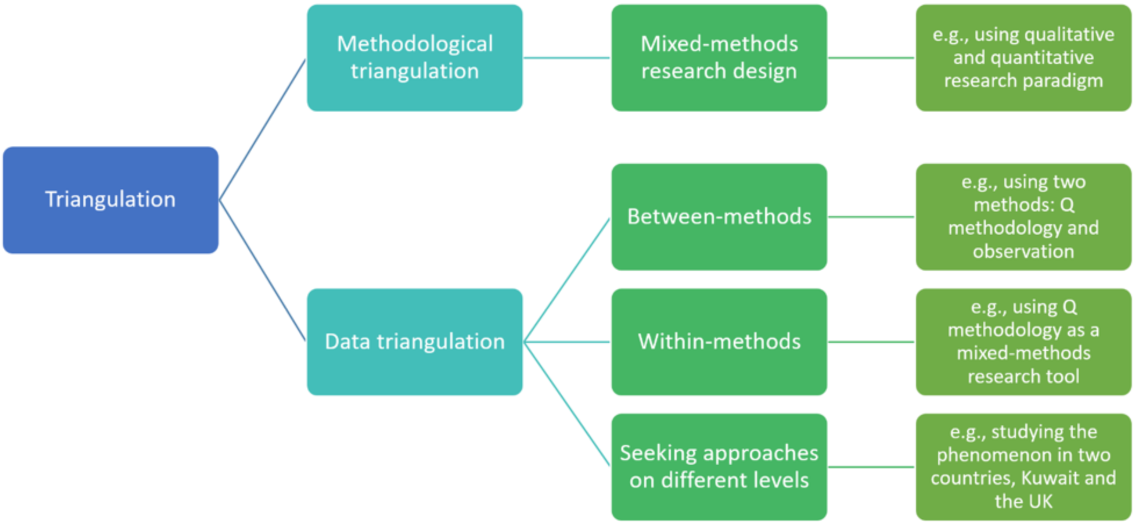


Figure 4-1 Types of used triangulation based upon Flick (2014) and Robson (2002)

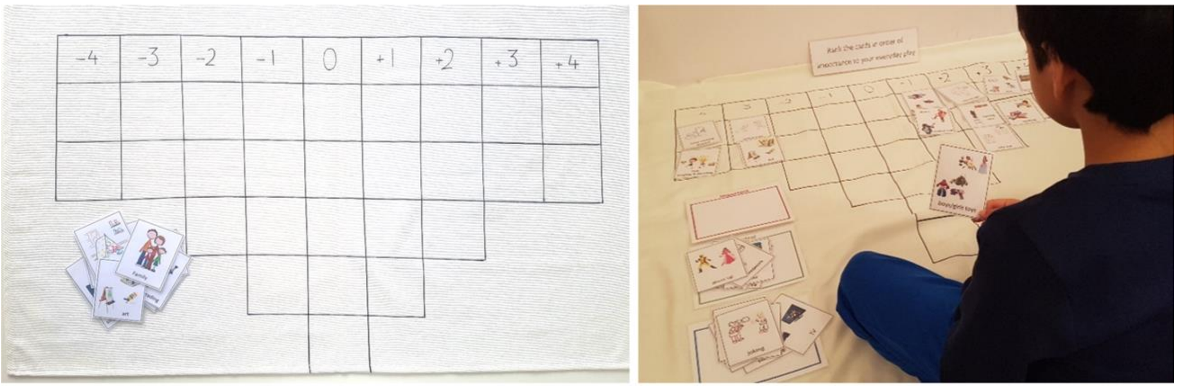


Figure 4-2 Q methodology

The second form of triangulation used was data triangulation (Figure 4-1). Q methodology was triangulated with observational data; hence, more than one method of data collection were used which is referred to as ‘between-methods triangulation’ (Robson 2002; Flick 2014). At the same time, Q methodology was a means of ‘within-method triangulation’ due to the fact that it is, by itself, a mixed-methods approach (see section 4.1.2 Q methodology); different methodological perspectives were taken in the framework of this single method (Watts and Stenner 2012; Flick 2014). Another data triangulation type considered was seeking approaches on different levels rather than only collecting more data on the same dimension (Flick 2014). This was attained by studying the phenomenon from two different cultures (i.e. Kuwait and the UK), two different settings (i.e. children’s hospital ward and hospice), and two different generational groups (i.e. children and caregivers); these variables are detailed in the next section (4.2 Research settings and participants). As a consequence, all these helped to enhance the data and enabled the study of the phenomenon from different angles and perspectives.

Prior to the selection of the two methods used, Q methodology and observation, a list of possible research methods and data source options were developed to guarantee thorough consideration of all potential options (Mason 2002). Account-related practicalities and ethical issues were also considered in addition to the children’s ages (Mason 2002; Christensen and James 2008a). The selection of the methods was based on their possibility to obtain children’s perspectives on several elements related to play and the environment, and therefore there were several possible data-collection methods. The list comprised, in addition to the selected methods, interviews and photo elicitation, diaries and photo diaries and other standardised questionnaires (presented in Appendix E). Despite the usefulness of these methods in informing the topic under study, the selected Q methodology and observation helped to move from only describing children’s views on play to understand the social and physical environments of play for children with LTC/LLC across cultures. This study was also built on the available studies; for example the literature was used to form the concourse of the Q methodology (see 4.3.1 Developing the Q set). Furthermore, the Q methodology allowed for systematic mapping of shared viewpoint on the studied phenomenon which would be difficult to attain from administering standard questionnaire or interviewing alone. Additionally, those other methods were found to either exclude large numbers of the population, relying on, or accessing, people's retrospective accounts or expected to be highly biased by the caregivers' interruptions (Mason 2002; Robson 2002). This is in addition to the point that children with LTC/LLC may experience communication difficulties besides, as Warming (2005) stated, children do not always prefer to talk. Therefore, the natural observational data collected directly from the healthcare environment alongside the Q methodology findings assisted in exploring the studied area from a very different and unique perspective.

4.1.2 Q methodology

Q methodology is a mixed-methods research approach, which uses an inductive research model and has close alignment with aspects of pragmatism which underpins this research (Stephenson 1980; McKeown and Thomas 2013). Using Q methodology, participants in this study were asked to prioritise aspects, in this case related to children's play environment according to their importance (e.g., play equipment that children prefer to play with or people who are important to be available to play). This method configures the basis for a science of subjectivity; acknowledging individuals' personal perspectives (Stephenson 1980; Brown 1993; Thorsen and Størksen 2010). Thus, it provided multidimensionality in the data by systematically capturing subjectivity; however, it also undertook rigorous statistical alongside the qualitative analysis (Watts and Stenner 2012) which is detailed next in 4.3 Method 1: Q methodology.

Q methodology is exploratory, designed to understand the personal viewpoints of a group of participants as a whole (Watts and Stenner 2012). Hence, the focus within the Q methodological studies is not on individuals' differences, as in the traditional R methodology. R methodology is concerned with testing prior assumptions and theories, focusing on the participants themselves by comparing the participants in specific traits or characteristics (Watts and Stenner 2012; McKeown and Thomas 2013). The participants in Q methodological studies, on the other hand, are classified into subsets according to their shared viewpoints, whereas in R methodological studies the participants are grouped according to their similar characteristics (Watts and Stenner 2012). This difference is further elaborated in this chapter in 4.3.4 when the Data analysis is explained.

The Q methodology was an essential tool for addressing the research question from a unique angle compared to other methods (presented in Appendix E). It allowed the researcher to explore children's preferred play things and factors they believed were important in relation to the studied phenomenon. The use of the Q methodology thus assisted in understanding the concept of ‘importance’ as it relates to children’s play and identifying similarities and differences across cultures when the results were compared. In another word, the Q methodology allowed identifying the important factors within the social and physical environments from the participants perspectives in a systematic way. Both, qualitative and quantitative approaches were utilised via this method. This identification of factors contributed to knowledge of what a supportive play environment entails for children with LTC/LLC, while they receive inpatient healthcare services. This knowledge, as a consequences, can assist in prioritising aspects to consider and focus on when providing care to children living with LTC/LLC and developing/modifying the healthcare settings. The methods used in Q methodology also look and feel like a fun game-like instrument for the children as well as for the adults. Hence, it allowed the participants to play an active and essential role in expressing their viewpoints. This, as suggested, made participation less threatening (see Chapter 8 – 8.1.4 Power-relationship), particularly for those who find that verbal expression to strangers is difficult (Ellingsen et al. 2014). Evidence supports that its nature, form and process, allow participants to feel at ease when making individual choices (Thorsen and Størksen 2010; Watts and Stenner 2012; Ellingsen et al. 2014). Nevertheless, it aided the children’s perceptual understanding which can be limited by their ages and developmental levels (Thorsen and Størksen 2010; Ellingsen et al. 2014). Q methodology has been used in several studies with young children; researchers illustrated that its easy-to-use nature engaged children in research, and in that children were able to respond well to the way it is applied (Storksen et al. 2012; Ellingsen et al. 2014). Stephenson (1980) particularly demonstrated that children by the age of four develop the essential skills to participate in a Q methodology: they can communicate, have developed notion of ‘me’, understand self-referents when choosing between items related to themselves, and are able to make groups when considering categorisation, i.e. important/unimportant or agree/disagree (detailed in 4.3.3 Data collection section later in this chapter). However, these required skills might pose challenges on its use with children with cognitive impairments; this led to considering observation as another method.

4.1.3 Observation

The discussion around childhood in literature did not exist before the sixteenth century as hypothesised by Ariès (1962). When the concept of childhood started to be deconstructed, it was however based on adults’ assumptions about the lives of children (Lowe 2012), though, observation is a powerful research technique to balance this view. The process of observation can be considered as the only method to allow direct noting and recording of what the participants do and listen to what they say within the natural settings (Robson 2002; Flick 2014; Lichtman 2014; Bryman 2016; Robson and McCartan 2016).

Most observational concepts in qualitative research were drawn from anthropological research; anthropologists spend months, or even years, with a specific group with the aim of gaining deep understanding of a specific culture (Robson 2002; Lichtman 2014; Bryman 2016). In this study the observation was used an as exploratory approach for discovering aspects of the children's world (Robson 2002; O'Kane 2008; Flick 2014; Robson and McCartan 2016). Given that less is known about what happens in relation to children's play within the inpatient healthcare settings, observation made it possible to get a more comprehensive picture of the context. It was central to a range of dimensions; dimensions which include social actions, behaviours, relationships and the interactions with the social or physical contexts (Mason 2002). It allowed data to be generated for real-life situations in exploring children's play and the different social and physical environmental factors associated with their play. However, this required more time to be spent within the group being studied (Robson 2002). As a consequence, more synthesis abstraction and organisation of the data was necessary, all of which was managed and will be discussed in 4.4 Method 2: Observation.

In addition to the advantages of the use of observation, some children have very limited ways of expressing themselves. This method allowed the use of visual methodologies which promotes the inclusion of children who are frequently excluded from research due to their vulnerability and lack of competence as usually reported (Ford et al. 2017). Numerous research studies have been conducted with children using visual records (Carter 2005; Randall 2012a; Rindstedt 2014; Pinchover et al. 2016; Carter et al. 2017). Photos were used as a medium to record directedness and keeping a visual record of the data. Photos can record, preserve, store and display information with controlled subjectivity when compared to other forms of field notes which can add rigour to the findings of the study (see 4.4.5 Quality of the observational data). Nevertheless, the children in this study were shown their photos and deleted the ones which they did not like, and some of them took pictures as well, all of which helped to ensure that the children's voices, images and perspectives were presented in this study. Ethical considerations in regard to the image use are detailed in Chapter 5 – 5.6 Data protection and confidentiality.

4.2 Research settings and participants

4.2.1 Research settings

The Q methodology and observation were used in collecting data from Kuwait and the UK, as previously mentioned, as two study communities (detailed in Chapter 2 – 2.4 The culture). It was important to gain awareness of national and international parameters influences on the within-communities' differences for their impact on the phenomenon of children's play and the environment (Qvortrup 2008). In particular, a children's hospital ward and hospice were selected as the inpatient healthcare settings. These two settings are common facilities in which children with LTC/LLC receive inpatient healthcare and places where children may experience their last few days and die (Håkanson et al. 2017). Therefore, generating data on the environmental factors within these settings helped to answer the research question. Nevertheless, from the literature review (in Chapter 3) it was evident that areas other than home were a major concern; children were not able to continue their normal routines and play with their toys when away from home. In addition, literature found that this created an unbearable situation for the children. Accordingly, targeting children's play in such environments can assist in taking the findings further to ensure that children's optimal care, including play, is addressed within these settings. Moreover, the hospices are designed to meet the child's physical, social emotional and spiritual aspects; this study enabled the researcher to find out whether these children's needs are being met in terms of the environmental factors related to their play in particular. Children's hospice, as referred to in this study, is an organisation that provides palliative care services, specialist respite care, and end-of-life and bereavement support (International children's palliative care network 2015). It is worth noting here that the care systems at the two hospices, where the data were collected in this study, differ slightly. In Kuwait, the care within the hospice setting was to have the whole family to facilitate quality of time and allow them to take a rest from sole responsibility of caring for the child at home. Conversely, in the UK, children primarily spend their time with the hospice staff and not their families to give the parents time out with their partners and other children. In contrast, the hospital wards were almost similar in terms of the systems they followed where the care is focused on symptoms and disease management and not on respite. It is important to highlight that studying children's play at home or in their school environments would help understand and support these children's play; however, this requires separate studies to address their different and unique positions.

4.2.2 Participants' selection criteria

Within the mentioned research settings, data were collected from two participants' groups: children and their caregivers. Children are the best source of information about issues relevant to them while their caregivers can provide useful insights into children's day-to-day patterns (Scott 2008). In this study the term *caregiver* was used, and not *parent*, because it refers to whoever was the primary person taking care of the child, including parents, grandparent or paid caregiver/personal assistant. Children participated in both Q methodology and were observed, and the caregivers participated in the Q methodology only. Despite this, when caregivers were around the child during the observation, they were part of the observation, but the intention was not to focus on the caregivers' presence by itself; they were part of the environmental factors being observed.

The participants were purposefully sampled with relevant consideration for the criteria presented in Table 4-1. This purposive sampling allowed recruiting the most informative cases who facilitated gaining an in-depth understanding of the studied phenomenon; an essential technique in exploratory studies (Mason 2002; Neuman 2014; Bryman 2016). Beside the diagnosis of LTC/LLC to be included in the study and admission to one of the settings, the selection of children's age range, 5-11 years old, was to represent middle childhood ages. According to the literature, play varies between the different childhood groups with regard to their development; when early childhood is compared to middle childhood play for instance (Berk 2013). Play has its primary significance in each age group including the middle childhood and it is one of their essential needs in this period for normal development (benefits of play discussed in 1.2.1 Play) and shaping children's lives and future (Florey and Greene 2008). This age group was also studied in particular because children beyond this age reach their adolescence where they cease typical childhood games (i.e. more directed to adulthood life preparation as preparation for higher education); thus, play occupation becomes less central to their lives, and on the other hand, there are some more practical difficulties of including younger children (Scott 2008; Berk 2013). This does not suggest that the play of children within middle childhood group is the same by acknowledging the age range and the cultural influence (discussed in Chapter 2); however, as the healthcare facilities are designed to be used by different people with different ages, abilities and needs, the shared viewpoints and concerns were more important than focusing on the differences. Furthermore, the age difference was taken into consideration in the analysis process (despite the fact that it was not found to be related to the findings; see Chapter 7). Nevertheless, there are also undoubtedly gaps in literature on children's LTC/LLC play generally and in middle childhood in particular, as demonstrated in Chapter 3. Additionally, the 5- 11 year age range covers children in primary/junior schools, according to the education systems in both Kuwait and the UK.

The cohort of the children who participated in this study were not homogenous in terms of their chronological age and intellectual/ cognitive abilities. For the purpose of this study, they were considered as one group. This is because the healthcare facilities are designed to be used by children of different ages, with different abilities and needs. The shared viewpoints and needs of the children were thus relevant to the study and this was deemed more important than focusing on the differences between them. Their differences were not important for the context of the study. Accordingly, this facilitated our understanding of the features of universal designs in play environments, for the purpose of developing environments that suit the abilities and needs of differing children. Universal designs are interventions that can be used to target environments, products and services for the purpose of allowing anyone to use the resources regardless of their age, capability or cultural background (Design for All Foundation). Therefore, a single solution can be used for users with different potentials.

Table 4-1 Participants' sample criteria

Participants	Criteria	Inclusion criteria	Exclusion criteria
	Children	▪ Diagnosed by their medical consultant as having a LTC/LLC using Hain and Devins (2011) directory. ▪ Admitted to either a children's hospital ward or a hospice. ▪ Was between 5–11 years old at the time of the study. ▪ *Judged by a responsible clinician to be medically stable and have the mental capacity to participate at the time of the study.	▪ People who do not speak Arabic or English, languages that the researcher can understand.
	Caregivers	▪ Aged 18 years old or over. ▪ Caregiver of a child fitting the above criteria.	

*criteria specific for participating in Q methodology not observation

Other specific criteria for the recruitment of children to participate in Q methodology were that they must be medically stable and have the mental capacity to participate. Neither of these last two criteria was considered for children's eligibility to take part in the observational method. This decision was due to the fact that these do not affect the data-collection process; however, they were expected to have an impact on children's play which is evidenced in the Findings Chapter (6.2.2 Caregivers' group and 6.3.1 Children's play characteristics). All the aforementioned criteria were declared to and approved by the ethics committees when their approval was obtained for this study (see 5.1 Ethical approval section in Chapter 5).

4.2.3 Participants' recruitment procedure

Following relevant clinical and institutional ethical and research governance approvals (see Chapter 5 – 5.1 Ethical approval), the researcher met staff within each setting, explaining the study and its sample criteria. The clinicians within the research field reviewed their current inpatient registry of the setting. Clinicians identified participants who were eligible for the study. Children/caregivers who satisfied the inclusion criteria of the study were contacted initially by their lead clinician to explain the study and invite them to participate. Willing participants were then contacted by the researcher in-person to be provided with a full explanation of the research, including using the poster advertisement (see Appendix F) and participant information sheet (see Appendix H), and to answer any questions they may have (ethical considerations regarding participants recruitments are detailed in Chapter 5). The clinicians excluded some patients based on their subjective judgements, as cases unsuitable for participation because of their condition, and/or other factors in their lives (e.g., excluding a mother who was very distressed because of the deterioration in her child's condition). Although this is not a valid measure to determine safety for the participants in research, considering the ethical aspects of this research, this protected children and their caregivers from any risk of psychological harm acknowledging that talking about children's play or being observed for some people can be uncomfortable. The spectrum of Children's Palliative Care Needs (Shaw et al. 2015), explained in Chapter 2 (2.1 Children with life-threatening and life-limiting conditions), was used to classify the children's palliative care needs (further used in Chapter 6: Findings). Each child was classified by their lead clinician.

The researcher followed the same procedure in all the settings for the recruitment in both methods, starting each session by obtaining the participants' consents (see Appendix I) and case report form (see Appendix J); which are further detailed in Chapter 5: Ethical consideration). It was the participants' decisions alongside the eligibility criteria to choose which method to participate in, where some participated in both. The process of engagement in each method is detailed next, starting with the Q methodology followed by the observation.

4.3 Method 1: Q methodology

Using Q methodology (Figure 4-2) allows for the systematic exploration of the participants' subjective viewpoints (Watts and Stenner 2012) on the importance/unimportance of factors within the social and physical environments (defined in Chapter 1 – 1.2.2 Environment) that are associated with the children's participation in play. These factors were presented on cards, called a Q set, that were developed for the purpose of this study (the process of Developing the Q set is detailed later in this section). Thus, the participants were asked to rank-order the Q set along a continuum from most important to most unimportant, generating the quantitative data. This process of ranking is referred to as Q sorting (Brown 1993; Valenta and Wigger 1997; Watts and Stenner 2005, 2012). During the Q sorting, participants were encouraged to give verbal information and comments on the different environmental factors presented on the cards forming the qualitative data, which were very valuable later in the analysis (see 4.3.4.2 Qualitative data analysis and merging the data) in discovering their rationale behind the positioning of each item within the Q set (Ellingsen et al. 2014).

The process of carrying out a Q methodology passed through several stages which are presented in Figure 4-3 and detailed next. Initially the development of the Q set is explained, followed by the piloting work. Then, the data collection and analysis process are explained and finally the quality of the data is reviewed.

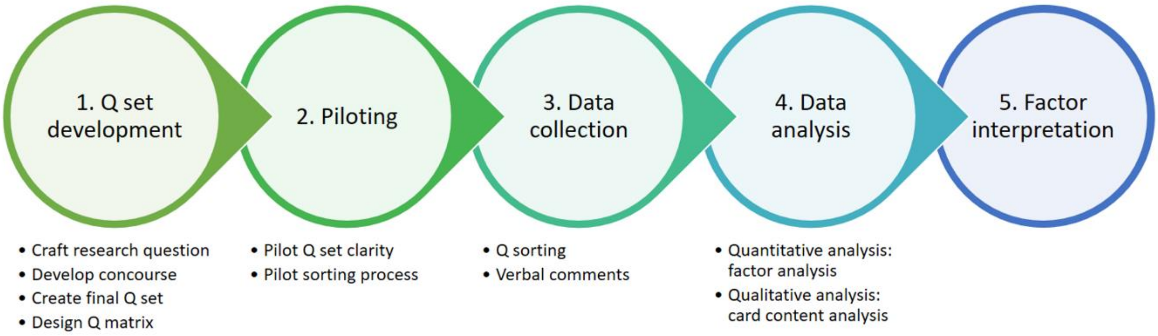


Figure 4-3 Q methodology process based upon Watts and Stenner (2012)

4.3.1 Developing the Q set

In order to develop a Q set to carry out this study, several steps were adopted. It was essential to start with a research question. Thus, once the topic area was identified, the research question for the Q methodology was crafted (Brown 1993). This format enables designing a concourse to create the Q set which is a collection of issues surrounding the studied topic. After that, the Q matrix was designed; this is a diagram on which the participants place the sorted cards in order (Figure 4-2).

Q methodology question and the concourse: The following question was the basis for developing the concourse: 'What are the important aspects of the social and physical environmental factors related to children's play at hospital/hospice setting?' The concourse, which is the raw material for Q methodology, included the possible social and physical environmental factors related to children's play. It was collected from a variety of sources to produce as many items as possible to attain good coverage of the topic. This was managed through extensive reference to the academic literature, existing questionnaires (i.e. questionnaire related to children's play or the environment in relation to individuals' occupational participation) and conversations with experts in this field (see Table 4-2) (McKeown and Thomas 2013).

The findings of the scoping review (presented in Chapter 3) were used as well as other reviewed literature related to children's play from the fields of psychology and occupational therapy. In addition, occupational therapy theories and frameworks were reviewed, as all of them discussed the relevance of the environment. The available standardised questionnaires concerned with play or the environment were also reviewed (examples presented in Table 4-2); this search was not limited to children's versions, as adults' questionnaires on the environmental factors were also considered. In addition, two informal discussions were conducted with occupational therapists who are working with children. Based upon these sources, 240 items of interest were generated (see Appendix K).

Table 4-2 Sources of collecting the Q methodology concourse

Sources		Examples
1. Academic literature	a. Literature review	-Review literature related to the play of children with LTC/LLC
	b. Occupational therapy approaches	-Canadian Model of Occupational Performance and Engagement (Townsend and Polatajko 2007) -Model of Human Occupation (Kielhofner 2008)

Sources		Examples
2. Conversations	c. Informal discussion	-Discussions with two occupational therapists working with children
3. Questionnaire	d. Standardised environmental assessments	- Participation and Environment Measure for Children and Youth (Coster et al. 2012) - Test of Environmental Supportiveness (Skard and Bundy 2008)
	e. Standardised play assessments	-Children's Assessment of Participation and Enjoyment (King et al. 2000) -Test of Playfulness (Skard and Bundy 2008)

Developing the Q set: A well-designed Q methodology study usually begins with generating an overly large number of items of a concourse. This practice is crucial to generate as much coverage of the topic as possible, and the items are then refined to be more selective to a specific number of statements. Thus, having an effective final Q set was created by inclusion of a representative concourse of the range of the possible opinions and perspectives (Watts and Stenner 2012). However, achieving a manageable number of cards in the Q set (also called Q sample/Q items), was crucial to facilitate the sorting process for the participants (Watts and Stenner 2012). This was achieved by the researcher following her subsequent examination of the significance and clarity of the 240 items (Appendix K) of the concourse. Similar statements were removed, others were grouped using more general terms to broaden the item coverage and its semantic content (Watts and Stenner 2012). For example, item number 19 in Table 4-3 - active play in children's sample - was presenting different types of play including playing catch, running, jumping and so on. The same idea was applied for the board games card, item number 18 in Table 4-3, to include for instance the connect four and snakes and ladders games.

The sampling of the Q set, from the concourse, was conducted using unstructured sampling in which the relevant subject matter was broken down into the identified key themes of the study without setting specific number to be included for each theme (Watts and Stenner 2012; McKeown and Thomas 2013). In this study, it was broken down into the social and physical environmental factors in relation to children's play. Accordingly, this type of sampling allowed fluidity in the process of sampling, avoiding under- or over-sampling to specific dimensions, instead covering all ground smoothly and effectively (Watts and Stenner 2012). In addition, unstructured sampling is a highly recommended approach when studying underdeveloped concepts (McKeown and Thomas 2013).

The Q items were developed in a way to avoid making the participants feel limited or frustrated by failure of balanced coverage provision, especially given the studied population, who had deficits in their physical abilities to participate in play (e.g., limited movement because of being attached to an infusion) or their available choices (e.g., being isolated due to the precautions related to the condition). The clarity of the cards and representativeness of the set was guaranteed by consulting four experts in the field and piloting (see next section on 4.3.2 Piloting). Natural language was used on the cards and a parallel style of phrases was retained throughout the whole set (Krueger et al. 2001); for example in Table 4-4 item number 16, 'My child to have easy access to outdoor area', and item number 33, 'My child to play videogames'. Negatively expressed statements were avoided as they can introduce a confusing double negative statement (Krueger et al. 2001; Krueger et al. 2015). In addition, value-laden, technical and complicated words were also minimised (Watts and Stenner 2012; McKeown and Thomas 2013). Besides that, each card was developed to present only one concept, avoiding any overlapping that might occur.

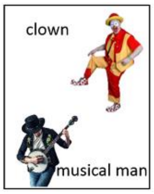
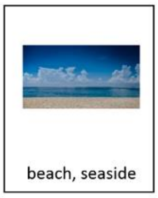
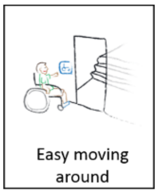
This resulted in 28 items which were used with children (presented in Table 4-3) and 45 with the caregivers (Table 4-4) as there were two generational's groups. Thus, the age of the participants was taken into consideration during the development of the Q set to achieve two age-appropriate Q sets. Generally, 40 to 60 items are recommended as any smaller number may limit adequate coverage and a larger sample can be too demanding when it comes to the process of item sorting (Watts and Stenner 2012; McKeown and Thomas 2013). However, it was crucial to consider a smaller number of items for the children as participants. This conclusion was consistent with Thorsen and Størksen (2010), who highlighted the necessity of considering children's developmental stages. Krueger et al. (2001) also proposed sorting with as few as 20, as a possibility. As an example, Storksen et al. (2012) used 20 items with 5-year old children and found this number effective and manageable. Nevertheless, a very satisfactory analysis was derived from 25 Q items in a study by Watts and Stenner (2005). Therefore, it was decided to use a smaller Q set for children in this study compared to the caregivers' one.

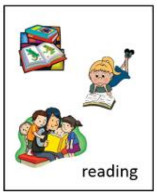
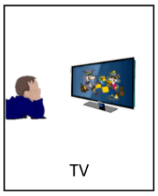
The caregivers' sample was an expansion on the children's set, with more items. These extra items are highlighted in Table 4-4. Some of these were more abstract concepts, the focus of the items was from the perspective of adults (e.g., item 2: People assist my child to play, and item 3: How my community think children should be). In addition, there were some concepts that can be easily understood by the children (e.g., item 39: My child to play different ball games, and item 19: Availability of playground equipment); however, they were not included in the children's Q set because it was crucial to consider prioritisation for achieving a manageable Q sample for the children to sort. It worth noting that for both sets, the children and caregivers, the UK set was one card less due to cultural difference which is elaborated on later in this section (i.e. 28 items for children in Kuwait and 27 items used in the UK; 45 items for the caregivers in Kuwait and 44 in the UK).

After deciding on the final Q set for the children, these items were then converted into pictures and piloted (see 4.3.2 Piloting). Although a Q set usually takes the form of statements, a strength of this methodology is that it allowed the selected items to be presented as visual images (Krueger et al. 2001; Ellingsen et al. 2014). The pictures assisted children with limited vocabulary, or those who needed assistance to read in order to get meaningful responses (Ellingsen et al. 2014). However, short phrases/words were written below each picture because children can vary greatly in their development at any given age. When the Q set was converted into pictures, caution was taken to limit ambiguity and any unnecessary and distracting details (Storksen et al. 2012; Ellingsen et al. 2014). In addition, a professional graphic designer was consulted regarding the pictures in the Q set. All the pictures used were either self-developed or used with permission from the developers.

The Q set contained photographic images, drawings and illustrations (see Table 4-3). The variation was to represent the statements with the best available and most appropriate option of visual representation. Less attention was given to unifying the medium (i.e. to only use photos not drawings) because its effect does not seem to influence children's receptive skills by the age of five and their understanding of appearance and reality (Flavell 1986). The focus with the caregivers was on the statements, rather than on the visual images, with the latter only acting as visual aids.

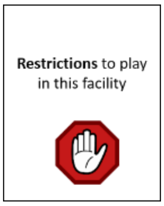
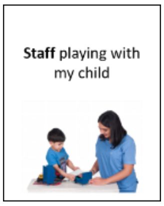
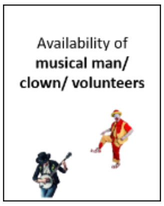
Table 4-3 Children's Q set

Item no.	Picture	Item no.	Picture	Item no.	Picture
1	 Family	2	 doctor/nurse	3	 swimming
4	 clown musical man	5	 joking	6	 Like my age
7	 Like me	8	 pets	9	 weather
10	 beach, seaside	11	 outdoor	12	 active play
13	 Toys for my age	14	 boys/girls toys	15	 dress up
16	 Easy moving around	17	 Private play area	18	 playroom
19	 Getting toys	20	 art	21	 singing & dancing

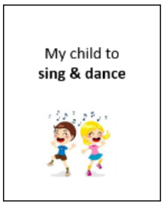
22		23		24	
25		26		27	
28*					

*item only used in Kuwait's sample

Table 4-4 Caregivers' Q set

Item no.	Picture	Item no.	Picture	Item no.	Picture
1*		2*		3*	
4*		5*		6	
7		8*		9	

10*	Organised **group activities** for children 	11	Telling **jokes** 	12	Availability of playmate of same **gender** as my child 
13	Availability of playmate of same **age** to my child 	14	The **weather** condition 	15	Availability of outdoor **blue space** (e.g. beach or seaside) 
16*	My child to have easy **access** to outdoor area 	17	Availability of outdoor **green space** 	18	Availability of **playroom** 
19*	Availability of **playground** equipment 	20	Availability of **pets** 	21	Availability of **private space** for my child's play 
22	The facility's **accessibility** to my child's to use/move around 	23*	Sufficient indoor space within the facility that **allows active play** 	24*	Sufficient space to accommodate **number of children** 
25*	Availability of child size designed **furniture** 	26*	Good **maintenance** within the facility for the equipment and the building 	27*	Availability of playing space where is it easy for me to **supervise** my child during play 
28	**Location** of games and toys 	29	Availability of **age-appropriate** play equipment 	30	Availability of **gender** appropriate play equipment 
31	My child to watch **TV, videos & DVDs** 	32	My child to play with **personal tablet** (ipad) 	33	My child to play **videogames** 

34	 My child to read and listen to **stories**	35	 My child to do **art & craft**	36	 My child to play **board & card** games
37	 My child to do **cooking & baking**	38	 My child to play with **blocks, trains, cars & puzzles**	39	 My child to play different **ball** games
40*	 My child to play with **musical** instruments	41	 My child to **sing & dance**	42	 My child to participate in **imaginative/ pretend** play
43	 My child to engage in **water** play/ **swim**	44	 My child to participate in **active play** (run, bike, hide & seek, Jump rope)	45**	 Availability of **paid caregiver**

*items only used in the caregivers' Q set not children's sample
**items only used in Kuwait's sample

The last point to discuss in the development of the Q set is the cultural aspect. The cultural differences between Kuwait and the UK impacted the development of the Q set in several ways. The first point was the one extra item that was used only in the Kuwait version of the set, the 'paid caregiver'. It was an important socio-environmental factor worth consideration as such personnel are available in most houses in Kuwait and have role in taking care of the child. According to 2017 statistics, there are 669,000 such personnel (Tariq 2017). This number is considered huge when compared to the total population living in Kuwait: they are estimated as 14.8% of the total population (The Public Authority for Civil Information 2018). Secondly, the culture had an impact on choosing the most appropriate visual images representing the outdoor item in the Q set. For further elaboration, the outdoor areas varied according to the country and its climatic conditions. In the UK, the typical outdoor area is green in nature, where in Kuwait it is more human made, reflecting the colours of building and construction (see Table 4-5). Nevertheless, translating the phrases (and all the other used forms; further discussed in Chapter 5 – 5.3 Support for participants) was also necessary. It is worth noting that in Kuwait, both versions were used, the Arabic and the English. This duality was because of the high percentage of non-Kuwaiti, English-speaking people living in Kuwait (The Public Authority for Civil Information 2018).

Five of the participants from Kuwait, two children and three caregivers, completed the Q methodology using the English version.

Table 4-5 An example of different visual images used for the same item

The statement	Kuwait’s version	UK’s version
Outdoor area		

Q sorting distribution: Each item within the Q set was printed on cards and laminated. The children’s Q items were 10x8.5 cm each and the caregivers’ items size were 8.5x7 cm each as suggested by Watts and Stenner (2012); not too small so the participants cannot read and handle them, at the same time not be large to accommodate space for sorting them. The participants distributed the Q set cards on the Q matrix (Figure 4-4), which is an enlarged diagram printed on a big piece of fabric (sized 1.5m x 1m) with blank spaces on which the cards were arranged in the participant’s order of preference. The ranking scale ranged from a positive pole (the most important) running through zero to the other, negative, end (the most unimportant) (Brown 1993). The spread range in this study was a nine-point distribution (+ 4 to -4) for the children, and an eleven-point range (+5 to -5) for the caregivers (Figure 4-4). These ranges were selected according to the guidance by Brown (1980) suggested based on the number of items within each Q set. Watts and Stenner (2012), in addition, highlighted the importance of considering this guidance in offering better in-depth discrimination between the Q items. Figure 4-4 shows two grids for each participant’s group which was necessary to accommodate the extra one item in the Kuwait version than the UK because of the cultural difference.

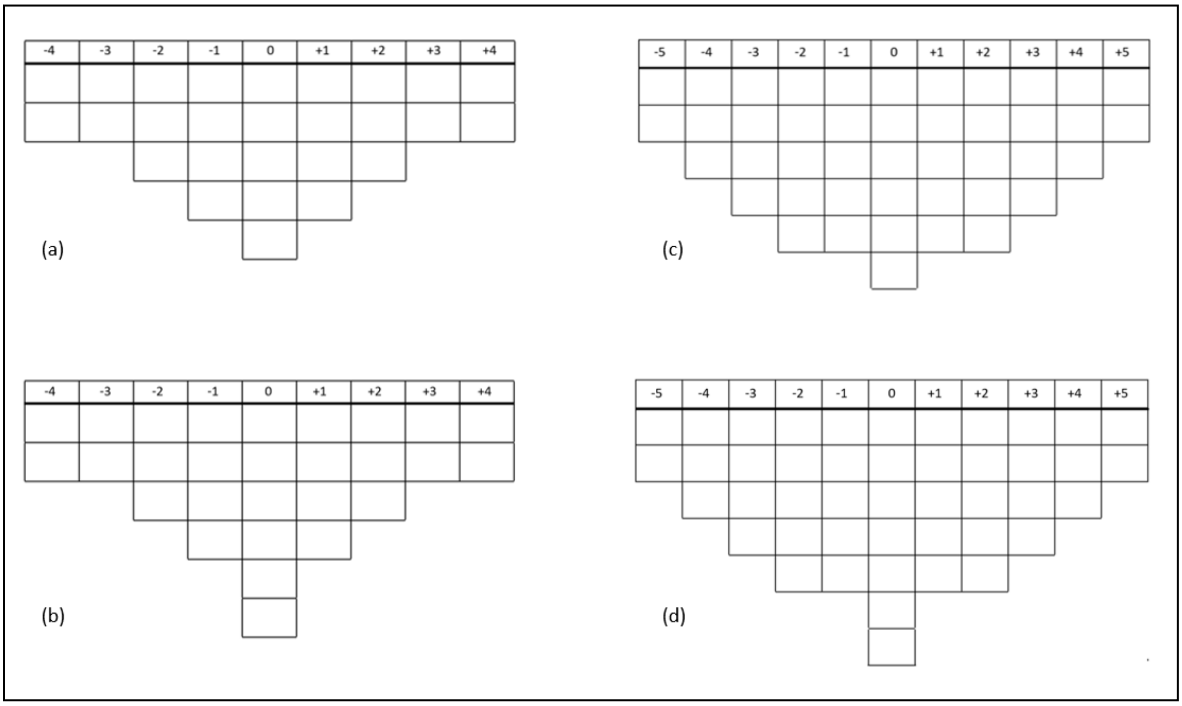


Figure 4-4 Q matrices (a) represents children Q matrix in the UK and (b) for the children in Kuwait. (c) is the caregiver's Q matrix in the UK and (d) in Kuwait

Forced choice normal distribution was utilised in the Q matrix for the sorting process, which required a specific number of items to be ranked under each value (Table 4-6). This forced choice is more convenient during the sorting and provides less ambiguous data when compared to the free distribution (Watts and Stenner 2012). Although the latter sounds as if it gives participants more freedom, Watts and Stenner (2012) highlighted that it places a greater burden on participants by complicating the sorting process which at the same time does not add any additional data in regard to the Q methodology analysis.

Table 4-6 Allowed number of items for each ranking value in Q methodology

Children	Ranking value	-	+4	+3	+2	+1	0	-1	-2	-3	-4	-
	Number of items	-	2	2	3	4	5*	4	3	2	2	-
Caregivers	Ranking value	+5	+4	+3	+2	+1	0	-1	-2	-3	-4	-5
	Number of items	2	3	4	5	5	6**	5	5	4	3	2

*six items for Kuwait
**seven items for Kuwait

Greater numbers of items placed towards the centre reflected a respondent's relative indifference, and cards to be sorted at the poles represented the extreme views. Thus, a ranking of +5 indicated stronger importance of an item than one under the +2 value. The order of the items under each of them, in each ranking column, makes no difference to the item's importance (Watts and Stenner 2012).

4.3.2 Piloting

The piloting helped ensure the creation of a broadly balanced and representative set of items, limiting biased representation towards a particular opinion and to pre-test the clarity of the pictures and the wording used (Watts and Stenner 2012). During the process of developing the children's Q set, the selection of represented pictures for each statement was piloted with four normally developing children, not living with LTC/LLC, from both Kuwait and the UK (4, 5, 6 and 8 year-old children). Cards were presented to each child individually, without any written word, and each child was then required to explain the picture from their own perspective. Their comments were recorded. Accordingly, adjustments and changes were made in order to present a clearer final set. Table 4-7 shows some examples of the pictures which were changed accordingly, in response to the children's comments.

Table 4-7 Examples from piloting Q set

The Q statement	Old picture used during the piloting	The used picture in the final Q set
Family	 Interpreted as 'taking photo'	
Peer at similar age	 Interpreted as 'family'	
Water play	 Interpreted as 'water fight'	

The process of sorting was also tested. Therefore, after this initial exercise of testing the items' clarity, the whole sorting process was piloted to normally developing children living without LTC/LLC and their caregivers to consider the general comparability of the administration within two different countries. The researcher recruited three children aged five, seven and eight years conveniently and two caregivers (of eight- and ten-year-old children). As a consequence, the researcher took a few decisions to consider reflecting on what she noticed herself during the piloting and the feedback she got from an experienced researcher with children who observed one of the piloting sessions with an eight-year-old boy. The decisions made included the followings: 1) the researcher to make clear the aim of the study, as there is no right or wrong to the participants' answers; 2) avoid the use of professional language and use more simplified terms; 3) use exact introduction and explanation of the study procedures; 4) watch her body language to be more open and relaxed; 5) build rapport and social trust with participants prior to data collection and engage in some play with children; 6) give the participants the cards, Q set, to hold when sorting; 7) avoid the *why* questions when trying to understand the rationale underlying cards' positions; instead use *what* and *how* questions; and 8) ask all the participants to start sorting by dividing the Q set into the three categories: important, unimportant and neutral (explained and rationalised in the next 4.3.3 Data collection). This breaking down made the sorting easier for the participants, both the children and the caregivers. Despite this, caregivers were initially given the choice of whether to start by classifying the cards into three groups or not. The researcher noticed that it was more challenging for them and took more time when not sorting initially into three categories. As a consequence, all the participants were then instructed to start with an initial sort into the three groups.

4.3.3 Data collection

Once the Q methodology materials were developed and piloted, the participants were purposefully recruited as detailed previously (in 4.2 Research settings and participants section). The data were collected in person, rather than online or by post. 'Participant to researcher' is the ideal way to communicate when compared to the other distance data collection modes; taking into account preparation requirements before each sorting, misunderstandings about the written instructions, as well as costs in terms of time and/or money (Watts and Stenner 2012). Each participant sorted the Q set individually. The sorting took place wherever the participant felt comfortable (e.g., patient's room); however, the researcher paid careful consideration to ensure safety and confidentiality where access to the data collection space was open (see Chapter 5). The data collection involved two types of data: the participants' order of the cards (the quantitative data) and the participants' interview/verbal comments on the Q set (qualitative data).

Introducing the method: To ensure consistency, the researcher followed the same steps in administering the study and in collecting the data throughout the process with all participants. In order for the participant to start sorting, a large enough wide flat work area was employed to lay out the predesigned Q matrix (see Figure 4-2). This enabled the participant to visually review the entire picture. Figure 4-5 represents the Q sorting arrangement where the same definite research question (*'arrange the cards based on their importance to play'* detailed in the next section) was clearly placed at the top of the Q matrix and a set of instructions (Appendix L) was placed next to the Q matrix to be kept in front of the participants as they sort. These instructions were developed by the researcher in two versions, i.e. children and caregivers' instructions sheets, and in two languages i.e. Arabic and English (see Chapter 5 – 5.3 Support for participants on translation). The researcher also explained the instructions verbally and was available all the time to answer any question.

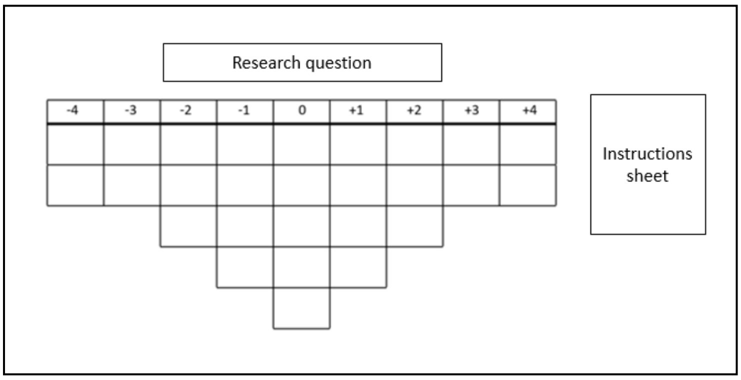


Figure 4-5 Q sorting arrangement

Q sorting: The Q sorting started when the cards were handed to the participant to start ranking them on the Q matrix. The participants were reminded of the purpose of their participation in exploring their viewpoints regarding the important/unimportant factors associated with children's play. The researcher instructed the participants as follows:

> 'In this study we are interested in knowing what matters to your play (your child's play) while at the hospital/hospice. On each one of these cards is an item related to your play (your child's play). Arrange them according to their importance when at the hospital/hospice. There is no right or wrong, it's all about you (your child) and what you think.'

To make the sorting process easier (as mentioned in the 4.3.2 Piloting section), the participants were advised to initially divide the cards into three categories (Watts and Stenner 2012) using pre-designed printed, labelled and colour-coded boxes (see Figure 4-6 and Appendix M) as follows:

a) Red: important (definitely important items to my (my child's) play);
b) Blue: unimportant (definitely unimportant items to my (my child's) play); and
c) Green: neutral (items which I am unsure about it in relation to my (my child's) play or which otherwise leave me with mixed feelings).

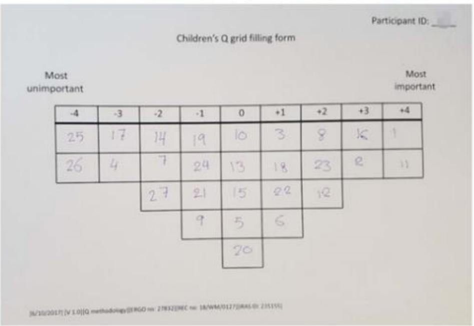
Figure 4-6 Q sorting categories

Following the guidance by Watts and Stenner (2012) on the sorting process, once the Q set was divided, the participant's attention was directed to the Q matrix and they were instructed to prioritise the 'important' category of items to break down the task. They were directed to spread the important cards out towards the right end of the matrix until the important pile was depleted. The highest rankings were given to the items which were most important; starting with choosing the most important two items (for the highest-ranking value, i.e. +5), then the next important three items (for the ranking value +4), and so on. Beginning with extremes and working inward as suggested by McKeown and Thomas (2013) can make the sorting easier as people usually are more confident in these strong feelings, unlike those in the middle. Then the participants prioritised the 'unimportant' items on the matrix by spreading them out towards the left end of the matrix until all items were placed. The lowest rankings were given to the most unimportant items. Last, the 'neutral' items were then sorted on the matrix between the two poles filling the gaps, i.e. the highest rankings for those felt to be more important and the lowest for those felt to be more unimportant.

The participants were thereafter asked to review the final placement of all items to ensure that the arrangement progresses from most important to most unimportant accorded with their points of view (Watts and Stenner 2012). They were encouraged to move the cards throughout the sorting if they felt they needed to ensure that the sorting represents what they believe in. Blank cards were available at the end, in case any participant thought there was an item to be considered/added. They were also asked to say what ranking value they allocated to it thus acknowledging the participants' viewpoints as crucial in constructing the knowledge and attaining richer and more detailed understanding (Watts and Stenner 2012). These exact procedures were followed for all the participants to ensure the trustworthiness of the collected data (further explained in 4.3.5 Quality of the Q methodology data as well as in Chapter 8).

Verbal comments: The participants were encouraged to make comments while sorting; information that constituted a supplementary data source (Watts and Stenner 2012; Ellingsen et al. 2014). Their verbal comments were recorded using an audio-recorder to discover the rationale behind the positioning of the cards (Brown 1993). Giving the participants the opportunity to explain the reasoning behind their choice selection was very valuable when the factors that emerged were interpreted (see 4.3.4.2 Qualitative data analysis and merging the data) (McKeown and Thomas 2013; Ellingsen et al. 2014).

Data recording: The participants' verbal comments were recorded by using two audio-recorders with external microphones. This allowed for the production of detailed transcripts and avoidance of any technical issue so as not to lose any data (Bryman 2016). This process was in addition to recording the exact location of each item immediately following a participant's choice, which was the participation's arrangement of the Q set. Each card was numbered on the back; they were flipped over to record the data on a separate prepared blank Q matrix sheet (see Appendix N) for each participant for analysis (see Figure 4-7). Also, a photo was captured for the arrangement of the cards by a camera, which was used only for the purpose of the research, as another method of keeping records for backup or any missing data.



Participant ID: [redacted]

Children's Q grid filling form

Most unimportant

Most important

-4	-3	-2	-1	0	+1	+2	+3	+4
25	17	14	19	10	3	8	16	1
26	4	7	24	13	18	23	2	11
		27	21	15	22	12		
			9	5	6			
				20				

Figure 4-7 Example on data-recording methods in Q methodology

4.3.4 Data analysis

Since the Q methodology is a mixed-methods research approach, each of the collected quantitative and qualitative data items were analysed using two different techniques. Factor analysis was utilised to analyse the quantitative data and card content analysis was used for analysing the qualitative data which are detailed below.

4.3.4.1 Quantitative data analysis

The participants' viewpoints, obtained by their completed Q sorts, were analysed using Q factor analysis. This technique was used to find the correlation between individuals' viewpoints (the Q sorts), in which the participants who have similar arrangement of the Q set were statistically grouped (Watts and Stenner 2012; Akhtar-Danesh 2016). Therefore, it reduces the many individuals' viewpoints into some meaningful groups, called factors. Accordingly, each factor presents a shared viewpoint of those participants who correlated higher in it. This correlation is called factor loading (Brown 1993; Ramlo 2016b). Factor loading significance and the considered cut-off point for each Q sort was calculated at P-value < 0.01 (see Appendix O for further details).

In Q methodological studies, the used factor analysis is called by-person factor analysis because each individual Q sort functions as a variable (Watts and Stenner 2012) in which it is different than the traditional factor analysis which is referred to as by-variable factor analysis used in R methodological studies (discussed earlier in the study's methodology: 4.1.2 Q methodology). This is because this type, the by-variable factor analysis, correlates individuals based on similar variables, rather than on viewpoints; variables such as traits or characteristics to create the factors that are designed for testing prior assumptions and theories (Brown 1993; Watts and Stenner 2012; Ramlo 2016b).

The Q factor analysis, by-person, was applied via the PQ method; a software specifically built to perform and facilitate the Q factor analysis (Watts and Stenner 2012; Schmolck 2015). Once the data were entered in this program, three main steps followed: 1) factor extraction; 2) factor rotation; and 3) creating factor array (see Figure 4-8). These steps were performed for each group of participants in the study: a) children from Kuwait; b) children from the UK; c) caregivers from Kuwait and; d) caregivers from the UK. The steps were run independently for each group because of the different number of cards used for each Q set. This was then followed by factor interpretation (presented in Chapter 6 – 6.2 Findings of the Q methodology) to understand the participants' viewpoints.

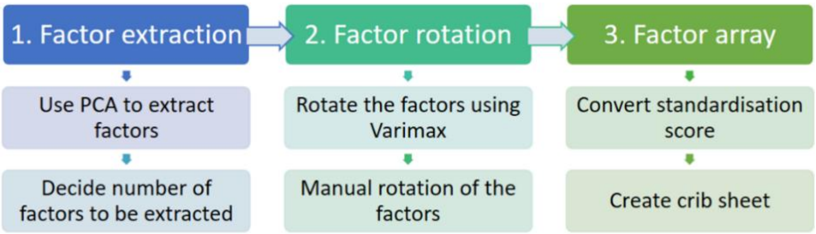


Figure 4-8 Process of Q factor analysis based on Watts and Stenner (2012)

1) Factor extraction was the first step in this analysis for deciding the number of factors – groups – to retain in order to explore the phenomenon (Field 2018). Principal Component Analysis (PCA) was used for the extraction. It is an exploratory factor analysis technique, which inductively finds the factors derived from the collected data; accordingly, it is recommended for exploratory studies (Watts and Stenner 2012). The software, using PCA, statistically provided the one best mathematical solution to extract the factors (Watts and Stenner 2012; McKeown and Thomas 2013). Centroid factor analysis, on the other hand, is another factor extraction technique and can be utilised to explore multiple best solutions rather than one solution. However, it was not adopted in this study because it is a strategy that is recommended with abduction/deduction analysis and for confirmatory purposes (Watts and Stenner 2012; McKeown and Thomas 2013; Ramlo 2016a). Additionally, centroid factor analysis is exposed to higher levels of subjectivity (Watts and Stenner 2012). It is worth mentioning that both methods – PCA and centroid factor analysis – are likely to give similar results and nowadays most researchers prefer to use PCA, which is considered a modern factor analytical choice (Akhtar-Danesh 2016; Ramlo 2016a; Field 2018).

Running the PCA option using the PQ method software automatically computed eight factors (Schmolck 2015). However, in order to find the shared viewpoints among the participants, smaller number of factor is needed. Several criteria were used to determine the number of factors to retain for the final analysis for the purpose of reducing the large number of variables, and finding relationships and commonalities in the participants' viewpoints (Brown 1980; Watts and Stenner 2012; Field 2018). These criteria are presented in Table 4-8. In order to meet these criteria, two factors were extracted for each group to achieve the best fit with the data.

Table 4-8 Criteria to determine number of extracted factors

Criteria	Definition
Kaiser-Guttman criteria	To have an eigenvalue[1] (EVs) of a factor greater than 1.00, because the larger the EVs is, the more variance[2] is explained by the factor (Brown 1980; Field 2018).
Two significantly loading factors	To have at least two significantly loading factors for each extracted factor. The significant factor loading was calculated at the 0.01 level using the number of Q set and the following equation: 2.58 x (1÷$\sqrt{\text{no. items in Q set}}$) (Watts and Stenner 2012). Appendix O details the significant loading value for each group.
Humphrey's rule	To have the result of multiplying the two highest factor loadings more than twice of standard error. The standard error was calculated using this equation: $1 \div \sqrt{\text{no. items in Q set}}$ (Brown 1980; Watts and Stenner 2012). See Appendix O for the standard error for each group.
Scree plots	To determine the number of factors for extraction by the point at which the slop was changed (Watts and Stenner 2012; Field 2018); illustrated in Appendix P.

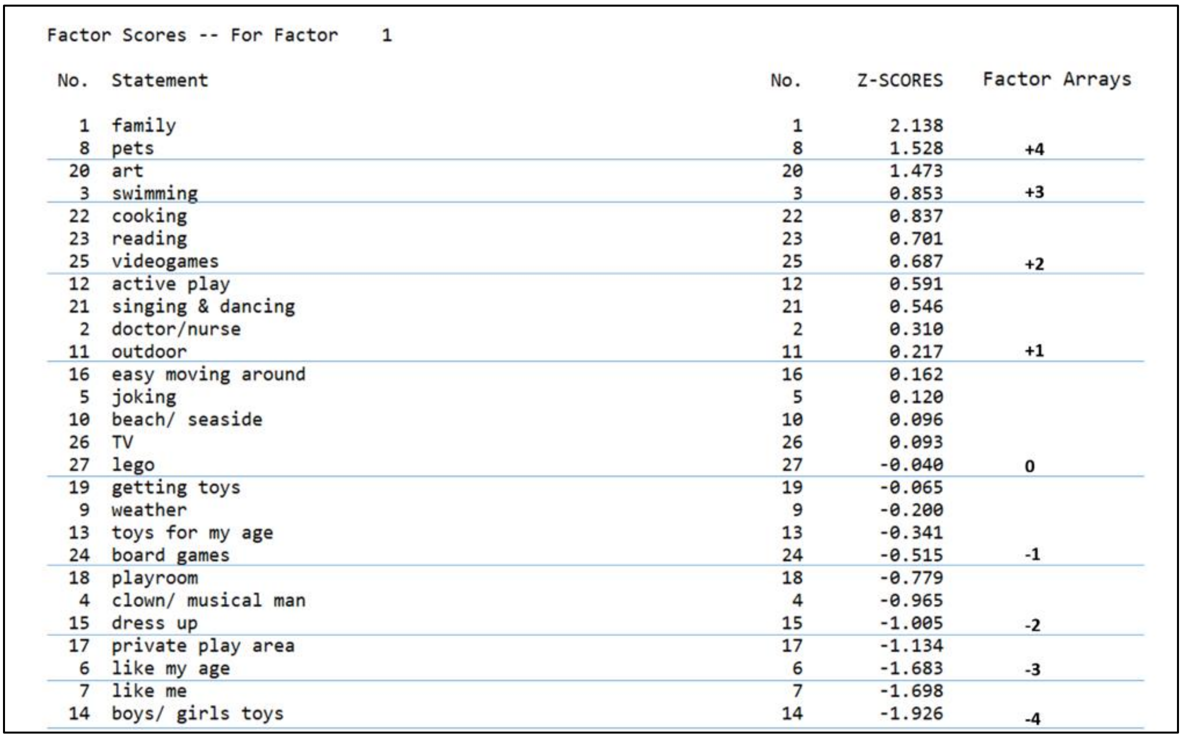
[1] Eigenvalue is the amount of variation within the data set explained by a factor (Field 2018).

[2] Study variance is the estimation of the average of the spread of the data. The larger the study variance is, the more it gives explanation and representation of the data (Brown 1980; Field 2018).

2) Factor rotation typically followed the factor extraction (Ramlo 2016a). The rotation was applied using two methods in two steps – varimax and manual rotation – for two main purposes. Initially, the varimax rotation was generated to get as much Q sorts (participants) as possible included in the extracted factors (Schmolck 2015). This was conducted to maximise the variance of each factor (i.e. the estimation of the average of the spread of the data); the larger the study variance is, the more it explains and represents the data (variance of 35% and above is considered a solid outcome for Q methodology) (Brown 1980; Watts and Stenner 2012; Akhtar-Danesh 2016; Field 2018). The varimax rotation was applied using the software which uses mathematical criteria to automate this procedure (Watts and Stenner 2012; Ramlo 2016a). This was followed by the second type of rotation, the manual rotation, also called by-hand rotation. The application of the manual rotation helped in maximising the separation between the factors (Akhtar-Danesh 2016). This was achieved by getting a Q sort to load significantly higher on a single factor and low in other factors to avoid the confounding effect, which is critical for factor interpretation (Watts and Stenner 2012; Moree; Schmolck 2015). This by-hand rotation was applied manually by the researcher; consequently, it was exposed to subjectivity (Akhtar-Danesh 2016). However, to overcome its subjectivity and utilise its benefits and avoid unreliable results, it was applied following the varimax rotation (Watts and Stenner 2012).

It is worth noting that, during the process of extracting and rotating the factors, the aim was to achieve the highest possible study variance (presented in Appendix O), and maximum coverage of number of participants represented by the extracted factors was thus borne in mind, i.e. the number of participants who loaded significantly on one of the extracted factors (Watts and Stenner 2012). Therefore, multiple tries were tested: at each try, a different number of factors were extracted and rotated. At each trial, these were compared and contrasted to reach a decision on the most appropriate way to represent participants' viewpoints and cover the largest possible range of perspectives.

<u>3) Factor array:</u> The extraction and rotation of the factors resulted in a correlational matrix and z-score illustrating the standardisation of the scores for the Q set. The software converted these scores into factor array (Watts and Stenner 2012; Schmolck 2015) in which each Q item's standardised score was converted to the original values used in the sorting process (i.e. +4 and -4) and this is called the factor array (Figure 4-9). This was used to create a model Q sort for each factor as in Figure 4-10 for ease of interpretation (Gallagher and Porock 2010).



```
Factor Scores -- For Factor    1

 No.  Statement                                  No.    Z-SCORES   Factor Arrays

   1  family                                       1      2.138
   8  pets                                         8      1.528        +4
  20  art                                         20      1.473
   3  swimming                                     3      0.853        +3
  22  cooking                                     22      0.837
  23  reading                                     23      0.701
  25  videogames                                  25      0.687        +2
  12  active play                                 12      0.591
  21  singing & dancing                           21      0.546
   2  doctor/nurse                                 2      0.310
  11  outdoor                                     11      0.217        +1
  16  easy moving around                          16      0.162
   5  joking                                       5      0.120
  10  beach/ seaside                              10      0.096
  26  TV                                          26      0.093
  27  lego                                        27     -0.040        0
  19  getting toys                                19     -0.065
   9  weather                                      9     -0.200
  13  toys for my age                             13     -0.341
  24  board games                                 24     -0.515        -1
  18  playroom                                    18     -0.779
   4  clown/ musical man                           4     -0.965
  15  dress up                                    15     -1.005        -2
  17  private play area                           17     -1.134
   6  like my age                                  6     -1.683        -3
   7  like me                                      7     -1.698
  14  boys/ girls toys                            14     -1.926        -4
```

Figure 4-9 Example on converting the z-score to factor array (screenshot from the PQ method software)

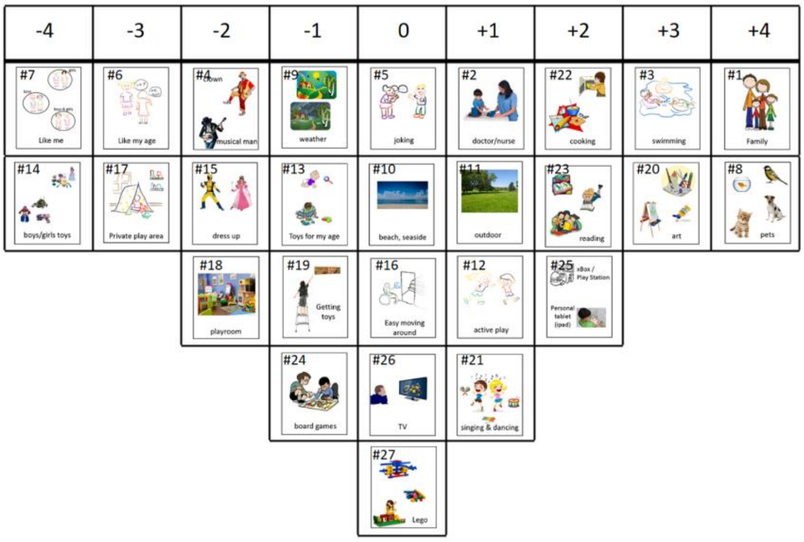


Figure 4-10 Example of a model of extrated foctor using factor array in Figure 4-9

These factor arrays were used to create a crib sheet (see Appendix Q) which was then utilised in interpreting each factor. The crib sheets included four sections: 1) the highest ranking items in this factor; 2) the lowest ranking items; 3) items ranked higher in this factor array than in other factors; and 4) items ranked lower in this factor array than in other factors (Watts and Stenner 2012). In addition, any other possible items can be added.

Prior to moving to the factor interpretation and the utilised qualitative data analysis, it is worth noting that second-order analysis was performed. This method was used to find out any association between the emergent factors of the different groups (Wong et al. 2004; Watts and Stenner 2012). For this second-order analysis, the data of the emergent factors were extracted and rotated as mentioned previously following the same steps. This, as a consequence, guided the understanding of the common subjective dimensions between the different groups in this study that emerged (further explained in Chapter 6 – 6.2 Findings of the Q methodology).

4.3.4.2 Qualitative data analysis and merging the data

In order to interpret the factors and understand the emerged factor array, the recorded participants' verbal comments were analysed. These assisted in investigating the participants' perspectives towards the different items in the Q set (Gallagher and Porock 2010; Watts and Stenner 2012). The audio-recordings carried out during the Q sorting were transcribed verbatim by the researcher and analysed using card content analysis (Gallagher and Porock 2010). In this stage, all the audio-recorded verbal comments were coded according to the Q set cards by creating a category for each item in the Q set. NVivo software was used as a data management package to assist in organising the data and for the coding. This consequently helped in the easy retrieval of the codes (Gallagher and Porock 2010). Therefore, during the interpretation of the factors, for each item in the Q set, the coded transcripts were reviewed to examine the rationale behind its level of importance (Watts and Stenner 2012). Similarities and differences of the codes for each item were considered between the participants who loaded significantly on a specific factor and also with other participants (Gallagher and Porock 2010). This accordingly helped in merging the qualitative data (participants' quotes) and the quantitative data (factor array; importance level of each item, i.e. from +4 to -4) to interpret the factors. Factor interpretation enabled understanding of the participants' viewpoints in regard to the different environmental factors related to children's play presented in Chapter 6.

4.3.5 Quality of the Q methodology data

To guarantee the robustness and trustworthiness of the findings, several methods were adopted in addition to what has been detailed in 4.1.1 Mixed methodology in relation to triangulation (Figure 4-1). Some are to be referred to later when demonstrating the observation method (see 4.4.5 Quality of the observational data).

Due to the differing nature of data within mixed-methods, each of the qualitative and quantitative data items has specific criteria for achieving trustworthy findings. However, regardless of the approach and data collection process, four main concepts were considered and each has a parallel meaning between the qualitative and quantitative paradigms, where both are being used in this thesis. The two main aspects are measurement validity/credibility and measurement reliability/dependability (Teddlie and Tashakkori 2009). The first type, validity/credibility, concerns the level of confidence and trust in the findings (Bryman 2016), while the consistency and stability of the findings refers to the measurement of reliability/dependability (Creswell 2014). The third aspect is the generalisability/transferability of the data which concerns the applicability of the findings to other contexts. Objectivity/confirmability is the last type which considers maintaining objectivity (Creswell 2014; Bryman 2016). These considerations started during the planning of the research project and were maintained during the collection of data, their analysis, and subsequent interpretation.

Figure 4-11 summarises the key addressed aspects in the relation to the aforementioned four concepts. Q methodology can be regarded as a valid method because of the predictable unprecedented levels of agreement when comparing the results of a single participant to the findings from a group of people who sorted the items as one group (Watts and Stenner 2012). In addition, several steps were adopted during its construction that corroborated its validity. The thorough literature search of the subject topic and having a clearly defined phenomenon of aspects to be studied assisted in confirming the coverage of these dimension during the Q sampling step. This consequently led to higher levels of validity (Teddlie and Tashakkori 2009; Gallagher and Porock 2010). Experts in the field were also consulted to assess the degree of the Q set in measuring the phenomenon (Teddlie and Tashakkori 2009). The developed Q sets were also piloted before their actual use in the study to guarantee that each item within the Q set was illustrating what was intended to be presented (Creswell 2014; Bryman 2016). As Palareti et al. (2015) highlighted, images interpretations cannot be assumed as carrying the same meaning. Also, during the piloting, children and caregivers in both Kuwait and the UK were asked so as to ensure that cultural influence was considered. This practice further increased the reliability of the Q set. Nevertheless, after their sorting, each participant was encouraged to review the whole configuration and to make any changes that can result in better representation of their viewpoints to ensure the trustworthiness of the collected data (Watts and Stenner 2012).

Furthermore, using good-quality audio-recorders preserved the study’s dependability. This is in addition to following the exact procedures and using systematic statistical applications of correlation and factor analysis techniques with all the data. During the analysis, the emerged factors were interpreted in combination with participants’ verbal comments which allowed greater understanding around each factor in relation to the context of the participants, minimising possible errors within the interpretation, and confirming the transparency in the findings (Gallagher and Porock 2010). Participants’ quotes were also acknowledged in the findings (see Chapter 6) to guarantee the confirmability and allow transferability of the data. The latter is also possible as thorough descriptions of those who loaded significantly were reported (Bryman 2016). Moreover, a research diary, audit trail and field notes were all kept throughout the research phases and helped in maintaining confirmability in the findings (Creswell 2013).

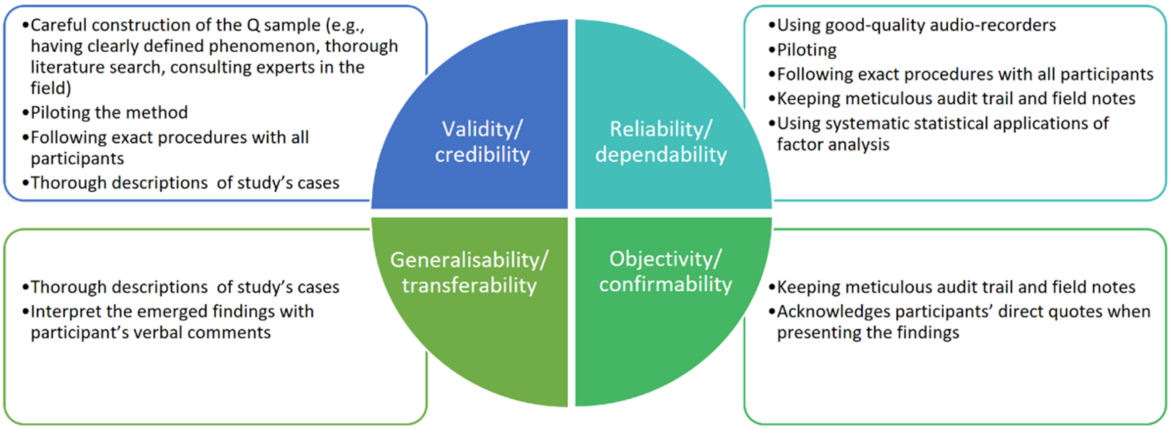


Figure 4-11 Examples on quality of Q methodology data

4.4 Method 2: Observation

The second adopted method was the observation to triangulate the Q methodology. It was used in a form of qualitative marginal participation. The justifications of these selections in addition to the procedures of the data collection, analysis and guarantee of the quality of the data are discussed in the following sections. All procedures were designed for the purposes of discovering children's play characteristics and patterns at the children's hospital ward and hospice, which also allowed the identification of the associated factors in the social and physical environments.

4.4.1 The qualitative observational approach

Types of observation can be found along a continuum of two extremes: structured and unstructured observations (Mason 2002; Robson 2002). In order to explore children's play and their action and reaction to different environmental factors, a qualitative approach was employed. This selection enabled richness of data gathered rather than being very selective in gathering structured data that are typically quantitative in style (Robson 2002; Bryman 2016). However, data were generated in a semi-structured format, taking into consideration the research question to define the related concepts for consideration (Mason 2002; Robson 2002). The data that were collected at the research site were systematically recorded using prior-planned guidance, in the form of an observational schedule (see Appendix R). This included recording the areas of observations, children's play behaviours, play tools, their interactions with others during play and any culture-play related issues comprising the social and physical environments (detailed in 4.4.3 Data collection). The flexibility of qualitative method and the semi-structured format allowed considering unexpected relevant items that were interesting to consider (Bryman 2016; Robson and McCartan 2016). This was anticipated to occur particularly because the data were collected from two research fields in two different cultures. Collection was also possible as the researcher in this study was the research instrument who collected the data. Consequently, any adopted role of the researcher in the field can significantly influence the way data are collected.

4.4.2 Marginal participation

As with the other observation types, the researcher can have varying roles from a complete participant to a pure observer, with each serving different purposes (Creswell 2014; Robson and McCartan 2016). The researcher in this study took the role of an observer, she observed the participants without participating or, if necessary, with only minimal participation in the research field (Bryman 2016). Her role was largely passive – a 'marginal participant' as described by Robson

(2002). The researcher did respond when the child asked to play for instance, but without leading the child; thus, not altering what the child was doing, or was intended to do. She utilised several techniques to manage the asymmetrical power with the children and minimise the social distance that might affect the data; these techniques are discussed in Chapter 8 (see 8.1.4 Power-relationship). The marginal role was practiced because the studied area is under-researched and the role of the participating observer was minimised as it can have a disturbing influence on the studied phenomenon and data gathering (Robson 2002; Bryman 2016). Thus, the researcher attempted to record the data as they were naturally occurring.

4.4.3 Data collection

Entering the field to collect the observational data required observing, listening, communicating, being, doing and thinking (Mason 2002). This could easily lead the researcher to become unfocused because of the huge amount of information involved (Mason 2002). Therefore, the researcher minimised these risks to achieve as successful observations as possible by carefully planning the data collection before entering the field (Lichtman 2014; Neuman 2014). This included dimensions of observations, i.e. what to observe, and how to generate and record the data given that observations are often time-, effort- and resource-consuming (Mason 2002; Robson 2002).

As this is an exploratory field research observation study, sampling was purposive in terms of participants, time and location (Mason 2002; Flick 2014; Neuman 2014). This technique of sampling allowed the selection of the most informative aspects of observation relevant to the research question for deeper understanding of the studied concept (Mason 2002; Neuman 2014). The participants' selection criteria (presented in Table 4-1) and recruitment procedures were as explained before in 4.2 Research settings and participants. Furthermore, each child was observed on two different days at different times of the day, morning and afternoon, each for one hour. This was helpful to sample the phenomenon at different times during the day to cover different aspects (e.g., different people they interacted with) and as many factors as possible (e.g., morning routines) which could be related to time of the day (Robson 2002; Neuman 2014). The specific selection of observational periods, i.e. times and days, for each child, depended on the child's stay within the healthcare setting and their willingness or capacity; for example, when the child became tired and wanted to sleep. Another considered dimension of observation was the researcher's location. In particular when the two observations occurred in the same area, the researcher placed herself at different positions rather than staying in one location as doing so could narrow the perspective when generating the observational data (Mason 2002; Lichtman

2014). Thus, she was able to get a sense of the whole site, keeping in mind choosing a place where it was comfortable to observe, listen and record.

Accordingly, once a participant was sampled and they gave the informed consent (detailed in Chapter 5 – 5.2 Informed consent section; see Appendix I), the researcher simply followed the child and observed them without any interruptions and started to record the data throughout the hour. Observational data were recorded as field notes which were the field research data, taken by the researcher at the research sites. They were recorded on several forms, depending on the time and purpose of recording; illustrated in Table 4-9 (Flick 2014; Neuman 2014). Some of the field notes were recorded during the observational sessions and others were followed (Figure 4-12).

Table 4-9 Types of used field notes

Data record form	Purpose
Jotted notes	Short memory triggers
Interview notes	Informal discussions with participants
Photographs	Keeping a visual record of the observations
Direct observation notes	Detailed observation notes
Analytic memos	Attempts to give meanings to the observations
Research diary	Personal and reflective notes on feelings, thoughts and actions

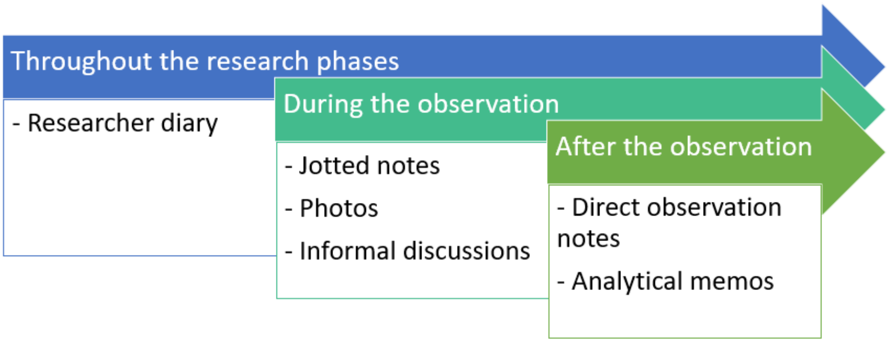


Figure 4-12 Data-recording procedure during the observations

Jotted notes were used as short memory triggers during the observation to subsequently develop detailed field notes later (Neuman 2014). They were recorded using the observational schedule

(Appendix R) which was developed using the study dimensions in addition to the recommendations in empirical literature on creating effective guidance (Neuman 2014; Bryman 2016). Despite the time that the design required, it subsequently reduced the observation time and enabled adequate consideration of matters related to the purpose of observation (Mason 2002; Robson 2002). This observational schedule guided the researcher to describe the observed physical and social environmental aspects and activities/events that occur during the observation period. It was also necessary to record the waiting time and to notice silence, gestures and laughter (Graneheim and Lundman 2004; Neuman 2014). The researcher also noted the informal discussions she engaged in, during the observations, with children, caregivers and clinicians, for the purpose of discovering unclear dimensions raised during the observation; for instance, children's everyday routines and people the child spends time with. The marginal participant role which was adopted by the researcher allowed the collation of this form of field notes (Neuman 2014).

Photographs were also collected during the observation. This form of visual information was gathered to support observations describing the physical environment in particular, and children's play. Creating a permanent record of a visual record assisted in cross-checking and minimised the risk of drawing dissimilar conclusions to enhance the trustworthiness of the study (detailed in 4.4.5 Quality of the observational data section) (Creswell 2014). It is noteworthy that the photos can present/reflect a particular stance or point of view; however, the researcher adopted location sampling, as mentioned, and took different locations at each observation to enhance their richness (Lichtman 2014). In this study, photos were optional and not mandatory for the child's participation (see Appendix I). They were taken subject to the participant's consent. This has been detailed in Chapter 5 (5.6 Data protection and confidentiality section). The children in the study were able to saw their photos on the camera, took some, and deleted the ones which they did not like.

Once the researcher finished the observation session, direct observation notes were immediately created in which the researcher generated detailed written descriptions, since it was usually difficult to generate those while in the field (Neuman 2014). It included what mattered, who was present and what occurred, including what was heard and observed, counting non-verbal aspects as well. During this process, the sequential structures of the events, social interactions, goals and feelings of individuals were taken into consideration (Neuman 2014). Also, the researcher's own words and behaviours within the research field were important and were noted. However, any researcher's thoughts, decisions or attempts at giving meaning to the observations were recorded in a separate section as analytical memos (Robson 2002; Neuman 2014). This guaranteed keeping what had been observed away from the researcher's analysis and interpretation during the data collection phase (Neuman 2014). This practice was crucial since the analysis is highly dependent on the researcher’s culture, background knowledge and previous experience. Thus, keeping both sorts of data separately acted to enhance the multiple interpretation of them later (Neuman 2014). Moreover, the researcher diary also contributed to the analysis and interpretations of the findings (Robson 2002; Neuman 2014). Throughout the research phases, it was used for reflective writing and keeping personal notes. It included feelings, emotions and thoughts more generally. Challenging and interesting situations were all part of this (Lichtman 2014).

Since the researcher in this study was the research instrument who collected the field notes, this was consequently expected to affect the quality of the data because of human nature. Possible explanations are the selective attention to specific aspects, an instinctive rush to judge based on initial information, the limited completeness of the picture due to the memory factor of poor recollection, and the influence of pre-existing expectations (Robson 2002; Neuman 2014). Therefore, identifying these possible risks and limitations prior to collecting the data was a crucial step that helped to counteract them as much as possible when in the field, thus limiting their negative influence on the data (Robson 2002). The adopted semi-structured approach and the marginal participant role assisted in addressing these issues in the following ways. Jotted notes were taken during the observations so the researcher was not to solely rely on memory (Robson 2002; Creswell 2014; Robson and McCartan 2016). The researcher tried to be more open minded by keeping the observations open to limit the effect of pre-existing expectations (Robson 2002). Conscious effort was employed to distribute the attention widely, pre-plan the sample location, and interact with different people within the setting (Robson 2002; Robson and McCartan 2016). Moreover, the developed observation schedule helped to deliver a more systematic way of recording as fully as possible (Robson 2002). Hidden contextual factors including cultural norms and the orientation of the field itself were also considered (Mason 2002). Nevertheless, the generation of good observational data required from the researcher to be good field listener and use appropriate interviewing skills (Robson and McCartan 2016). Thus, the researcher clarified her role, built a symmetrical relationship with the child and family being observed, and showed concern and interest in listening to the children (further discussed in Chapter 8: Reflexivity) (Eide and Winger 2005).

It is noteworthy that the researcher did not start a second observation until she had sorted the notes for the first one. At least half an hour was allocated to note-taking after each hour spent in the field to limit poor accuracy because of the influence of pre-existing expectations (Neuman 2014; Robson and McCartan 2016). The full report was prepared within 24 hours of the field session avoiding any delay in recording the data in order not to heighten the danger of producing seriously incomplete and selectively biased notes (Robson 2002; Lichtman 2014; Neuman 2014).

Furthermore, the different forms of the notes for each observation period were kept together. Data were recorded in order; each field was recorded on a new page using frequent paragraphs with wide margins. This facilitated making comments and adding notes (Neuman 2014). Technical aspects were considered, such as using quotation marks; double quotes were used for the exact recall and single quotes for paraphrasing. A notebook computer was used and it was very effective for creating a computer record using word-processing software (Robson 2002). Backup copies were routinely practiced (Neuman 2014), all of which helped in facilitating the analysis process.

4.4.4 Data analysis

The observational data were then analysed using content analysis, a widely used approach in studying exploratory and health-related topics (Hsieh and Shannon 2005; Vaismoradi et al. 2013). Utilising this approach enabled searching within the collected textual material and visual images for repeated ideas and trends to makes sense of their patterns, frequencies, and relationships in a systematic and an objective way (Hsieh and Shannon 2005; Vaismoradi et al. 2013). Additionally, it allowed the quantification of the data at the same time as analysing them qualitatively to reach an outcome of a condensed description of categories explaining the phenomenon (Elo and Kyngäs 2008; Vaismoradi et al. 2013).

Determined by the researcher’s exploratory purpose of this study, the content analysis was used qualitatively and inductively (Elo and Kyngäs 2008; Vaismoradi et al. 2013). The study’s aim also influenced the use of both manifest and latent content in the analysis process. The manifest content was useful when looking at the surface level in recording patterns and frequencies, particularly in the first cycle of coding (see the organising phase in this section); for instance, when considering the play types children engaged in. On the other hand, extending the analysis to cover the latent content helped to deal with interpretation during this phase by including the observed hidden associations and deeper meaning, exploring the enablers and barriers within the physical and social environments (Kondracki et al. 2002). This is further discussed in the cycles of the coding in this section.

Three phases of content analysis were followed as set out by Elo and Kyngäs (2008) framework; preparation, organising and reporting phases (see Figure 4-13). It was a non-linear process, allowing movement back and forth between the data and the analysis phases (Graneheim and Lundman 2004; Vaismoradi et al. 2013).

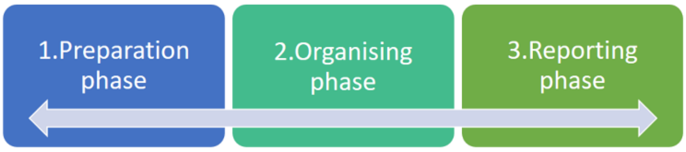


Figure 4-13 The process of content analysis for the observational data based upon Elo and Kyngäs (2008)

1) Preparation phase: The first phase started by selecting the participants as the ‘unit of analysis’ for this study, an independent element to be kept in mind during the analysis process as a context (Graneheim and Lundman 2004). Each participant’s observational notes and photos were considered as a unit. Hence, each unit was large enough as a whole, as well as not too narrow, and the boundaries between the units did not overlap (Elo and Kyngäs 2008; Campbell et al. 2013; Krippendorff 2013). During this phase, the researcher obtained an overall understanding of the data by immersing herself in them simply through reading the texts and viewing the photos several times (Elo and Kyngäs 2008; Vaismoradi et al. 2013; Vaismoradi et al. 2016). This enabled capturing the main features of the data and prepared the researcher for the next step of the analysis, which was the organising phase (Gibbs 2007; Elo and Kyngäs 2008).

2) The organising phase comprised two main processes: coding and creating categories (Elo and Kyngäs 2008). Coding was the primary tool to identify and label the data, as ‘meaning units’; that is, the words, sentences and photos that carried meaning to describe a feature of the phenomenon (Graneheim and Lundman 2004; Campbell et al. 2013; Saldana 2015). The indexing of the study data through coding facilitated the retrieval of all the coded data, examining the relationships and drawing the study’s findings (Gibbs 2007; Richards 2015). As an exploratory study, the coding was data-driven, described as ‘open coding’, to tease out what was happening, rather than imposing preconceptions from previous literature or theories (Gibbs 2007).

The process of coding was carried out in two cycles of coding (Table 4-10) by adopting two different analytic approaches, manifest and latent, to enhance the level of accountability (Campbell et al. 2013; Saldana 2015). The first cycle of coding was done as paper-based then transferred to the computer-based approach using NVivo software. Gibbs (2007) asserts that such practice of starting with paper-based coding is recommended in early stages as it allows flexibility, creativity, and ease of access to the data. During this cycle of coding, descriptive and structural coding methods were implemented. Although these two methods of coding are basic, they assisted in filtering the data to be more focused on the study’s objectives (Saldana 2015). Each method served a different purpose as illustrated in Table 4-10 (Richards 2015; Saldana 2015). Proceeding to the second cycle of coding, the researcher moved to a more analytical and advanced way of reanalysing the data (Gibbs 2007). A key goal for this second cycle was to develop categorical thematic organisation of the concepts identified during the first cycle (Saldana 2015). The second cycle of coding was applied to all the data on clean copy using focused and pattern coding (see Table 4-10). During this step the similarities and differences between the codes for the different settings were compared using matrix coding. Accordingly, themes emerged and led to the reporting phase.

Table 4-10 Coding methods used in each cycle and the purpose of their use

Cycle of coding	Method of coding	Purpose of coding	Example on its use
First cycle (manifest content)	a) Descriptive coding	Assigning basic labels to the data to identify the topics	Identifying the different play types children engaged in (e.g., active play, constructive play or communication play)
	b) Structural coding	Categorising related content to the study's objectives	Identifying possible physical factors (e.g., using non-play tools for playing or unfixed broken toys)
Second cycle (latent content)	a) Pattern coding	Identifying the emergent themes by drawing meaning out of data	Identifying association between presence of others and children's play (e.g., providing assistance or controlling the play)
	b) Focused coding	Developing categorical thematic organisation of the concepts identified during the first cycle	Identifying physical environmental factors (e.g., availability of play equipment and spaces and the easy access to these resources)

Considered aspects of coding: Based on the objectives of the study, three aspects were considered in the coding: 1) children's play; 2) the social environmental factors and; 3) the physical environmental factors. Play was used as defined in Chapter 1 (1.2.1 Play). However, to explore and classify the children's play participation, two classifications were considered: according to a) the nature of play type and b) the social participation in play. After reviewing the different classifications for types of play in the literature, Sheridan's (1977) description was used for the first classification and Parten (1932) for the second. These classifications were used with some adaptation in order to have more applicable categories specifically for this study. Appendix S illustrates the used classifications of play utilised in the analysis.

Sheridan's classification is a comprehensive one when considering the nature of play as she constructed the types by observing the behaviour of children in real-life situations. However, the researcher added two categories: play with electronic devices and language/communication play which were not in the list. Also, imaginative and pretend play which were already in the list were merged into one category. In regard to the social participation, Parten (1932) classified the play into six types. However, for the purpose of this study, children's play was analysed by merging these into three types only. Appendix T represents the classification sample sheet which was used for analysing every child's observation.

For the social and environmental factors, they were used as described in Chapter 1; referred to as:

- The social environment: the availability of people, their relationships, and the norms and expectations within that group (Turpin and Iwama 2011; American Occupational Therapy Association 2014).
- The physical environment: the natural and constructed surroundings including buildings, design feature of spaces and objects, or geographical features and their properties (Law et al. 1996; Kielhofner 2008; Turpin and Iwama 2011; American Occupational Therapy Association 2014).

3) Reporting phase: After achieving the final classification of the themes, the third stage was initiated: the reporting phase. The findings were discussed in this phase by describing the themes, comparing and contrasting the different factors, settings and countries (Elo and Kyngäs 2008). These are deliberated in the findings (Chapter 6 – 6.3 Findings from the observation).

4.4.5 Quality of the observational data

This section is a further expansion on what had been previously mentioned in 4.3.5 Quality of the Q methodology data with regards to measurements of data quality. As mentioned in reporting the quality of the Q methodology, robust and trustworthy findings could only be trusted if they were based on high-quality data (Robson 2002; Teddlie and Tashakkori 2009). The observational data were triangulated by collecting different forms of field notes (e.g., jotted notes, informal discussions and photos) which were approached at different levels (e.g., hospice and hospital) to enhance the study's credibility. This was in addition to the prolonged engagement in the field and the persistent direct observations (Teddlie and Tashakkori 2009; Lichtman 2014). During the generation of these data, confirmability was preserved by clarifying sources that might act to shape the data (Bryman 2016). This was also maintained by the adopted practice mentioned earlier in regard to the researcher’s style of interaction (i.e. maintaining as stable a pattern of interactions possible over time), her role in recording the data (e.g., avoid postponing data recording and rush to judgement) and the different utilised forms of field notes (Robson 2002). The photographs, in particular, captured the reality with controlled subjectivity when compared to other forms of field notes, minimised the gap between the researcher’s perspectives and facilitated communication regarding the findings, thereby adding rigour to the quality of the data. Figure 4-14 summarises the key addressed aspects in relation to the quality of the observational data.

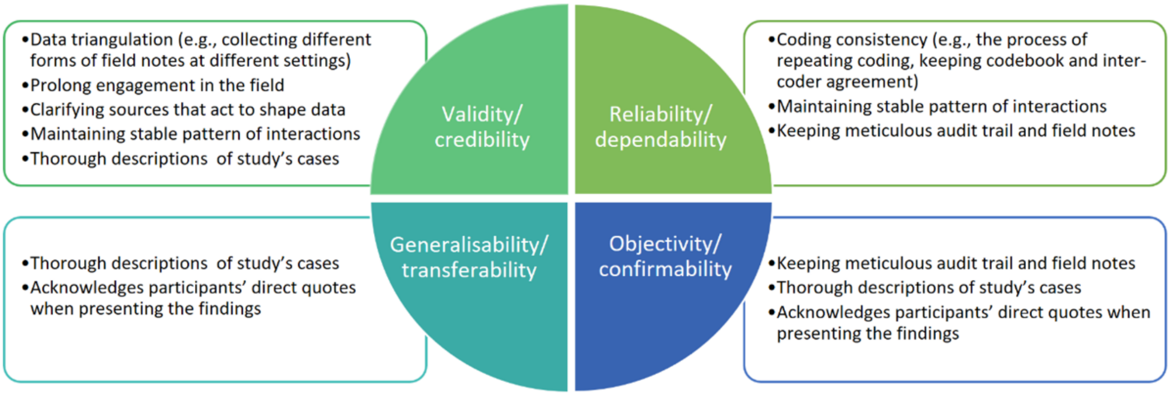


Figure 4-14 Examples on quality of observational data

Coding consistency, also called coding reliability, was important to guarantee interpreting the coding reliably to assure stable and consistent use of the codes over time (Gibbs 2007; Krippendorff 2013; Richards 2015). The first cycle of coding was performed twice, each time on a new clean copy, in addition to the use of a detailed codebook (Richards 2015). A list of used codes was kept in this book to label each code, provide each with a definition, and record any other notes related to it (Gibbs 2007; Campbell et al. 2013). Clear descriptions of the used codes were also significant to confirm the replicability of the coding (Campbell et al. 2013; Krippendorff 2013). Samples of the codes were checked by the academic supervisors to ensure consistency. This was followed by a discussion resulting in some of the codes being grouped and others negotiated in order to reach an inter-coder agreement (Campbell et al. 2013; Krippendorff 2013; Belotto 2018). A sample on the coding is presented in Appendix U.

Direct quotes from the participants were also acknowledged in the findings, Chapter 6. This acknowledgment supported the confirmability besides the thorough descriptions of the participants and settings (Creswell 2014; Bryman 2016). This enabled the generation of rich and comprehensive data for the research fields as well as the participants, thereby enabling transferability of the findings and their applicability to other contexts. Moreover, as highlighted before, the researcher kept a research diary that helped in keeping reflexive practice alongside meticulous records and an audit trail to preserve consistency and stability of the findings (Creswell 2014; Bryman 2016).

4.5 Data integration and interpretation

The previous discussion in 4.1.1 Mixed methodology section has highlighted advantages of implementing a mixed-methods research design in increasing level of confidence in the generated data and the depth in understanding the studied phenomenon (Moran-Ellis et al. 2006; Flick 2014; Neuman 2014). This cannot be achieved unless the data were truly mixed and integrated (O'Cathain et al. 2010). In this study, parallel design of analysing and interpreting mixed-methods research was employed (Teddlie and Tashakkori 2009; Creswell and Plano Clark 2018). Each of the Q methodology data and the observational data were initially analysed side-by-side. This was followed by interactive and interdependent explanations to interpret the data using the '*following a thread technique'* to merge the data (Tashakkori and Teddlie 2010; Moseholm and Fetters 2017). This technique took place at the analysis stage giving equal weight to both methods; both were utilised in interpreting each other (Moran-Ellis et al. 2006). After the initial analysis of each component and the identification of findings within each set of data, the identified key themes were tracked across the two datasets, looking for related information, creating a thread that generated a multi-faceted picture of the phenomenon (Moran-Ellis et al. 2006; O'Cathain et al. 2010). It included looking at possible confirmation, disconfirmation and expansion between the two datasets (Creswell and Plano Clark 2018). Whereby a comparison between the findings from both methods developed an integrated and comprehensive understanding of the phenomenon detailed in following chapters.

4.6 Summary of the chapter

In this research, parallel mixed-methods design was used, with a paradigm emphasis on the qualitative aspect. Q methodology and observation were the methods for collecting the data gathered from children living with LTC/LLC and their caregivers with regards to the healthcare environment and its different factors that were associated with children's play.

Each method's specific considerations and the process of data-gathering and analysis were illustrated. The Q methodology materials and the used Q set were developed by the researcher specifically for the purposes of this study. The cultural differences between the two countries and the two participations' generational groups were considered during the construction of the method. Consistently, the observations afford a flexible and multidimensional approach of gathering data regarding children's everyday play and the associated environmental factors. Observational data were collected in a qualitative, semi-structured format using different forms of field notes serving various aims. In this chapter it was also deliberated on the establishment of the data quality of both methods drawing on the trustworthiness of findings and how the data were integrated. A parallel design was used for analysing and interpreting the mixed-methods data which was achieved through adopting following a thread technique. The resultant findings are presented in Chapter 6. Prior to this, it is important to draw on the adopted considerations for meeting ethical practice which is discussed in the next chapter.

Chapter 5 Ethical considerations

Composing a sound ethical research project was an ongoing process initiated by the researcher since the planning phase of the study. It was the researcher's ethical-moral and professional obligation to protect the participants (Neuman 2014). The main dimensions considered were to not harm the participants, to guarantee their privacy, to maintain integrity of the research, and to avoid any improper practice (Glasper and Richardson 2010; Creswell 2014; Lichtman 2014). This is in addition to ensuring safe practice with children during research procedures (Lichtman 2014; Randall et al. 2015b). These issues are covered in this chapter by discussing the obtaining of ethical approval along with informed consent processes and practices to support the participants. Once the data were collected, the researcher continued adhering to best practice in research which is demonstrated in the truthfulness and accuracy of reporting of data and how these data were protected, maintaining the participants' privacy subsequent to their participation.

5.1 Ethical approval

Ethical approval was obtained prior to the commencement of data collection from the ethics committee of the Faculty of Health Sciences at the University of Southampton (UoS) via the Electronic Research Governance Online (ERGO) system (no. 27832, Appendix V.1). In addition, the researcher gained approval and permission from the sites where the study took place.

In Kuwait, approval was obtained from: a) The Standing Committee for the Coordination of Health and Medical Research at the Ministry of Health to access children's hospital ward (no. 1409, Appendix V.2); and b) The ethical committee of the children's hospice (no. BACCH/OUT/18/053, Appendix V.3). In addition, ethics approval in the UK was obtained from: a) The National Health Service (NHS) to access children's hospital ward through the National Research Ethics Service (NRES), the Black Country Research Ethics Committee (REC no. 18/WM/0127, Appendix V.4) and Health Research Authority (HRA) (Appendix V.5), in addition to the letter of access obtained from the Research and Development department from the hospital where the data were collected (Appendix V.6); and b) the ethics committee for the children's hospice (Appendix V.7).

5.2 Informed consent

Participation was voluntary; participants who were interested in the study were able take part during their period of stay within the healthcare setting. Participants were reminded that they could withdraw at any time without providing a reason and this would not affect the care that they were receiving. All the children were able to refuse to take part in the study or withdraw at any time, irrespective of their caregivers' wishes. Although children can consent for themselves in England, in Kuwait they cannot. An assent form (Appendix I) was used for children for their participation in this study; however, it had been used as consent. It was observed by the researcher that, with a few of the children, their caregivers were pushing the child to take part; but the researcher reminded them that it was the child's right to choose whether or not to participate and their decisions would be respected. These incidents related to the research-participant power relationship are detailed in Chapter 8 (8.1.4 Power-relationship). However, because of the consent system in Kuwait, the intention of having as similar process as possible in addition to adhering to good practice, when a child gave their consent either by oral agreement or written (if they wished to complete the form), permission on their behalf was also obtained from the legal guardian (Appendix I). The legal guardian was a person who had been legally assigned parental responsibility for the child (Health Research Authority 2017). For this reason, the term 'legal guardian' was used to differentiate from the caregiver's forms as a participant. The caregiver may or may not be the child's legal guardian as it refers to the person who is just providing care for the child without having the parental responsibilities, e.g., grandparent.

Participants were given a full explanation of the research aim and objectives, procedures, participants' rights, the potential risks involved and the implications of the study. These aspects have been detailed in the information sheets (see Appendix H) and the consent forms (see Appendix I). These forms also describe the data protection policy and how data are be handled with privacy and confidentiality (further discussed later in this chapter in 5.6 Data protection and confidentiality section). The channels for providing feedback and making complaints about the study were additionally clarified. In addition to presenting participants with these forms, the researcher made herself available to answer any questions that the participants had. Contact details were included on the information sheet in case the participants needed any further clarification, at a later date. The researcher ensured that each participant received the appropriate information sheet by organising them separately in labelled folders using different colours.

Different forms of the information sheet and the consent form were developed to cover the different aspects in terms of language (i.e. Arabic and English), level of understanding (i.e. children and adults) and the information required (i.e. participating in Q methodology or observation). Appendix G illustrates the different forms that were used. Each form was developed in both Arabic and English languages because these are the official and commonly-used languages in Kuwait and the UK. Although both the Q methodology and observations were collected simultaneously, this did not require the participant to take part in both. Therefore, to avoid superfluous information (Glasper 2010), a separate form was prepared for each method. Furthermore, because the participants included children as well as adults, the forms were developed to match their different needs and level of understanding. The children's forms have been designed to be more child-friendly, colourful and using simple language (Health Research Authority).

Although the intention while developing the forms was to have them look as similar as possible in the two countries, the participant information sheet which was used in Kuwait (see Appendix H.3) looks different than the ones used in the UK (see Appendix H.1 and H.2). This is because of the clarification required by the REC which was received after the phase of Kuwait's data collection commenced and after the approval of these forms was obtained from Kuwait. The recommendations by the REC committee were to split the children's information sheet into two, for ages 5 to 7 (Appendix H.1) and ages 8 to 11 (Appendix H.2) using more age appropriate language and pictures for each.

5.3 Support for participants

The study was planned and designed to take into consideration the critical nature of the children's conditions, the vulnerability of children, and their caregivers' potential for psychological distress. The researcher has had specific training in child protection issues (Randall et al. 2015a). She is a qualified occupational therapist. Her degree extensively enhances her skills in child protection and safeguarding. She has had two years' work experience specifically with children. She is Disclosure and Barring Service (DBS) checked and has completed the Good Clinical Practice primary and secondary care courses in addition to an Informed Consent in Paediatric Research course offered by the National Institute for Health Research. She also engaged in reading material on child protection and safeguarding and attended Southampton Local Safeguarding Boards workshops prior to the data collection. The researcher was oriented towards recognising and reporting child abuse when noticed (Randall et al. 2015a). It has been made clear to the participants in the information sheet and consent form that if the researcher during the study finds something that may affect the safety or well-being of the child or other children, the researcher will take appropriate action and talk to the responsible bodies concerned (Resnik and Randall 2018). The researcher was aware of the channels of reporting child abuse both in Kuwait and the UK. She was also aware of the need to give consideration to social and cultural aspects in safer research (Randall et al. 2015a).

Furthermore, the researcher paid considerable attention to minimise possible sources of discomfort for participants as much as possible during the planning and implementing of the study. Participants were asked to specify a suitable time for their participation. At each data collection session, the researcher ensured that the participant felt at ease. Their comments were always welcomed. Because observations were conducted over two days, on the second day of observation and before starting, each child's consent was obtained verbally to ensure they were still happy to continue. Nevertheless, the researcher's contact details were on the information sheet made available to the participants and child/family support contact details were provided on the information sheets (Appendix H); acknowledging that talking about children's play or being observed can be uncomfortable for some people, the researcher raised this point with the participants and made it clear to them.

The participants were also supported by ensuring they fully understood the study through the developed forms in both languages. These sheets were carefully prepared and piloted to ensure clarity and provide both children and caregivers with information in a language that could be easily understood (Glasper et al. 2010). The researcher herself translated all the used materials (i.e. participants' information sheets, consent forms, the Q set and its instructions) which were thereafter reviewed by a bilingual English and Arabic speaker. A few changes were made to achieve clearer meaning. However, the translation was not always straightforward; the researcher paid attention to the cultural differences (e.g., not to use the direct translation of the term 'ethnicity' in Kuwait's forms as it is culturally unacceptable) and to ensure conceptual equivalence (e.g., the translation of Q methodology set) (Im et al. 2016).

5.4 Truthfulness and accuracy in reporting the data

The collected data from this study are presented with accurate account of information. Withholding findings or disclosing only favourable positive perspectives was avoided (Creswell 2014). This was achieved by carrying out an appropriate analysis and reporting a diversity of perspectives (Creswell 2014; Lichtman 2014). This is in addition to what has been mentioned about the quality of data in both methods used in Chapter 4 (4.3.5 Quality of the Q methodology data and 4.4.5 Quality of the observational data). In particular, the use of collected photos and direct quotes from the participants in representing the findings assisted in building trust in these findings.

Nevertheless, careful consideration was paid to the translation of the participants' quotes. Most of the participants who participated in the Q methodology in Kuwait did it in Arabic; the collected participants' verbal comments were in Arabic. All the other data were collected in English, including the observational data which the researcher generated, in which only participants' quotes which were used in the dissemination were translated into English. Hence, the analysis was carried out using their Arabic transcripts to minimise the possible risk of mistranslation (Lopez et al. 2008; Im et al. 2016). The translation was done by the researcher and reviewed by another bilingual English and Arabic speaker, who is a native English speaker, as a recommended strategy for late-phase translation studies (Santos et al. 2015).

5.5 Researcher safety

With regards to the potential risks for the researcher, and in order to reduce any possible of inherent risk, she used appropriate transportation methods considering the time, and carried a charged mobile phone that had been pre-programmed to send quick alerts to an emergency contact in an emergency situation. This was in addition to carrying a torch when she intended to leave the research field after dark, taking note of emergency telephone numbers, and ensuring that a friend/family member had been informed about the lone work times and to be in contact. Distressing information was another potential source of risk for the researcher. For this reason, she kept a personal diary for reflection and consulted her academic supervisors when necessary.

5.6 Data protection and confidentiality

All the data were treated with care and confidentiality once obtained following the current Data Protection Act legislation and the Research Data Management Policy by University of Southampton (2018). This is further explained as follows by covering aspects of how participants' privacy was guaranteed, how data were stored, and what procedures were followed for sharing as well as destroying the data.

Participants' privacy: Participants' privacy was maintained by not having the participants' names attached to the data collected. Individual codes were allocated to the participants instead of their actual names to protect their privacy. Information was stored securely with restricted access. Only the primary researcher and her academic supervisors had access to the data. When a legal guardian asked about their child's responses during the study, they were directed to ask their children themselves. No one outside of the clinical team was needed to identify suitable participants or have a look at the patients' files.

Data storage: A crucial part of data protection is making data user-friendly, shareable and with long-lasting usability to ensure they can be understood and interpreted (University of Southampton 2018). Thus, data were assigned through the use of meaningful filenames and saved in recommended formats using software approved by the UoS (see data-management plan

Appendix W). The structure of folders and file-naming of the dataset were recorded in a spreadsheet with a track of how field notes, transcripts, audio-records and photos were kept.

The research data were collected by the researcher in two forms: print-based data and digital/electronic research data. All print-based data documents were labelled and securely stored in locked cabinets in private storage locations (in the PGR research office at the UoS). Electronic data were stored at a password-protected UoS computing facility. A camera, two recorders and a notebook computer were only used for the data collection of this research. These generated data were transferred using a USB cable to a computer, after which the data were removed from these devices.

The data which cannot be anonymised (e.g., recorded interviews) were stored securely with restricted access in a password-protected computer. In addition, personal data relating to the participants (completed consent forms and case-report forms) have sensitive information, so they were kept separately from the non-identifiable data in a different locked cabinet in accordance with UoS regulations with keys kept only by the researcher. Thus, folders had restricted access to retain anonymity.

Destroying data: Before the researcher’s graduation and prior to leaving the university, she will deposit all non-identifiable research data with Pure (a research information system used by the UoS). The data will be stored for at least 10 years from last use; then securely destroyed. However, identifiable data are to be stored until the end of the PhD programme in 2020, and then destroyed including the memory cards of the camera used by the researcher.

To enable the secure disposal of print-based data, they will be treated as confidential waste, which means sensitive research data that require destruction to ensure that the contents remain private. This will be done by putting these data in white woven sacks for collection as ‘confidential waste’. DBAN, a free disk-wiping utility, will be used for the destruction of the digital/electronic research data.

Sharing data and findings: When sharing/transferring large files containing sensitive identifiable data, SafeSend Service offered by the UoS was used so that files are transferred across the network securely, encrypted internally and externally, with access to data being very tightly and strictly controlled. Shared data through SafeSend are subject to the university’s data protection regulations and uploaded data are only held temporarily on the service, for a maximum of 32 days, after which they are automatically deleted.

For the participants’ data to be used, consent was obtained from the participants to allow data to be shared and reused (see Appendix I). The results of the study are being used in the researcher’s

PhD thesis and may be published at conferences or in academic journals. At all times, the confidentiality of the participants is being maintained and their privacy protected using pseudonyms in publications. For the use of photographs, this is subject to the participants' consent and was optional, not mandatory, to their participation. Additionally, they were given the right to choose how they agree for their data to be used including the format and medium. It is acknowledged that pixilating or masking facial photographs might not be enough for de-identifying the participant, but it is always subject to their consent (Bennett et al. 2019). Accordingly, the participants were asked to impose the level of confidentiality via the consent/assent form (see Appendix I) and the medium to be used. Only the participants who gave their consent appeared in the photos. When other children/staff appeared in the photos, their faces or any other identifying features (e.g., their names badge) were also pixilated, besides obtaining their consent; otherwise, the photo was deleted. However, the photos collected in the UK are conditioned to not be accessed online if used in any report or presentation as guided by the NRES Black Country REC.

5.7 Summary of the chapter

In this chapter, the ethical considerations, which were encountered during this research, were accentuated. This comprised several practices with the purpose of confirming not to harm the participants, ensuring their privacy and safety, and avoiding any improper practice. These were guaranteed by initially attaining ethical approval prior to commencing collecting data. In addition, participants' informed consent was obtained during the study. The researcher paid careful attention to the inclusion of children in research and adopted several implementations to preserve their rights, including consenting for themselves. The used consent forms and information sheets were developed and designed particularly to suit the participants in this study, respecting their age and language. This accordingly supported the participants and clarified their rights to them. Nevertheless, participants' privacy was maintained through the safe adopted methods of data storage, disposal and sharing. Accordingly, all the presented findings in the next chapter are shared while maintaining the participants' privacy throughout.

Chapter 6 Findings

In this chapter, the findings from the analysis of the mixed-methods data are presented. In the first part, the descriptive data for the participants in both methods are reported. Next, the Q methodology findings are presented, followed by the observational findings, all of which are then integrated to maximise the generated knowledge and enhance coherent understanding of the studied phenomenon.

6.1 Participants' descriptive data in Q methodology and observation

The sample size in this study is presented in Figure 6-1. The total number of children who were recruited was 42, and 16 of them participated in both methods (Figure 6-2). This resulted in 27 children who participated in the Q methodology (Table 6-1) and 31 children who participated in the observational study (Table 6-2). This is in addition to 39 caregivers who participated in the Q methodology (Table 6-3).

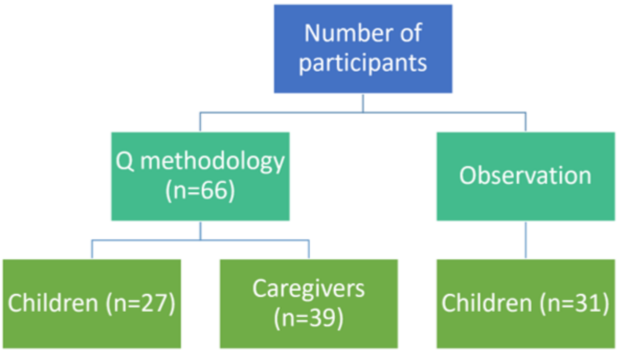


Figure 6-1 Number of participants in each method

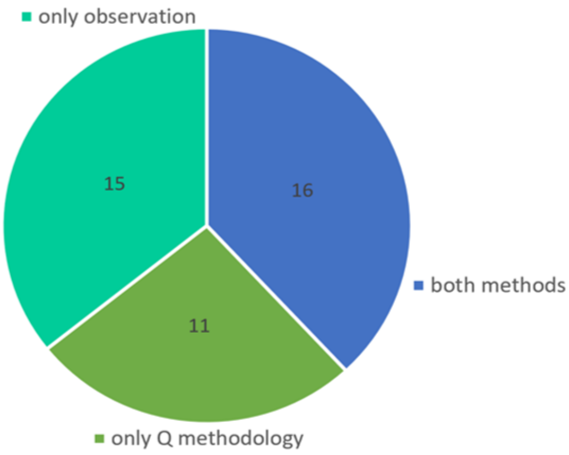


Figure 6-2 Number of children's participants and the methods they participated in (number of recruited children is 42)

Table 6-1 Descriptive statistics of children who participated in Q methodology

		Kuwait's participants	UK's participants	All participants
Characteristics		n (%)	n (%)	n (%)
Sample size		14 (51.9%)[1]	13 (48.1%)[1]	27 (100%)
Gender	Male	6 (42.9%)	6 (46.2%)	12 (44.4%)
	Female	8 (57.1%)	7 (53.8%)	15 (55.6%)
Age[2], mean(SD)		7.71 (1.97)	8.26 (2.06)	8.15 (2.03)
Research setting	Hospital	12 (85.7%)	12 (92.3%)	24 (88.9%)
	Hospice	2 (14.3%)	1 (7.7%)	3 (11.1%)
Ethnicity		12 (85.7%) Arab 1 (7.1%) African 1 (7.1%) South-Asian	12 (92.3%) White 0 Asian 1 (7.7%) Black 0 Mixed	
LTC/LLC	Neurology	1 (7.1%)	1 (7.7%)	2 (7.4%)
	Oncology	4 (28.6%)	5 (38.5%)	9 (33.3%)
	Haematology	5 (35.7%)	1 (7.7%)	6 (22.2%)
	Congenital	3 (21.4%)	0	3 (11.1%)
	Genitourinary	1 (7.1%)	3 (23.1%)	4 (14.8%)
	Cardiology	0	1 (7.7%)	1 (3.7%)
	Metabolic	0	2 (15.4%)	2 (7.4%)
Severity of the condition[3]	Yellow	11 (78.6%)	10 (76.9%)	21 (77.8%)
	Amber	3 (21.4%)	3 (23.1%)	6 (22.2%)
Response rate		93.3%	68.4%	77.1%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015), see Chapter 2; yellow: children living with a significant health need or a disability, whose risk of dying is expected before adulthood and; amber: children with increasing instability or progressive deterioration where death is expected in a few months to years.

Table 6-2 Descriptive statistics of children who participated in observation

		Kuwait's participants	UK's participants	All participants
Characteristics		n (%)	n (%)	n (%)
Sample size		13 (41.9%)[1]	18 (58.1%)[1]	31 (100%)
Gender	Male	4 (30.8%)	7 (38.9%)	11 (35.5%)
	Female	9 (69.2%)	11 (61.1%)	20 (64.5%)
Age[2], mean(SD)		6.85 (2.15)	8.28 (1.99)	7.68 (2.15)
Research setting	Hospital	10 (76.9%)	10 (55.6%)	20 (64.5%)
	Hospice	3 (23.1%)	8 (44.4%)	11 (35.5%)
Ethnicity		11 (84.6%) Arab 1 (7.7%) African 1 (7.7%) South Asian	15 (83.3%) White 1 (5.6%) Asian 1 (5.6%) Black 1 (5.6%) Chinese	
LTC/LLC	Neurology	2 (15.4%)	6 (33.3%)	8 (25.8%)
	Oncology	4 (30.8%)	3 (16.7%)	7 (22.6%)
	Haematology	4 (30.8%)	2 (11.1%)	6 (19.4%)
	Congenital	2 (15.4%)	2 (11.1%)	4 (12.9%)
	Genitourinary	1 (7.7%)	1 (5.6%)	2 (6.5%)
	Cardiology	0	2 (11.1%)	2 (6.5%)
	Metabolic	0	2 (11.1%)	2 (6.5%)
Severity of the condition[3]	Yellow	10 (76.9%)	14 (77.8%)	24 (7.4%)
	Amber	3 (23.1%)	4 (22.2%)	7 (22.6%)
Total hours of observation		26 hours	36 hours	62 hours
Response rate		86.6%	94.7%	91.1%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015), see Table 6-1 for further details

Table 6-3 Descriptive statistics of caregivers who participated in Q methodology

		Kuwait's participants	UK's participants	All participants
Characteristics		n (%)	n (%)	n (%)
Sample size		19 (48.7%)[1]	20 (51.3%)[1]	39 (100%)
Caregiver's age[2], mean (SD)		32.68 (6.6)	42 (11.3)	37.66 (10.62)
Caregiver's gender	Male	2 (10.5%)	6 (30%)	8 (20.5%)
	Female	17 (89.5%)	14 (70%)	31 (79.5%)
Research setting	Hospital	12 (63.1%)	12 (60%)	24 (61.5%)
	Hospice	7 (36.8%)	8 (40%)	15 (38.5%)
Educational level	Primary	4 (21.1%)	1 (5%)	5 (12.8%)
	Secondary	3 (15.8%)	3 (15%)	6 (15.3%)
	Higher education	12 (63.1%)	16 (80%)	28 (71.9%)
Relationship to the child	Father	2 (10.5%)	6 (30%)	8 (20.5%)
	Mother	13 (68.4%)	12 (60%)	25 (64.1%)
	Grandparent	0	1 (5%)	1 (2.6%)
	Paid caregiver	4 (21.1%)	1 (5%)	5 (12.8%)
Ethnicity		15 (78.9%) Arab 2 (10.5%) African 2 (10.5%) South Asian	18 (90%) White 0 Asian 0 Black 1 (5%) Chinese 1 (5%) Mixed	
		The caregivers' children details		
Children's gender	Male	10 (52.6%)	12 (60%)	22 (56.4%)
	Female	9 (47.4%)	8 (40%)	17 (43.6%)
Children's age[2], mean (SD)		6.5 (1.5)	7.6 (2.06)	7.08 (1.86)
Children's LTC/LLC	Neurology	3 (15.8%)	5 (25%)	8 (20.5%)
	Oncology	6 (31.6%)	5 (25%)	11 (28.2%)
	Haematology	6 (31.6%)	3 (15%)	9 (23.1%)
	Congenital	3 (15.8%)	2 (10%)	5 (12.8 %)
	Genitourinary	1 (5.3%)	1 (5%)	2 (5.1%)
	Cardiology	0	2 (10%)	2 (5.1%)
	Metabolic	0	2 (10%)	2 (5.1%)
Severity of the children's condition[3]	Yellow	11 (57.9%)	14 (70%)	23 (59%)
	Amber	8 (42.1%)	6 (30%)	16 (41%)
Response rate		79.1%	95.2%	86.6%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015), see Table 6-1 for further details

As detailed in the three descriptive tables (Table 6-1; 6-2 and 6-3), the number of participants in both countries were similar. The children's health conditions varied but the common diagnoses were haematology and oncology. The participants mainly fall within the yellow group and a few in the amber group, with none from the red category according to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015) (detailed in the Background Chapter 2 – 2.1 Children with life-threatening and life-limiting conditions). Hence, the study sample included children whose risk of dying is expected before adulthood, but not within the next few months thus suggesting that the data were skewed towards patients with palliative care needs rather than end-of-life needs. This was because the clinicians guided the researcher towards this population.

The majority of the participants in Kuwait were Arab and in the UK they were White which is in line with the populations' statistics in both countries (The Public Authority for Civil Information 2018; MH government 2019). Participants self-identified their ethnicity in this study. Most of the caregiver participants were mothers; however, fathers, grandparents and paid caregivers were also recruited. Their educational levels varied with the majority having higher education which is the case in the general population in the UK but not in Kuwait (i.e. the largest group in the Kuwait population are those who did not complete their higher education according to the The Public Authority for Civil Information (2018)). Further details of the participants' characteristics according to the setting (i.e. hospital and hospice) can be found in Appendix X.

The length of stay for the recruited children varies. However, the researcher was aware not to recruit participants on their first few days of admission and also if it was their first admission to the hospital. This decision was to limit the bias of less experienced children who may be still not aware about their new routine at the inpatient setting or what might be their needs because of their lacked experience. The response rates in almost all of the settings were high, despite the fact that within the hospices the recruited number was lower. This is because of the hospices' low case load of children who satisfied the study's criteria. Three participants withdrew from the study (Q methodology) – two children and one mother. For one of the children, it was the researcher who reminded the child about his right to withdraw (see 8.1.3 Participants' rights and confidentiality). The other two participants decided by themselves not to continue. For the child, he did not want to do the unimportant cards and the mother indicated that she did not feel in a position to do it.

A group of children in this chapter are referred to as 'children with complex needs'. These are children who needed significant additional support and intensive ongoing care on a daily basis because of their physical disabilities and cognitive impairments (National Institute for Health and Care Excellence 2019).

6.2 Findings of the Q methodology

In the following section, the factors' interpretations are presented, which are the findings of the Q methodology. This was performed by merging the results of the statistical factor analysis with the card content analysis of the transcribed participants' verbal comments which were explained in Chapter 4. As mentioned in the 4.3.4 Data analysis section, the analysis was conducted independently for each of the four participant groups: 1) children from Kuwait; 2) children from the UK; 3) caregivers from Kuwait; and 4) caregivers from the UK. Despite the fact that two factors were extracted for each of the aforementioned groups (see 4.3.4.1 Quantitative data analysis in Chapter 4), there was a high association among the children themselves in the two countries as well as the caregivers. For further clarification, factor 1 extracted for the children in Kuwait was almost similar to factor 1 extracted for the children in the UK, and the case was the same for factor 2. This was also confirmed when the second-order analysis was run (explained in Chapter 4 in 4.3.4.1 Quantitative data analysis section). Therefore, the similar factors in the children's groups were interpreted together and presented next demonstrating participants from both countries in one factor, and the case is the same for the caregivers. Accordingly, two viewpoints/factors emerged for the children (each consists of two factors) and another two viewpoints/factors for the caregivers, irrespective of the country.

In the following sections, each factor is presented by initially reporting the study's variance with the factor eigenvalue (their level of significance is discussed in Chapter 4 – 4.3.4.1 Quantitative data analysis and illustrated in Appendix O) followed by demographic information of the participants who loaded significantly in this factor. Appendix Y shows the factor loading of all the participants and indicates the significantly loading Q sorts. The Q defining items follow, supported with accompanying data from the factor arrays (Appendix Q) and excerpts from participants' comments to help make sense of the data. It is noteworthy that, in this study, the spread range of the Q ranking, the factor arrays which is used in the following factor interpretation was nine-points distribution for the children's groups, ranging from +4 (most important) to -4 (most unimportant) and for the caregivers it was an eleven-points range, from +5 (most important) to -5 (most unimportant).

6.2.1 Children's group

Factor 1: the social experience of play

This factor represents factor 1 in Kuwait and factor 1 in the UK (Appendix Y). Kuwait's children's group had a rotated eigenvalue of 2.80 and explained 20% of the study variance; the rotated eigenvalue in the UK group was 2.86 which explained 22% of the study variance. Twelve participants, six children from each country, were significantly associated with this factor. Table 6-4 shows the characteristics of children who loaded significantly on this factor; that is, children who held the viewpoint represented by this factor more strongly than other participants. All of the children from the UK were female, while three from Kuwait were male. Their average age was 8.5 years. All the children from Kuwait were Arab and all those from the UK were White. They were recruited from the hospitals, except for two from the hospices. The children had a variety of conditions, with the majority of them under the yellow rating for the severity of their illness.

Table 6-4 Details of children loaded significantly high in children's factor 1

Participant code		Country	Setting	Age (in years)	Gender	Ethnicity	Diagnosis	Severity of the diagnosis[1]
1.	P03	Kuwait	Hospital	8	Male	Arab	Congenital	Yellow
2.	P23		Hospital	9	Male	Arab	Haematology	Yellow
3.	P33		Hospital	5	Female	Arab	Oncology	Yellow
4.	P37		Hospital	8	Female	Arab	Oncology	Yellow
5.	P38		Hospital	10	Male	Arab	Neurology	Amber
6.	P44		Hospice	5	Female	Arab	Oncology	Yellow
7.	P54	UK	Hospice	8	Female	White	Oncology	Amber
8.	P58		Hospital	11	Female	White	Genitourinary	Yellow
9.	P80		Hospital	9	Female	White	Cardiology	Amber
10.	P87		Hospital	9	Female	White	Haematology	Yellow
11.	P89		Hospital	11	Female	White	Genitourinary	Yellow
12.	P91		Hospital	10	Female	White	Metabolic	Yellow

[1]According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

In this factor, the importance of the social environment was demonstrated by the children's perspectives. The children enjoyed playing with others, in particular family (Table 6-5: item number #1: with factor array score +4 (most important) in Kuwait and +4 (most important) in the UK; referred to as (#1: +4, +4)) and pets (#8: +3, +4). This was also in line with their responses to other items which were linked with a playmate, regardless of level of importance placed on these forms of play as in arts and crafts (#20: +4, +3), water play (#3: +3, +3), active play (#12: +2, +1), joking (#5: +2, 0) and electronic devices (#25: +1, +2). P23 commented on the electronic devices stating: *'taking my cat and playing with her on the PlayStation.'* This is in spite of the fact that some of these play activities can be played alone. These children appreciated being with anyone who is interested in play, including the healthcare team (#2: 0, +1) and clown or musical man (#4: -1, -2) and paid less attention to having a playmate at a similar age (#6: -4, -3) or gender (#7: -3, -4); *'it doesn't really matter'* as reported by P87. These last two items, the playmate age and gender, differentiate this factor as being placed at the end of the negative grid. This means it was extremely unimportant for these children.

Given that these children did not prefer to play on their own, they conferred less importance on having a private play space (#17: -2, -3) and were less concerned about the accessibility in the settings in terms of moving around easily (#16: -1, 0) or the location of play equipment (#19: -2, -1). P37 commented on such items as *'mummy is with me,'* thereby placing less attention on her level of independence. Spaces which allow social interaction were of neutral importance because it was always good to them having other spaces such as green outdoor areas (#11: 0, +1), blue areas (#10: +1, 0) and playroom (#18: -1, -2). Despite the fact that the latter had lower value than the others, P89 explained the reason from her personal viewpoint when she said:

> P89: 'It's boring.'
>
> The researcher: 'Boring. You think the playroom is boring.'
>
> P89: 'Because you have to play on your own.'
>
> The researcher: 'Okay, what would you like to have in the playroom to make it more fun? What would be the things that you would like to add?'
>
> P89: 'Maybe more activities like group activities.'

The main difference between the two groups, children in Kuwait and children in the UK, was regarding the appropriateness of play equipment concerning the age- (#13: -4, -1) and gender-specific toys (#14: 0, -4). The age was more important in the UK whereas the gender had higher importance for the children in Kuwait.

Table 6-5 Factor array for children's factor 1

		Factor array	
item no.	Q set	Kuwait factor 1	UK factor 1
1	family	+4	+4
2	doctor/nurse	0	+1
3	swimming	+3	+3
4	clown/musical man	-1	-2
5	joking	+2	0
6	like my age	-4	-3
7	like me	-3	-4
8	pets	+3	+4
9	weather	0	-1
10	beach/ sea side	+1	0
11	outdoor	0	+1
12	active play	+2	+1
13	toys for my age	-4	-1
14	Boys'/ girls' toys	0	-4
15	dress up	0	-2

item no.	Q set	Factor array	
		Kuwait factor 1	UK factor 1
16	easy moving around	-1	0
17	private play area	-2	-3
18	playroom	-1	-2
19	getting toys	-2	-1
20	art	+4	+3
21	singing and dancing	0	+1
22	cooking	-1	+2
23	reading	+1	+2
24	board games	-2	-1
25	videogames	+1	+2
26	TV	+1	0
27	Lego	+2	0
28	paid caregiver	-3	-

Factor 2: conditions of play

This factor represents factor 2 in Kuwait and factor 2 in the UK (Appendix Y). The rotated eigenvalue for the Kuwait's children group was 2.80 and it explained 20% of the study variance and in the UK the rotated eigenvalue was 1.95 and explained 15% of the study variance. Eight participants were significantly associated with this factor; their details are presented in Table 6-6. Their average age was of 8.1 years. They were all recruited from the hospitals. Five of them were from Kuwait with the majority being female. Most of the children from Kuwait were Arab and all the others from the UK were White. Haematology diagnosis was more common in Kuwait and oncology in the UK, with the majority of them under the yellow rating for the severity of their conditions.

Table 6-6 Details of children loaded significantly high in children's factor 2

Participant code		Country	Setting	Age (in years)	Gender	Ethnicity	Diagnosis	Severity of the diagnosis[1]
1.	P01	Kuwait	Hospital	11	Female	Arab	Oncology	Yellow
2.	P07		Hospital	9	Female	Arab	Congenital	Amber
3.	P08		Hospital	6	Female	Arab	Haematology	Yellow
4.	P12		Hospital	5	Female	South-Asian	Haematology	Yellow
5.	P18		Hospital	7	Male	Arab	Haematology	Yellow
6.	P63	UK	Hospital	7	Male	White	Oncology	Yellow
7.	P71		Hospital	8	Male	White	Oncology	Yellow
8.	P73		Hospital	11	Female	White	Genitourinary	Amber

[1] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

The children who significantly loaded on this factor prioritised the conditions of their play in terms of some of the play equipment, spaces and playmates. They were very selective in their play choices regarding both the social and the physical items; accordingly, their selections of the play conditions guided their play. Despite the family being highly ranked (Table 6-7: item number #1: with factor array score +4 in Kuwait and +4 in the UK; referred to as (#1: +4, +4)), they would prefer to have a playmate of a similar age (#6: -1, 0) and gender (#7: 0, +1), when compared to factor 1. They did not consider the availability of pets (#8: -1, -3) to be essential for their play. These children preferred to play with age- (#13: +1, +2) and gender-appropriate toys (#14: +2, +2) when available, as P63 clearly stated that he would play with *'only boys' toys.'* Those children were found to prioritise being indoors; accordingly, they did not care much about the weather (#9: -1, -4). They were neither concerned about the availability of outdoor blue spaces (#10: -2, -1) nor swimming and water play (#3: -3, -4). The latter was extremely unimportant for this group. P07 laughed when she was asked about water play and replied: *'I'm at the hospital, why do I need to swim?'* Neutral importance placed on private play area (#17: 0, -1) on the other hand, the playroom (#18: +4, +4) was a distinguishing item, this is in addition to arts and crafts play (#20: +2, +3). When P18 was asked about the importance of the playroom (#18: +4, +4), he answered *'because I love drawing,'* accordingly, suggesting a high level of selectivity in their choices.

Despite the previously mentioned similarities, the culture influenced the children's choices of importance ascribed to a number of items. The clown and/or musical man (#4: -3, +1), accessibility of the setting (#16: -2, +3) and location of play equipment (#19: -4, 0) were more important in the UK, whereas in Kuwait dress up (#15: +3, -1) and green outdoor area (#11: 0, -3) had higher importance. However, these differences are consistent with this factor by informing the condition that the children wanted for their play. P01 reported *'being outdoor is change of scenery… to play ball with my brothers.'*

Table 6-7 Factor array for children's factor 2

item no.	Q set	factor array Kuwait factor 2	 UK factor 2
1	family	+4	+4
2	doctor/nurse	-2	-2
3	swimming	-3	-4
4	clown/musical man	-3	+1
5	Joking	0	0
6	like my age	-1	0
7	like me	0	+1
8	pets	-1	-3
9	weather	-1	-4

item no.	Q set	Factor array Kuwait factor 2	 UK factor 2
10	beach/ sea side	-2	-1
11	outdoor	0	-3
12	active play	+1	-2
13	toys for my age	+1	+2
14	boys'/ girls' toys	+2	+2
15	dress up	+3	-1
16	easy moving around	-2	+3
17	private play area	0	-1
18	playroom	+4	+4
19	getting toys	-4	0
20	art	+2	+3
21	singing and dancing	0	-1
22	cooking	-1	-2
23	reading	+2	0
24	board games	0	+1
25	videogames	+1	0
26	TV	+1	+2
27	Lego	+3	+1
28	paid caregiver	-4	-

After presenting the two factors, it is important to re-emphasise that children in factor 1 prioritised being with others. They were less concerned about what to play or who to play with. They will take any play opportunity that is with others. Accordingly, it was the social experience which guided their play. On the other hand, children in factor 2 were more selective in their play choices; thus, their selections of the play conditions directed their play. Although these children liked to be with family or playmates, they could also find pleasure in solitary activities such as art, drawing and reading. However, in both factors, family (#1) and the arts and crafts activities (#20) were always highly ranked, whereas common neutral importance was placed on most of the play activities including board games (#24), electronic devices (#25), watching TV (#26), engaging in reading (#23) and singing and dancing activities (#21).

There were a few distinguishing items in the extracted factors of the children in Kuwait and children in the UK; these items were similar in each country. The level of importance placed on independence was higher in the UK sample than in Kuwait in terms of the ease of moving around the setting (#16) and the ability of accessing toys independently (#19). However, in Kuwait, engaging in dressing up (#15) was typically higher than in the UK. For the two factors of children in Kuwait, the availability of a paid caregiver (#28) was extremely unimportant to children's play.

It is worth noting that most of the children did not add any extra card at the end of their sorting. A few children suggested certain items that had already been covered by the Q set. The children were suggesting items which were more examples of the already covered items such as playing basketball, having a show and doing gardening activities. Therefore, the researcher directed the children to the similar card in the set and asked the child if they wished to change its position.

6.2.2 Caregivers' group

Factor 1: being with others but concerned about the child's condition

This factor represents factor 1 in Kuwait and factor 1 in the UK (Appendix Y). In Kuwait, it had a rotated eigenvalue of 3.8 and explained 20% of the study variance and in the UK it had a rotated eigenvalue of 6.0 and explained 30% of the study variance. Twenty caregivers were significantly associated with this factor. Their characteristics are detailed in Table 6-8. Nine of them were from Kuwait, with the majority being mothers and recruited from the hospitals. Their average age was 38.25 years. All the caregivers from Kuwait were Arab and those from the UK were White. Around half of their children were male and their average age was 6.9 years. The severity of their conditions for the majority was yellow and their diagnoses were varying with oncology and haematology as most common.

In this factor, the emphasis was on children's needs of being with others and sharing good play time. Accordingly, having family and friends (Table 6-9: item number #6: with factor array score +5 in Kuwait and +5 in the UK; referred to as (#6: +5, +5)) was highly ranked. Some of the participants, mothers in particular, highlighted the importance of the father's presence on children's play.

> P13: 'Her father is more important than me because I'm with her during the treatment and injections but he's with her for entertainment'.

Thus, they were more concerned about the availability of someone to share the good moments with. This aspect was expanded by the caregivers' comments on some play types as their children enjoy it with others like card and board games (#36: 0, +1), doing arts and crafts (#35: +2, +3) and listening to stories (#34: 0, +2). P72 said *'She loves being read to and having children around her being read too. She absolutely loves it.'* Accordingly, less importance was placed on private play spaces (#21: 0, 0).

Table 6-8 Details of caregivers loaded significantly high in factor 1

			Caregiver’s details				Caregivers’ children details			
Participant code	Country	Setting	Age (in years)	Gender	Relationship to the child	Ethnicity	Age (in years)	Gender	Diagnosis	Severity of the diagnosis[1]
1. P09	Kuwait	Hospital	26	Female	Mother	Arab	6	Female	Haematology	Yellow
2. P13		Hospital	37	Female	Mother	Arab	7	Female	Haematology	Amber
3. P14		Hospital	40	Female	Mother	Arab	5	Male	Haematology	Yellow
4. P19		Hospital	28	Female	Mother	Arab	7	Male	Haematology	Yellow
5. P21		Hospital	37	Female	Mother	Arab	7	Male	Haematology	Yellow
6. P34		Hospital	28	Female	Mother	Arab	5	Female	Oncology	Yellow
7. P39		Hospice	30	Female	Mother	Arab	10	Male	Genitourinary	Amber
8. P43		Hospice	30	Female	Mother	Arab	5	Female	Oncology	Yellow
9. P45		Hospice	30	Male	Father	Arab	5	Female	Oncology	Yellow
10. P59	UK	Hospital	35	Female	Mother	White	11	Female	Genitourinary	Yellow
11. P64		Hospital	40	Male	Father	White	8	Male	Oncology	Yellow
12. P65		Hospital	45	Male	Father	White	7	Male	Oncology	Yellow
13. P69		Hospital	29	Female	Mother	White	10	Male	Oncology	Yellow
14. P72		Hospital	45	Female	Mother	White	8	Female	Haematology	Yellow
15. P75		Hospital	44	Female	Mother	White	5	Male	Cardiology	Yellow
16. P76		Hospital	44	Female	Mother	White	8	Female	Haematology	Yellow
17. P78		Hospital	50	Male	Father	White	7	Male	Haematology	Yellow
18. P81		Hospital	37	Female	Mother	White	9	Female	Cardiology	Amber
19. P96		Hospice	63	Male	Father	White	5	Male	Congenital	Yellow
20. P97		Hospice	61	Female	Mother	White	5	Male	Congenital	Yellow

[1] According to the Spectrum of Children’s Palliative Care Needs (Shaw et al. 2015)

In order for the child to get fun play time, having a playmate of a similar age (#13: +4, 0) was important from the caregivers' perspective, and this was the reason for having the paid caregiver (#45: -5) as a distinguished unimportant item.

> P21: 'It depends on the age [of the paid caregiver], if she is young, can interact, accept from the children. Someone who is 25 years is not same as 40 and 45.'

Thus, the caregivers were concerned about the children's needs for someone who is willing to share play. This was apparent regarding the play specialist (#8: +3, +4). This item in particular was always referred to as an influence of the positive relationship on child's care. This aspect, the relationship, was also identified in regard to the healthcare staff to play with the children (#7: 0, +2). Their play was not very essential to children's play; rather, the relationship which can be developed through play and jokes (#11: +1, -1) was highlighted in their comments. P19: *'he (the child) loves joking too much. He will not feel the injection if you were joking with him.'* Children can always get support and encouragement from this interaction (#1: +4, +5); that was important to their play. Children not only needed verbal encouragement but also assistance (#2: -1, 0) which can help in facilitating play interaction. P81 commenting on the assistance factor said, *'that's why we have a playroom, isn't it?'* The playroom (#18: +4, +4) was a distinguishing item in this factor facilitating children's play interaction with others.

Despite the importance placed on interaction and being surrounded by others, the children's health conditions and their low immunity levels were holding back the children's participations in groups as was reflected by the caregivers' answers. This was apparent in the low ranking of organised group activities (#10: 0, +1) and to have a clown or a musical man (#9: -2, -2) despite their importance, as the participants commented.

> P09: 'it's very nice when clowns coming in, with music and dancing for the children they change their moods … [but] we cannot always join that and be with other people because of her (the child's) immunity.'

This influence was also extended to the availability of pets (#20: -5, -1). Consistently, the caregivers placed high importance on the maintenance of the equipment (#26: +3, +3) and the space to accommodate a certain number of children (#24: +2, +2) because of the infection prevention. Although the caregivers acknowledged the restrictions' negative influence on their children from enjoying their time (#5: -2, -3), they agreed that there should be some in place for the children's care (i.e. children's immunity level). This influence of the children's condition was also applicable to other items such as weather (#14: -1, -5), green (#17: +1, -2) and blue spaces (#15: -3, -5) and the access to these areas (#16: -4, -1).

> P34: 'not important at all here at the hospital (referring to active play: #44: -4, -2). These need outdoors and our weather is not good for outdoors. Sometimes it is not good for her health to go and play outside… in Kuwait it cannot be. Because most of the time the weather is dusty, it's hot, cold.'
>
> The researcher: 'what about times where the weather is good in Kuwait?'
>
> P34: 'no, when my daughter is sick, I will not take her outside... when they are in pain; that's nothing. There are more important things than that.'

As the caregivers were prioritising, the number of play activities which required active movement was ranked as not essential including active play (#44: -4, -2), water play/swimming (#43: -3, -4) and ball games (#39: -3, -4). On the other hand, less negativity was directed to specific play types that are more sedentary in nature, in particular when the children were instructed not to move. P97 mentioned: *'this is good, the stories when he needs to be absolutely still.'* This was found regarding watching TV (#31: +3, +2), playing with personal tablets (#32: +1, +1) and reading stories (#34: 0, +2).

It is worth noting that the playmate gender (#12: +2, -3) and the availability of playground equipment (#19: +2, -3) were more important for the participants in Kuwait than in the UK in this factor.

Table 6-9 Factor array for caregivers' factor 1

item no.	Q set	factor array Kuwait factor 1	 UK factor 1
1	support and encouragement	+4	+5
2	assistant	-1	0
3	community think	-1	-4
4	free play time	-2	1
5	restrictions	-2	-3
6	family and friends	+5	+5
7	doctor/ nurse	0	+2
8	play therapist	+3	+4
9	musical man/ clown/ volunteers	-2	-2
10	organised group activities	0	+1
11	jokes	+1	-1
12	playmate gender	+2	-3
13	playmate age	+4	0

item no.	Q set	Factor array Kuwait factor 1	 UK factor 1
14	weather	-1	-5
15	blue space	-3	-5
16	easy access to outdoor	-4	-1
17	green space	+1	-2
18	playroom	+4	+4
19	playground	+2	-3
20	pets	-5	-1
21	private space	0	0
22	setting accessibility	0	+4
23	indoor space for active play	+1	+3
24	space for number of children	+2	+2
25	child-sized furniture	+1	0
26	good maintenance	+3	+3
27	space to supervise	+2	+1
28	getting toys	-2	+2
29	age-appropriate play equip	+5	+3
30	gender-appropriate play equip	+3	0
31	TV, videos, DVDs	+3	+2
32	personal tablets	+1	+1
33	videogames	-1	0
34	Stories	0	+2
35	arts and crafts	+2	+3
36	board and card games	0	+1
37	cooking and baking	-1	-3
38	blocks, trains, cars and puzzles	0	-1
39	ball games	-3	-4
40	musical instruments	-3	-1
41	sing and dance	-4	-2
42	imaginative/ pretend play	-2	-2
43	water play/ swimming	-3	-4
44	active play	-4	-2
45	paid caregiver	-5	-

Factor 2: conditions of play according to the child's abilities

This factor represents factor 2 in Kuwait and factor 2 in the UK (Appendix Y). In Kuwait it had a rotated eigenvalue of 2.85 and explained 15% of the study variance and in the UK it had a rotated eigenvalue of 3.8 and explained 19% of the study's variance. Thirteen caregivers were significantly associated with this factor (Table 6-10); six of them were from Kuwait, with the majority being female. More than half of them were recruited from the hospices. Their average was 38.53 years.

Half of the participants from Kuwait were Arab and the majority in the UK were White. Most of the children were male and were in the amber category of severity for their conditions. The children's average age was 6.7 years.

The caregivers who significantly loaded on this factor were caring for children with very complex needs with more physical and cognitive impairments; accordingly, their children's special needs were reflected in their choices. In these, their prioritisation of the Q items was highly associated with possibilities of facilitating their children's play and objects or areas which they can use. When the caregivers commented on the availability of family and friends (Table 6-11: item number #6: with factor array score +5 in Kuwait and +5 in the UK; referred to as (#6: +5, +5)), they emphasised the importance of grown-ups, including the healthcare team (#7: +3, +3) and play specialist (#8: +3, +1) in addition to the paid caregiver (#45: +5) in Kuwait. Thus, having a playmate of a similar age (#13: +1, -3) or gender (#12: -2, -4) was not one of their primary concerns. In addition, a number of play activities were linked to having an adult take part. P93 commented on the stories (#34: 0, +3):

> 'With an adult, an adult. And it's kind of a musical book then actually he'll spend a short period by himself, but it tends to be more adult-led.'

These can all be linked to the level of assistance (#2: +3, +4) these children needed in order to play. As this factor tended to present children with very complex needs, play activities that did not require higher mental capacity attracted higher rankings such as using musical instruments (#40: +4, +3), personal tablets (#32: -2, +4) and watching TV (#31: +2, +1), in addition to listening to stories (#34: 0, +3).

> P56: 'he (the child), for example, has got lots of different apps on it (the personal tablet) with lots of noise. It is about having noise really... It is just a bit different than TV all the time I guess and different to the musical instruments or listening to someone reading a story.'

Table 6-10 Details of caregivers loaded significantly high in factor 2

Participant code		Country	Setting	Caregiver's details				Caregivers' children details			
				Age (in years)	Gender	Relationship to the child	Ethnicity	Age (in years)	Gender	Diagnosis	Severity of the diagnosis[1]
1.	P04	Kuwait	Hospital	38	Female	Paid caregiver	South-Asian	8	Male	Congenital	Yellow
2.	P28		Hospice	50	Male	Father	Arab	7	Male	Oncology	Amber
3.	P29		Hospital	23	Female	Paid caregiver	African	5	Male	Neurology	Amber
4.	P30		Hospital	27	Female	Paid caregiver	African	6	Female	Congenital	Amber
5.	P31		Hospice	38	Female	Mother	Arab	7	Male	Oncology	Amber
6.	P32		Hospice	34	Female	Mother	Arab	5	Female	Congenital	Amber
7.	P47	UK	Hospice	66	Female	Grandmother	Mixed	8	Female	Oncology	Amber
8.	P56		Hospital	39	Female	Mother	White	6	Male	Neurology	Amber
9.	P84		Hospital	29	Female	Mother	White	5	Male	Metabolic	Yellow
10.	P85		Hospice	34	Female	Mother	White	8	Female	Neurology	Amber
11.	P93		Hospice	42	Female	Mother	White	7	Male	Neurology	Yellow
12.	P94		Hospice	41	Female	Mother	White	11	Male	Metabolic	Yellow
13.	P95		Hospice	40	Male	Father	White	5	Female	Neurology	Amber

[1] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

The musical instruments (#40: +4, +3) was a distinguishing item in this factor and one of the highest ranked pieces of play equipment. When this form of play activity was compared to those that required more attention and active movement, a number of items were noted by the caregivers as not being applicable including card and board games (#36: -4, -5), clowns or musicians (#9: -3, +1), videogames (#33: -2, -5), imaginative/pretend play (#42: 0, -3) and joking (#11: +1, -3). P84 commented: *'I don't think he really understands board games.'* This aspect was also reflected in the association between the community view of how children should be (#3: -5, -4) and the children's play. P28 stated: *'no, he doesn't know about them at all... it doesn't influence him because he's unaware of it.'* Accordingly, the caregivers paid less attention to the cultural aspects attached to the appropriateness of the tools their children play with, neither the age (#29: -2, -1) nor the gender-appropriateness of the play equipment (#30: -3, -4). They were more concerned about their children's opportunity to play. Thus, they highlighted the importance of having play equipment that was appropriate to the child's abilities and this also included the furniture (#25: +2, -2). Hence, the availability of different resources was useless when the children were not able to use them; this involved the accessibility of the setting (#22: 0, +2) and the maintenance of the setting itself and its equipment and play resources (#26: +4, +1) also.

> P93: 'they used to have a sensory room (at a hospital), but nothing ever worked… It tends to be a playroom but it's not always accessible, the playroom is up small steps so for someone in a wheelchair [it is difficult]…'

Other play activities were less negatively ranked despite the multi-skills that might be needed which was the case for arts and crafts play (#35: -3, -2), building blocks and puzzles (#38: 0, -2), active play (#44: -2, -2), cooking and baking (#37: -5, -1), balls games (#39: 0, -3), singing and dancing (#41: -1, 0) and using the playground equipment (#19: +1, -1). This was due to the possible adaptations that could be made to play with or use them.

> P95: 'She wouldn't necessarily enjoy cooking or baking but she might enjoy the texture of the ingredients… she'll be holding some of the materials.'

Therefore, the child may not engage as intended but will do so in their own way. One of the participants also added to this point by commenting on having indoor space for active play (#23: +2, +2):

> P31: 'not so much about running but just rolling around and pulling himself up. Just that space to move so that's important… if on a ward with other people where there is no space, he finds his bed and he hates it. He gets so frustrated and that makes the whole process more stressful.'

Hence, number of items can make a difference; for example possible opportunities are having indoor space for active play (#23: +2, +2), playroom (#18: +2, 0), private play spaces (#21: +2, +2), green outdoor areas (#17: -1, +2) and access to these areas (#16: -1, +3). Despite their somewhat neutral importance, the caregivers thought these would be good to have.

> P30: ‘She (the child) cannot [go out] because of all the machines attached to her body and the oxygen but it’s something that’s good to have.’

The distinguishing items between the participants in Kuwait and the UK were regarding the use of personal tablets (#32: -2, +4) and swimming and water play (#43: -4, +5). However, understanding the caregivers’ viewpoints can explain their similar perspectives, which is that children can play differently but in their own way, to the level of their ability, as mentioned earlier; for example, in Kuwait P32 commented regarding personal tablets: *‘she doesn’t know how to use it. She will throw it and break it.’* P47 stated: *‘She likes swimming, aaah the seaside … She will play with it (sand) and then she will throw it at the end.’*

Table 6-11 Factor array for caregivers' factor 2

item no.	Q set	factor array Kuwait factor 2	 UK factor 2
1	support and encouragement	+4	+4
2	assistant	+3	+4
3	community think	-5	-4
4	free play time	0	0
5	restrictions	0	-2
6	family & friends	+5	+5
7	doctor/ nurse	+3	+3
8	play therapist	+3	+1
9	musical man/ clown/ volunteers	-3	+1
10	organised group activities	+1	-1
11	jokes	+1	-3
12	playmate gender	-2	-4
13	playmate age	+1	-3
14	weather	-4	-1
15	blue space	-3	+2
16	easy access to outdoor	-1	+3
17	green space	-1	+2
18	playroom	+2	0
19	playground	+1	-1
20	pets	-1	0
21	private space	+2	+2
22	setting accessibility	0	+2
23	indoor space for active play	+2	+2
24	space for number of children	+3	0

item no.	Q set	Factor array Kuwait factor 2	 UK factor 2
25	child-sized furniture	+2	-2
26	good maintenance	+4	+1
27	space to supervise	-1	+1
28	getting toys	+1	0
29	age-appropriate play equip	-2	-1
30	gender-appropriate play equip	-3	-4
31	TV, videos, DVDs	+2	+1
32	personal tablets	-2	+4
33	videogames	-2	-5
34	stories	0	+3
35	arts and crafts	-3	-2
36	board and card games	-4	-5
37	cooking and baking	-5	-1
38	blocks, trains, cars and puzzles	0	-2
39	ball games	0	-3
40	musical instruments	+4	+3
41	sing and dance	-1	0
42	imaginative/ pretend play	0	-3
43	water play/ swimming	-4	+5
44	active play	-2	-2
45	paid caregiver	+5	-

To summarise the caregivers' factors; while the focus of factor 1 was more on the social aspects for the children's play experience, participants in factor 2 placed greater attention to the conditions of play to match their children's play abilities. This aspect in factor 2 was clear in terms of the distinguishing items, including the level of assistance children needed to play (#2) and the use of musical instruments (#40) being highly ranked. However, the participants in both factors shared two main consensus items which were ranked as being extremely important: the availability of family and friends (#6) and the child's need for support and encouragement (#1).

After presenting the two caregivers' factors, it is worth mentioning their specific consideration regarding the hospices. The participants who were recruited from the hospices, both from Kuwait and the UK, compared their experiences between the hospice and the hospital settings. They primarily acknowledged the role of the healthcare team (#7).

> P47: 'that never comes (in the hospital to the healthcare team playing with the child). I've been in a hospital setting but here (at the hospice) what happens is really important. Having these people (healthcare staff) interacting with her (the child).'

The participants also acknowledged the different activities organised for the children at the hospice. Commenting on the playroom (#18) item, P45 said, *‘here (at the hospice) it’s not necessary [to have a playroom] but at other hospitals [it is important]’*; thus, acknowledging the different organised activities and the atmosphere created.

> P85: ‘there is a volunteer who comes in to the hospice… I think having somebody to entertain is a little bit more important.’

This can be linked to the children’s free play time (#4); as P94 said: *‘All his time is free for play’ so it’s always good to have different resources to occupy the child’s time.’*

Another crucial point to consider from the Q methodology is the extra items identified by the caregivers. After completing the Q sort, the participants were asked to highlight missing statements or perspectives. A few of the caregivers who did that had common suggestions in both countries. The participants suggested having sensory play and toys that match the children’s abilities. One of them expanded further on this by recommending specially designed apps matched to the children’s abilities. In Kuwait, three participants suggested having a cinema at the hospital, whereas in the UK other things were suggested such as the need for a good internet connection (i.e. it relates to a variety of other things that children do such as playing online with friends and watching YouTube), the need for play areas other than the child’s bed, and the presence of the teacher’s influence on the children’s interactions.

6.3 Findings from the observation

Observing 31 children resulted in 62 hours of observations (Table 6-2). Analysing the collected field notes during these observations using content analysis (see 4.4.4 Data analysis) shed light on a number of social and physical enablers and/or barriers environmental factors in the four settings of observations: 1) Kuwait’s hospital; 2) Kuwait’s hospice; 3) the UK’s hospital; and 4) the UK’s hospice. However, before doing so, the main characteristics of children’s play observed are described. Therefore, the identified themes which is covered in this section are the overall play characteristics of the children followed by more details on each setting and then analysis of the social and physical environmental factors (Table 6-12).

Table 6-12 Identified observational themes

Identified themes	Sub-themes
Children's play characteristics	Observed play behaviours and areas of play
	Children's social interactions during play
Social environmental factors	Assistance and facilitation of the children's play
	Child's autonomy
Physical environmental factors	Availability and accessibility of resources
	Used equipment qualities and properties

6.3.1 Children's play characteristics

The first identified theme is the children's play characteristics in terms of the following two aspects: 1) the observed play behaviours and areas of play; and 2) the children's social interaction during play. This is worth emphasising in order to get an overall sense about that daily play and the context in which the data were collected before presenting the environmental factors. This also facilitates understanding the associated social and physical environmental factors related to the children's play.

In these observations, various aspects related to children's play were covered. The children had different abilities and health conditions presented in Table 6-2 (further details comparing each setting is available (Appendix X.2)). The children were also observed in different areas including patient's private and shared rooms, new and old wards, playrooms, sensory rooms, corridors, waiting areas, outdoor and treatment rooms during the presence of different people, including the children's families (e.g., parents, siblings, grandparents and paid caregivers) and staff members within the healthcare settings (e.g., nurses, doctors, physiotherapists, play specialists and technicians). This is in addition to the presence of the other patients and their families. Table 6-13 illustrates each child who participated in the observation and the setting they were recruited from.

Table 6-13 The children and their participation code in the observation

Participant code		Country and setting	Age	Gender
1.	P02	Kuwait hospital	11	Female
2.	P06		8	Female
3.	P10		6	Female
4.	P11		5	Female
5.	P15		5	Male
6.	P16		5	Female
7.	P17		9	Female
8.	P22		7	Male
9.	P26		5	Male
10.	P35		8	Female
11.	P41	Kuwait hospice	5	Female
12.	P42		10	Male
13.	P46		5	Female
14.	P52	UK hospital	7	Female
15.	P57		11	Female
16.	P66		8	Female
17.	P70		8	Male
18.	P74		5	Male
19.	P77		7	Female
20.	P79		9	Female
21.	P83		5	Male
22.	P88		9	Female
23.	P90		10	Female
24.	P48	UK hospice	11	Male
25.	P49		9	Female
26.	P50		9	Female
27.	P51		11	Female
28.	P55		8	Female
29.	P60		7	Male
30.	P61		10	Male
31.	P62		5	Male

Observed play behaviours and areas of play

The two most common play types that the children engaged in were playing with electronic devices and constructive play (see Appendix S). Children considered the first type of play, playing with electronic devices, as part of their everyday activities when they were asked about their routine. P22 (recruited from Kuwait) stated: *'I only play with the phone. If the phone was not charged, I will sleep;'* and P57 (recruited from the UK) stated: *'Eat, sleep, internet and talk.'* The majority of the children's time was spent in their room playing with electronic devices, particularly on their beds at the hospitals (Figure 6-3), although this screen play was not only restricted to the patient’s room but also occurred in other areas including the playroom (Figure 6-4). Figure 6-5 shows one of the participants who, during the two hours of the observation, was in the same position doing the same activity, despite the fact that the data were collected on two different days and at different times. It is worth highlighting that the availability of an internet connection was required for most of the children’s play with electronic devices; for instance, watching YouTube and playing online games. By using the internet, some of the children’s play was also playing online with others.

Figure 6-3 Playing with electronic devices on the bed

Figure 6-4 A child playing with a laptop in a playroom

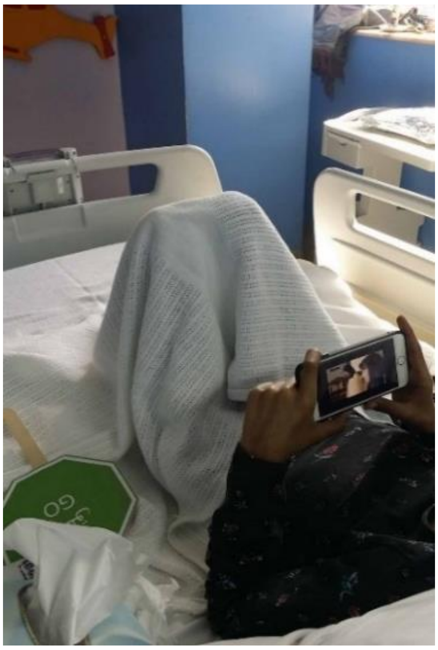


Figure 6-5 A child at Kuwait's hospital used the same electronic device retaining the same position during the two observations

Adults were observed *doing the play for the children* – in particular for those with complex needs who appeared to have poor cognitive and language skills in regard to their ages. This was observed at the UK's hospice in addition to the case of one child at Kuwait's hospital. They were either moving the child passively to interact with toys or playing in front of the child (Figure 6-6).

(a) (b)

Figure 6-6 Grown-ups doing play for the children a) Playing with a tablet in front of the child and b) Moving the child's hand passively over the musical tool to get sounds

Most of the children's play was observed in patients' rooms and playrooms at the hospitals, whereas in the hospices, it also comprised outdoor play and play on the floor in the sitting area. It is worth mentioning here the effect of isolation on some of the children's play. They were unable to use other areas at the hospitals, apart from their own individual room, such as the playroom or to share play equipment. For example, P22 who was in isolation, was in his individual room at the hospital, and wanted to leave frequently, mentioned that he was feeling bored and wanted to leave the room: *'I'm feeling bored, I want to get out of the room… I want to go to the playroom.'* His mother suggested bringing him toys from the playroom but he replied saying: *'But I want to go out.'*

Children's social interaction during play

Limited play interaction between the children was observed. This was largely in shared areas. When they did interact, it was for very short periods during group activities or with their siblings. In particular, at the playroom in Kuwait, none of the children who had been observed there interacted at all despite the fact that there were several children within the same room during the observations. Most of the children's cooperative play in both countries was with grown-ups (e.g., their parents, play specialists, volunteers or the researcher). This included different types of play such as language play, games with rules, pretend and explorative play, but primarily constructive play (Figure 6-7). Because the researcher was adopting the marginal role (4.4.2 Marginal participation), she only engaged in some play when the child suggested it, to establish rapport with the child, or when there was a long duration of passive observation (e.g., a child spending almost all the observation time watching YouTube).

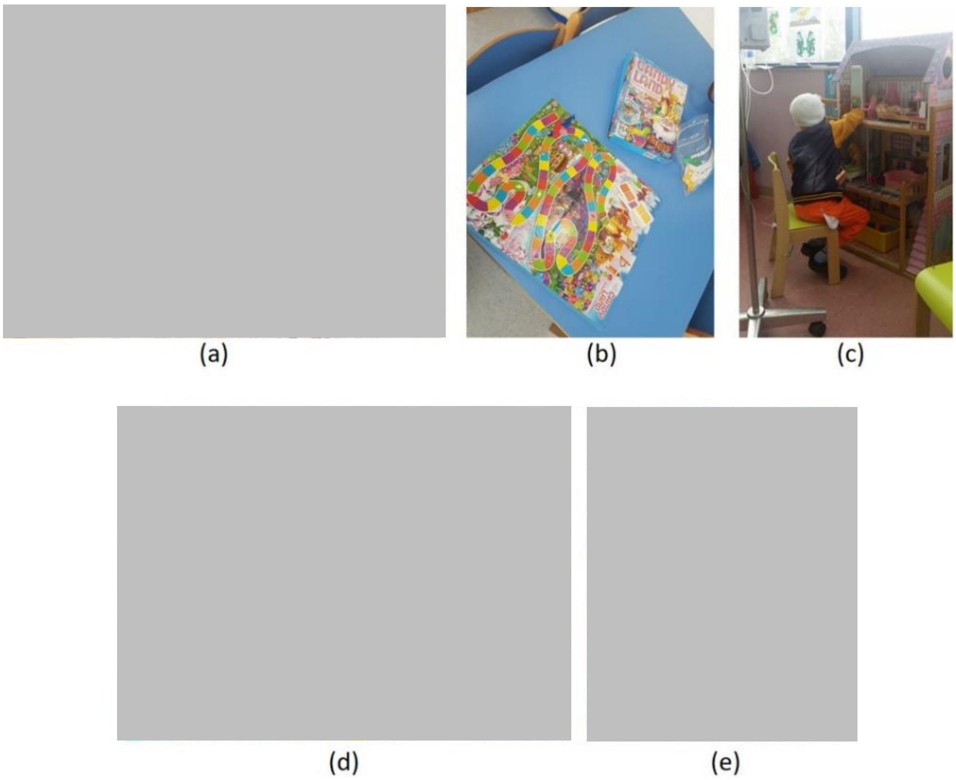


Figure 6-7 Types of play children played with grown-ups (a) language play; (b) games with rules; (c) pretend play; (d) explorative play; and (e) constructive play

With regards to the healthcare team, they rarely talked about or engaged with the child's play, particularly those at the hospital. Their interaction was mostly with the parents. P35 pretended to be a thief and covered herself with a blanket when the healthcare team, the police as she imagined, entered her room. However, they did not respond to her play because when they entered this patient's room, they discussed with the mother the child's case and left the room without interacting with the child. Very few of them would interact with the child asking about what they were doing. At the hospices, on the other hand, more interaction was observed to be initiated by the healthcare team. The mother of P46 mentioned that her daughter does not know that the doctor in the hospice is a doctor because of the way he interacts with her.

In the following section, what was observed in regard to the children's play at the observed four settings is presented. It is with more emphasis on the same aspects of their play (i.e. their play behaviours, areas and social interactions) but specifically to each setting to allow the transparency of the findings. Table 6-14 is a summary of the common features in each setting and Table 6-15 is a profile for each of the four research sites.

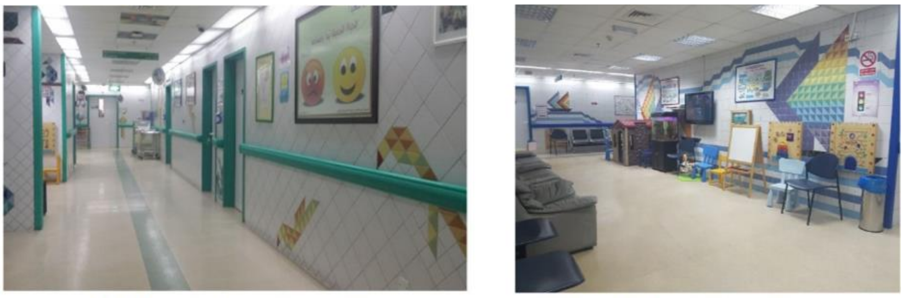
Table 6-14 Common features of children's play observed in each setting

		Setting			
Aspects of children's play		Kuwait's hospital (n=10 children)	The UK's hospital (n=10 children)	Kuwait's hospice (n=3 children)	The UK's hospice (n=8 children)
Accompanied person		Mostly mothers	Mostly mothers, some with both parents	Family members	Hospice staff
Common play types		Mostly solitary play with electronic devices and cooperative constructive play		Constructive play	Explorative, language play and playing with electronic devices
Social interaction with	Family members	No play interaction	Limited play interaction	Limited play interaction	They were not available at the hospice
	Other children	No play interaction	Minimal parallel play interaction	Parallel play interaction	Limited play interaction
	Staff at the setting	No play interaction	Limited play interaction	Engaged in play	Engaged in almost all children's play
	Frequent playmate	Usually played on their own	Play specialist	Family members	Hospice staff
Play area		Patient's room, in particular on the bed. Few in the playroom.		Playroom, the cafeteria and outdoor	Indoor area/sitting room, playroom, sensory room and outdoors

Table 6-15 Profile for each of the four research sites

<table>
<tr><th colspan="2"></th><th colspan="4">Setting</th></tr>
<tr><th colspan="2">Observed aspects</th><th>Kuwait’s hospital</th><th>The UK’s hospital</th><th>Kuwait’s hospice</th><th>The UK’s hospice</th></tr>
<tr><td rowspan="4">Social setting</td><td>a. Family members</td><td colspan="3">Can be available (depend on the family; see Table 6-14)</td><td>They were not available at the hospice</td></tr>
<tr><td>b. Healthcare team</td><td>Doctors, nurses, physiotherapists and child-life specialists. No occupational therapists are employed at this setting</td><td>Doctors, nurses, physiotherapists and play specialists. No occupational therapists were available during the observations</td><td>Doctors, nurses, and child-life specialists. No occupational therapists are employed at this setting</td><td>Doctors, nurses, carers and play specialists. No occupational therapists are employed at this setting</td></tr>
<tr><td>c. Animal</td><td>Nothing available</td><td>Fish tank (in one ward) and sometimes therapy dog (but was not part of any observation)</td><td>Fish tank at the entrance of the hospice</td><td>Nothing available during the observations</td></tr>
<tr><td>d. Group activities</td><td colspan="4">Organised frequently for the children</td></tr>
<tr><td rowspan="4">Physical setting</td><td>a. Decoration</td><td colspan="2">Some areas are designed as child friendly considering colours, decorations and furniture</td><td colspan="2">All the setting was child-friendly designed</td></tr>
<tr><td>b. play equipment</td><td colspan="4">Play equipment for almost all different types of play was available</td></tr>
<tr><td>c. Internet access</td><td>Self-provided</td><td>Provided by the hospital</td><td>Children were not observed to use any electronic device</td><td>Provided by the hospice</td></tr>
<tr><td>d. Accessibility</td><td colspan="2">No access to outdoor area and the indoor accessibility depend on the child’s ability</td><td colspan="2">Restricted access to outdoor area and the indoor accessibility depend on the child’s ability</td></tr>
</table>

At Kuwait’s hospital (Figure 6-8), ten children were observed (see Appendix X.2 for more details on the children). Most of them were with their mothers; if not it was a grandmother or a paid caregiver. Only one father was present; however, this was during the mother’s presence, and three of the children had their siblings. Only one child played with her brother but this was facilitated by the researcher. The children rarely played with their caregivers or the healthcare team and did not interact with other children. Their only cooperative play was with the researcher or with the play specialist in the playroom; frequently engaging in constructive (e.g., making roads for cars) or pretend play (e.g., pretend school play). Solitary playing with electronic devices was the most common type of play that children engaged in when compared to all other play things, although children also engaged with others, sometimes playing online. Only one child participated in active play and his play was deemed unacceptable by the mother because he was throwing tissues in a bowl filled with water. Most of the play was observed in the patient's room, in particular on the bed, and a few times in the playroom; however, the playroom was empty most of the time. Two of the observed children were in isolation and, therefore, did not leave their rooms.



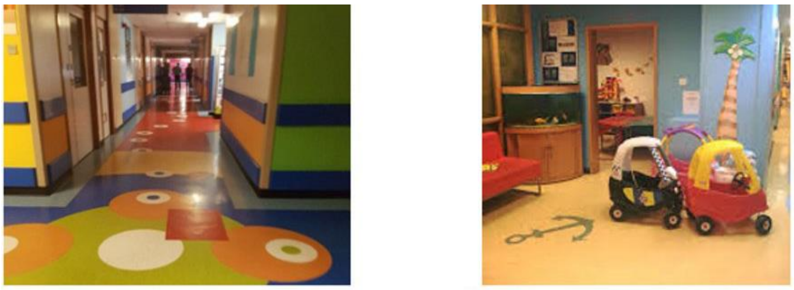
(a) Hospital ward's corridor (b) Hospital ward's waiting area

(c) Playroom

(d) Patient's room

Figure 6-8 Kuwait's hospital

At the UK's hospital (Figure 6-9), ten children were observed (see Appendix X.2 for more details). Except for one child who was with her grandparents at the hospital, all the others were with their mothers, a few were with both parents, and none had their siblings with them during the observations. Many of the children engaged in cooperative play, in particular with the play specialist (e.g., playing Lego and making slime) but also engaged with some mothers, fathers and teachers in addition to the researcher. The observed parallel play was also common in constructive play (e.g., drawing or making card). This type of play in addition to language play were the only cases during which the children interacted with each other, although it was very minimal interaction and occurred in a form of group activity. The children had the chance of some discussions and pleasant talks with the healthcare team about the different play activities they were doing (e.g., a doctor interacted with one of the children about the story he was making). As in Kuwait's hospital, the most common play was solitary play with electronic devices. The UK hospital also offered children videogames to borrow and play in their own rooms. Most of the children spent their time in the patient room; three of them were in isolation. Play specialists and teachers spent some time with the children in the patient room. The other children were observed in the playroom.



(a) Hospital ward's corridor (b) Hospital ward's waiting area

(c) Playroom

(d) Patient's room

Figure 6-9 The UK's hospital

At Kuwait's hospice (Figure 6-10), three children were observed (see Appendix X.2 for more details). As the care system at Kuwait's hospice was to facilitate quality time for the children and their families, the whole family was invited to the hospice. All of them were with their mothers, one father was there, and two had their siblings. There was some play interaction between the siblings but not with the other children. The members of staff at the hospice also joined the children in their play, and only one of the mothers did. Children spent their time at the hospice according to the pre-planned organised schedule of activities by the hospice. Most of the play was either parallel (i.e. during group activities) or cooperative play (e.g., a child playing with her sibling’s bicycle). The majority of the planned play activities were constructive play (e.g., decorating frames and colouring activity). One of the children also participated in language play by singing and imitating the movement of the song and this was with the hospice staff members. Most of the play took place in indoor areas, either the playroom or the cafeteria. The latter was able to accommodate a number of individuals as it had enough tables and chairs for a large group of people participating in the same play activity (e.g., children and their families, hospice staff, charities’ presenters and volunteers). Despite the wide indoor space for indoor active play, there was a specified time for outdoor play, where active play was observed. Only in Kuwait’s hospice no play was observed with electronic devices or games, children and their families followed the planned activities and electronic devices were not part of the schedule.

(a) Indoor area

(b) Outdoor area (c) Play area

(d) Activity room (e) Cafeteria

Figure 6-10 Kuwait's hospice

At the UK's hospice (Figure 6-11), eight children were observed (see Appendix X.2 for more details). According to the concept of the hospice in the UK, children were to spend their time there with the hospice staff to allow their families respite from caring. All but one of the children at the hospice appeared to have complex needs and limited cognitive and communication abilities. For these children, their play was selected by the staff; the hospice staff members were the ones choosing and, on many occasions, doing the play for the child. The areas children spent their time in during the observations were also the decision of the staff member caring for the child, either to take the child indoors (e.g., to sitting room, playroom or sensory room) or to be outdoors. The children participated in three types of play at similar levels which were explorative, language play and playing with electronic devices. The majority of their play with electronic devices was solitary (e.g., watching YouTube) and language play was parallel (e.g., group singing activity) where there was limited-to-no interaction between the children.

(a) Indoor area

(b) Outdoor area

(c) Activity room

Figure 6-11 The UK's hospice

The presented findings in regard to what children played, the areas they played in, and their social interactions during play can explain and provide an overview of children's play within the inpatient healthcare settings. This illustration is highlighting some environmental factors associated to children's play that are demonstrated in the next two identified themes, the social and the physical environmental factors.

6.3.2 Social environmental factors

Two sub-themes emerged from the theme of social environmental factors these were the children's requirement of assistance and facilitation for their play and the child's autonomous play (Table 6-12).

<u>Assistance and facilitation of the children's play</u>

Children with complex needs were always with an adult who facilitated their play in getting objects to use and spaces to be in (Figure 6-6). Other children had difficulties in using small objects in particular in their constructive play, such as fitting together Lego bricks, getting glue or simply removing the lid of a colouring pen (Figure 6-12). P74 for example spent more than one hour building a Lego model with a play specialist who provided him with verbal and physical assistance. Another example on verbal assistance was the play specialist reading the instructions for P52 to make slime.

(a) (b)

Figure 6-12 Physical assistance children needed (a) to get glue and (b) to fit Lego bricks

On some occasions, the children did not require assistance – only facilitation of play was needed. This included making the playthings more accessible for the child to play by suggesting, preparing or facilitating group activities. One of the mothers placed various pieces of play equipment on the child's bed where he was sitting (Figure 6-13) as a way of suggesting different things for him to play with. Additionally, the children were asked what they wanted to do and sometimes given various options. The suggestions were provided by the play specialists and mothers most of the times. When a mother suggested that the child play, it was almost always for the child to play on their own and not to share the play experience with them. The play specialists, on the other hand, would sometimes suggest sharing play with the child and at other times suggest that the child play on their own.

Figure 6-13 Caregiver suggesting play by puting all available play equipment in front of the child

The children acknowledged the importance of the play specialist. P90 said *'[the play specialist's name] is the best thing here (at the hospital).'* This was when her mother disagreed about making slime and the play specialist promised to do that with her. The play specialists were responsible for organising group activities in the four settings and inviting the children to attend such as the group organised activity which took place in the UK's hospital corridors as in Figure 6-14, and preparing pizza. Although limited interaction between the children was observed, when children shared the same table within the shared areas (e.g., playroom), they looked at each other and copied each other, which only happened in the UK. P79 decided to draw Spiderman's hand on her pillow case which she was decorating when she saw that the other child on the same table had Spiderman's hand on his pillow case. The children also directly suggested specific drawings and colours for each other to use.

Figure 6-14 Organised group activity

Particularly at the hospitals, there were a number of children who were observed spending most of the two-hour observation on sedentary activities (e.g., watching TV or playing with electronic devices); this was with regard to their physical abilities of independency. All of them who the researcher suggested she played with agreed. However, this suggestion was during the last ten minutes of the observation, to limit its influence on the children's routine. For a number of participants in both countries, when the researcher initially introduced the study, the caregivers replied by saying that the child spent all the time on electronic devices. P10's mother said: *'I will tell you from now, she (the child) will just be in her bed playing with her iPad.'* However, this was not the case during the two hours of observation. The child herself asked the researcher if she could play with her. The child also suggested different types of play including hand-clapping games, pretend school play and colouring, and the researcher engaged with her in all of her suggestions (Figure 6-15). During the colouring, the researcher positively commented saying to the child: *'Very nice, you are doing a good job.'* To this, the child replied: *'I don't have anybody to play with... I get bored, this is why I use the iPad.'* Parents were the usual companion with children at the hospitals. In almost all cases, when children were using electronic devices, the caregivers were using their own devices too. Additionally, on very rare occasions, the siblings were there with the child and, as highlighted, there was limited interaction with the other children in the settings.


(a) (b)

Figure 6-15 A child playing with the researcher (a) playing school pretend and (b) colouring

Child's autonomy

When the children got control, they used different equipment as play tools. An example of this is P57 who lifted the bed very high when the doctor gave her the bed controller and said *'you take the control now'* after she reclined the bed to do the check (Figure 6-16). Another example is the child in Figure 6-15 (a) who used the doctor's clipboard which was attached to her bed to engage in pretend school play.

Figure 6-16 A child having the bed controller

The healthcare team interrupted the children’s play frequently to undertake some medical procedures; after a doctor left her room P88 said: *‘Just angry about interrupting the game.’* Several times children stopped their play and were just waiting for the medication, to start play again.

On some occasions it was the mothers who interrupted and sometimes to control their children’s play. Several mothers repeated the same suggestion over and over to convince the child (e.g., going to the playroom). Additionally, they asked the children for their opinions regarding specific things related to their play, but they frequently did not wait for a response. This was observed with children who both could and could not communicate easily. P16’s mother asked her daughter if she wanted to watch a YouTube video and she gave her the device with the video playing to watch without waiting for the child’s answer. Furthermore, they also made choices related to child’s play without asking the children. For instance, P83 had a funny face sticker book and the mother decided to tear all of the sticker pages out and spread them in front of the child (Figure 6-17). She did that despite the fact that P83 did not agree and said to her: *‘you are breaking my book.’* Moreover, some of these children’s play was not allowed by the mothers. For instance, one child (P66) wanted to make a card for her brother but the mother did not allow her to do so because it was not his birthday.

Figure 6-17 Caregiver to control how the child plays by tearing the sticker pages

The children also were occasionally offered few play options limiting their play choices. For example, P46 was engaging in a colouring play activity, as can been seen in Figure 6-18. There were only three colours available which the play specialist was choosing for the child. When the researcher interrupted and asked the child about which colour she wanted, P46 replied saying *'pink'* which was none of the three prepared colours.

(a) (b)

Figure 6-18 A child engaging in colouring (a) having limited colour choices and (b) high level of physical assistance

Frequently, the children's play was controlled by the level of assistance received. An example of this is the play specialist who was holding the brush with the child and moving it, writing the child's name, suggesting some drawings and initiated the drawing; passively moving the child's hand by moving the brush (Figure 6-18, b). P79 was doing a puzzle and her mother was sitting next to her. The mother kept suggesting pieces of puzzles and trying to do some of it despite the child saying to her several times not to *'no please mommy.'* The mother commented *'Oh! It is difficult not to. I have to not interrupt the play.'* Some of the grown-ups' negative comments also made children change their play. This same child (P79) changed the puzzle she was doing when her mother said: *'it is too difficult for her. Four puzzles together, too difficult,'* when actually it was not challenging for her age.

Nevertheless, a very obvious play control was the adults doing the play for the children as mentioned previously. They were choosing the type of play and they were playing for the child. For example, a staff member caring for P49 brought her a tablet and put it in front of the child, and the staff member was the one playing for the child as in Figure 6-6 (a). The staff at the hospice decided to let P48 play with a special computer device. They spent more than ten minutes just trying to work out how to print the child's drawing while the child just sat doing nothing. They wanted one copy to hang in the hospice and another one for the child's mother.

6.3.3 Physical environmental factors

Within this theme, some of the identified sub-themes were crucial enablers while others, on the other hand, acted as barriers to children's play as previously found in the social environmental factors. The availability of the resources and the objects' properties were important; however, the key element in this theme was the easy access to the resources.

Availability and accessibility of resources

The different settings had different available areas where children were able to play with a massive amount of play equipment (Figure 6-19). From what was observed, almost all sorts of play things were available in large quantities including board games, arts and crafts things, figures, pretend play equipment, stories, DVDs, Lego and puzzles. The children could also borrow things for several days to have in their rooms. In addition, at the hospices, they had specialised equipment adapted to children's special needs such as wheelchair-accessible ferris wheel, wheelchair trampoline, and head movement-controlled computer (Figure 6-20). However, what was of great influence on children's play was the accessibility to these available resources.

Figure 6-19 Available play equipment; almost all sorts were available

Figure 6-20 Specialised adapted equipment

The aforementioned specialised equipment (Figure 6-20) was rarely used; in fact no child was observed choosing any of these. It was the hospice staff, as previously mentioned, who were choosing and doing the play for the group of children with complex needs. In addition, at Kuwait's hospital, there was an outdoor playground (Figure 6-21); however, the hospitalised children had no access to it. Furthermore, the playroom in Kuwait for example had specific opening hours; it opens between 8:00 the morning and closes at 12:30 pm in the afternoon and at the weekends. This is in addition to it sometimes being closed for other reasons, and children were not allowed to eat or drink in it (Figure 6-22). Also, children were not allowed to get play things which were kept in the cupboard in the playroom by themselves.

Figure 6-21 Outdoor playground at Kuwait's hospital

نأسف للإزعاج
سيتم فتح غرفة الألعاب الساعة
1 ← 11

Kacch team

opening hours for Today
11 → 1
Please inform the nurses if you need Somthing to Play
KACCH Team

Figure 6-22 Playroom restrictions in Kuwait

The children were observed to select play equipment with easy access in the settings. For example, most of the children at Kuwait's hospital played with the toy in Figure 6-23 when they entered the playroom; simply because it was almost always on the table in the middle of the room. Additionally, considering the patients' rooms, the researcher rarely found play equipment in the patients' rooms apart from electronic devices (Figure 6-24). In Kuwait, only two children had a few playthings, these were donated gifts from volunteers and charities for hospitalised children. In comparison to the children in the UK, all the children had their teddies with them, and a few had other things as Lego and art stuff; however, they were rarely observed playing with these, unless they were with others. The electronic devices were very easily accessible to the children, usually on the child's bed or on the table next to them. Some of the children had access to more than one device; for instance, they had mobile phones, tablets and videogame consoles.

The possibility of infection and being in isolation restricted the children from using some of the available play resources. One of the children's play activities was negatively influenced by not getting headphones to continue playing online and chatting with friends. This is in addition to the fact that they were not able to leave the patient's room. The example of P22 was previously mentioned who repeatedly said that he wanted to go to the playroom.

Figure 6-23 Children choose play with easy access

(a)

(b)

Figure 6-24 Play things at patients' room (a) Patients' rooms in Kuwait and (b) in the UK (the electronic devices are circled with blue and the teddies with red)

Used equipment qualities and properties

The negative influence of the improper maintenance and quality of the equipment used was observed in Kuwait's hospital. This was particularly in regard to the children's use of the infusion (i.e. intravenous infusion and volumetric pump on a stand with five-wheel base). This limited the children's independence in mobility which affected their moving around to play. The children required assistance to propel its wheels to move between rooms or to go and grab play equipment. In contrast, the children's movement at the UK hospital was not restricted to the use of infusion, which was easily controlled. They were observed moving around the ward and manoeuvring independently. None of the children at Kuwait's hospice was using any medical devices or mobility aids but in the UK's hospice the children who used devices were dependent on them for their mobility. This is in addition to the fact that most of them who required assistance to be propelled had complex needs.

Another issue in regard to children's use of equipment was mentioned previously under the social environmental factor for the assistance the children needed to play. As in Figure 6-12, the children needed physical assistance to use some of the play equipment. Many playthings were not easy for the children to control.

Moreover, during the observation at the UK's hospice, the staff were using specialised equipment (e.g., the head movement-controlled computer) with some children. When the researcher asked about how frequently such tools are used, the answer was related to staff training. The staff recently had training on using such specialised equipment suggesting why it was used.

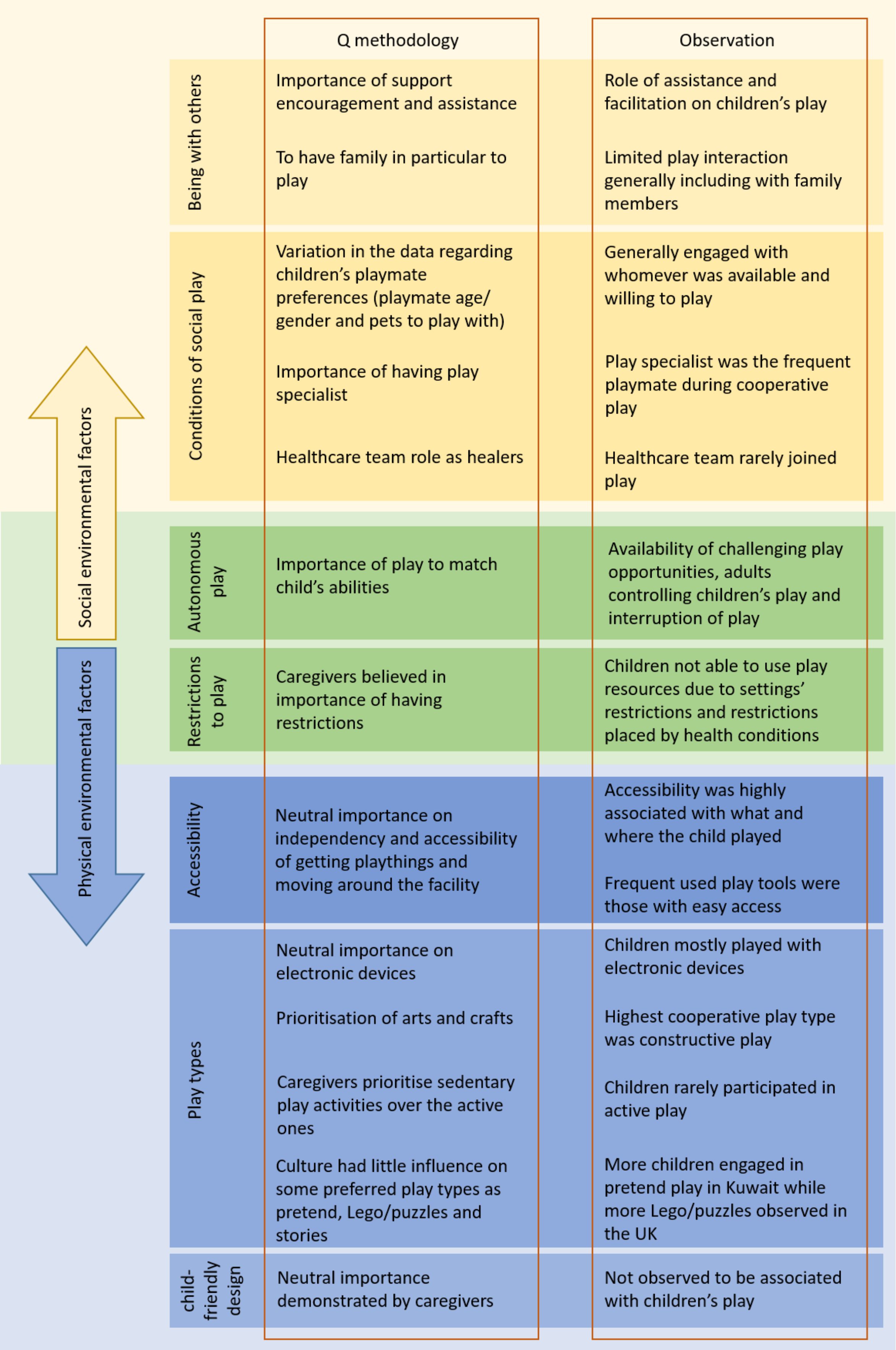
Summary of the observational findings

To summarise the observational findings, the children's everyday play, was associated with a number of factors. Most of these were similar in all settings and a few were specific to a setting or culture. The children's health conditions and their abilities were important components to consider during the analysis. The children mostly engaged in solitary playing with electronic devices and cooperative constructive play, playing on the patient's bed or in the playroom at the hospitals, whereas in the hospices it was usually decided by the hospices' staff members. Most of the children's interactive play was with grown-ups (e.g., play specialist, research or mother) and very rarely with other children. In Kuwait, their play was even less with others. From what has been observed, a number of enablers and environmental barriers have been identified within the social and physical contexts. The children frequently required assistance and facilitation for their play, particularly when it was not play with electronic devices. Despite this, sometimes the provided assistant was negatively associated with the children's level of control over their play; children needed someone who was willing to share play with them. The observed settings were well equipped with different resources; however, it seemed that the accessibility to these resources had a crucial role in what the children played with. This is in addition to these resources' specification and ease of use when considering the children's abilities.

6.4 Integration of the findings

Using following a thread technique (explained in Chapter 4 – 4.5 Data integration and interpretation section), the data collected from the Q methodology and observation were integrated to further explore key issues and ultimately understand and synthesise the findings resulted from this mixed-methods study. The resulted integrated findings are presented in Figure 6-25.

Being with others: The social play experience was essential for the children's play. This provided them with support, encouragement and assistance. The assistance was more obvious in the observation. The participants reported positively when the children were surrounded by others particularly the family as resulted from the Q methodology. This is despite the limited observed play interaction with them.



	Q methodology	Observation
Being with others	Importance of support encouragement and assistance To have family in particular to play	Role of assistance and facilitation on children's play Limited play interaction generally including with family members
Conditions of social play	Variation in the data regarding children's playmate preferences (playmate age/ gender and pets to play with) Importance of having play specialist Healthcare team role as healers	Generally engaged with whomever was available and willing to play Play specialist was the frequent playmate during cooperative play Healthcare team rarely joined play
Autonomous play	Importance of play to match child's abilities	Availability of challenging play opportunities, adults controlling children's play and interruption of play
Restrictions to play	Caregivers believed in importance of having restrictions	Children not able to use play resources due to settings' restrictions and restrictions placed by health conditions
Accessibility	Neutral importance on independency and accessibility of getting playthings and moving around the facility	Accessibility was highly associated with what and where the child played Frequent used play tools were those with easy access
Play types	Neutral importance on electronic devices Prioritisation of arts and crafts Caregivers prioritise sedentary play activities over the active ones Culture had little influence on some preferred play types as pretend, Lego/puzzles and stories	Children mostly played with electronic devices Highest cooperative play type was constructive play Children rarely participated in active play More children engaged in pretend play in Kuwait while more Lego/puzzles observed in the UK
child-friendly design	Neutral importance demonstrated by caregivers	Not observed to be associated with children's play

Figure 6-25 Integrated findings

Conditions of social play: In regard to the playmate, some of the children needed or had very specific play choices while others would join any play opportunity. These differences depended on a number of factors including children's play preferences, availability of playmate and some social norms. For the children's preferences there was variation among the groups as presented in the emerged factors of the Q analysis, which comprised differences in their choices of playmate age, gender, pets and paid caregiver. However, the observation was generally characterised by limited play interaction with all.

Although some children specified preferred playmates; during the Q sorting for the play activities, the children were asked about their preferred playmate for that particular play, but they frequently responded by saying whoever is available. In relation to this, the play specialists were highlighted by the caregivers' Q sorts as valuable and willing to share play with the children. As demonstrated in the observational findings, most of the children's cooperative play was with the play specialists.

The children held the perspective that the healthcare team role is not to join play as a social norm. The healthcare team's interactions with children were limited to a few of them who only talked a little to the child about what they were doing/playing. This could be related to a lack of education about/ limited training on the use of play, not viewing play as part of their professional role/ their other job roles responsibilities, their heavy workload/ lack of time or valuing play less than other methods. When children feel fear and anger towards the healthcare team, they may avoid interacting with them. This negative feelings towards the healthcare team was reported by some children in this study and also reported in previous evidence (Nabors and Liddle 2017). Children may associate painful procedures with the team members if they are frequently exposed to those procedures.

Autonomous play: One of the aspects which the participants related to the high importance of being with others was because of the negative influence of the conditions on the children's capabilities in their use of the play resources. This included the play types they can engage in and spaces they can be in. Furthermore, the health conditions left the children needing assistance in facilitating their play. This on the other hand was related to interrupting the children's autonomous play occasionally. This was evident in the observation when the adults were doing play for the children as an example. The caregivers highlighted this point in their Q sortings by demonstrating the importance of having play that matches the children's abilities. This point is also emphasising the physical properties of the play resources corresponding to what children can use.

Restrictions and accessibility: Another factor related to the children's play was the restrictions within the settings. In the playroom at Kuwait's hospital for instance, the children were not allowed to pick play equipment by themselves; the play specialist was responsible for that. However, the caregivers believed in the importance of these restrictions despite acknowledging its negative influence on their children's play. This was linked to their immunity level and to control sources of infection transmission. Furthermore, due to the restrictions, the children who were in isolation were not able to enjoy some of the play resources. The caregivers demonstrated these points by associating it to a number of items in the Q methodology including having volunteers, clowns, musicians and other group activities where their children cannot join in. This was also applicable to the inaccessibility of outdoor spaces.

The accessibility concept emerged from the observation as a main concern as to where and what the children can play. It influenced the children's play participation including both the social and physical play aspects. However, the participants, both the children and the caregivers, placed neutral importance on it when sorting items as the accessibility of the buildings, to outdoor areas and in getting toys.

Types of play: From the extracted factors, it was demonstrated that the participants had relatively little concern for the type of play activities the children to engage in. Most of the play types were classified under the middle neutral columns. An exception was the arts and crafts play activities which were prioritised by the participants in their Q sortings. Furthermore, it was the second highest play they were observed participated in following their play with the electronic devices. None of the emerged factors, for both the children and the caregivers, had playing with electronic devices as highly prioritised despite this being the most often observed type of play. The participants rationalised this neutral level of ranking during the sorting by their verbal comments prioritising being with others. This was illustrated earlier (in 6.3.2 Social environmental factors) when one of the children (P10) mentioned using these devices because of feeling bored. Another child (P70) answered when asked about what he does: *'probably watch YouTube.. (silent) but this is still boring.'* Also, a caregiver explained that by:

> 'I'll be honest because there is so much technology that she does play with, but I prefer her playing with children and communicating because at the end of the day the iPad is always there. The fact is that being stuck here for so long, she needs to get in with children so that she can get out of her mood. The iPad and videogames are fun and kids like fun but they do not make children happy; they don't. They pass time but they don't make children happy. And I really want her (the child) to be happy. There are things that make her happy.' (Mother of 5-year-old girl in Kuwait)

The caregivers generally placed higher importance on play activities that were sedentary in nature (e.g., watching TV and reading stories) than on more active ones (e.g., ball games). As cultural differences, playing with blocks/Lego, puzzles, imaginative and pretend play had higher importance in Kuwait whereas reading and/or listening to stories were more important in the UK. More children in Kuwait were observed engaged in pretend play, whereas more Lego were found in patients' room in the UK's hospital.

Child-friendly hospital/hospice design: It is worth noting that despite the child-friendly designed settings, considering the decorations and the child-sized furniture, this was not observed to be linked to the children's play. Children were observed in both highly modern wards/rooms and others in very old ones and no difference in play was evident. Frequently there were adult-sized chairs and tables and the children were able to successfully complete their play using them. This is in addition to the fact that the caregivers paid less attention to this point in their Q sorting. However, these child designs might carry indirect positive impact on play.

6.5 Summary of the chapter

Ninety-seven participants were included in this study comprising children and caregivers taking part in Q methodology and observation recruited from four settings in Kuwait and the UK. The collected Q methodology data resulted in two extracted factors for each group which were presented. These factors highlighted two main viewpoints which are the importance of the social play experience and the required conditions of children's play. This was followed by presenting the three identified themes from the observational data: the children's play characteristics and the social and physical environmental factors. The sub-themes of these factors included the assistance and facilitation required for the children's play, children's autonomous play, the availability and accessibility of play resources and the qualities and properties of the used equipment in relation to children's play. The resultant findings from the two datasets and participants' groups were then integrated, drawing on the main aspects associated with children's play in the last section. This is brought together in the following Discussion Chapter.

Chapter 7 Discussion

This study is the first to explore the social and physical environmental factors that are associated with the play of children living with LTC/LLC. The aim of this study was also to understand the nature of these children's playing and to identify the related factors needed for a supportive play environment. In this chapter the findings from the mixed-methods design are integrated and discussed. These aspects are discussed in relation to the existing body of literature surrounding the topic of play and LTC/LLC, with reference to occupational science. The chapter comes to a close by a reflection on the study's implications, strengths and limitations and recommendations for future research.

7.1 Discussion of the main findings

7.1.1 Overview of the major research findings

The findings of this study demonstrate that, regardless of the differences in children's cultural backgrounds, age, gender, condition and the condition's severity, children have very similar play needs and play choices. The factors that emerged from the Q methodology highlight the importance of being with others for the children if they are to play. However, restrictions in children's social play is associated with the children's health conditions. These health conditions influenced and directed the children's selections regarding their playing. The observational findings were complementary; there was very limited social play, which was restricted to only a few types and in specific areas. Although different play tools were available, inaccessibility was found to considerably restrict the children's play opportunities. Occasionally, children required adults to assist and facilitate their participation in play leading to a restriction in their autonomous play. These points are discussed further in the following sections of this chapter in relation to three main overarching concepts that were identified: a) the social experience of play, b) the accommodation of children's limitations in play and c) the access to play resources. This discussion will be followed by the culture-related specific findings.

7.1.2 The social experience of play

Being with others

One of the central findings of this research was that being with others is one of the children's needs which is required to be met before they can satisfactorily engage in play. This finding is supported by previous research which has shown the children's general need for companionship when hospitalised (Angstrom-Brannstrom et al. 2013; Nabors and Liddle 2017; Witt et al. 2019) and a few studies demonstrated that point with reference to children’s play (Wilson et al. 2010; Adistie et al. 2019).

This study’s data showed that the participants greatly valued the physical play resources (e.g., availability of play space and equipment) when they were related to increase children’s opportunities for playing with others. The playroom, as an example, was frequently linked to their social play. This association between the playroom and the social play is likely because children can find more people willing to share play in the playroom, as demonstrated in the literature (Wilson et al. 2010; Lambert et al. 2014a). When the children in this study were unable to interact with others in the playroom, some of them said that that they found that situation to be ‘boring’.

The participants’ prioritisation of being with others could be linked to their need for continuity in their normal everyday living, as noted in the literature review above (Chapter 3) (Rabiee et al. 2005; Aldiss et al. 2009; Graham et al. 2015; Verschoren et al. 2015; Nabors et al. 2019; Witt et al. 2019). From the findings of this study the uncertain nature of the LTC/LLC prognosis, and particularly the possibility of death, did not appear to alter children’s needs of being with others or their needs to play and live their childhood. However, social withdrawal is very common among adults receiving palliative and end-of-life care; at least in part because of social embarrassment caused by their conditions’ consequences (Costello 2018).

Palliative care in children is different from the care provided for adults, given that children continue through their developmental stages and the rate of their survival is higher than for adults with LTC/LLC (McNamara-Goodger and Feudtner 2012; Baker et al. 2015). This distinction in the PPC can confirm the importance of parallel planning, as highlighted in Chapter 2 (2.1 Children with life-threatening and life-limiting conditions). It has been documented that children living with the possibility of their death are more concerned with time they have left to enjoy their lives; a perspective which is unlike that their carers and their surrounding community (Bluebond-Langner et al. 2012). Those adults who surround such children are mostly concerned with hope for a cure, which sometimes leads to ignoring other aspects of the children’s lives (Hynson 2012). Hence, it is important to allow time for a child with LTC/LLC to engage in activities that contribute not only to that child *becoming* (e.g., age-related activities such as schooling) but also *being* a child who can and does play. It is crucial to consider play from the children’s perspectives; in particular because environments that can encourage children’s participation in play should also meet and support the children’s need to experience social play.

The negative impact of LTC/LLC on the social play experience

The findings of this study are consistent with previous research acknowledging that living with LTC/LLC places limitations on the children's play experiences (Aldiss et al. 2009; Gibson et al. 2010; Silva and Cabral 2014; Graham et al. 2015; Mufti et al. 2015; Graham et al. 2018; Nabors et al. 2019; Witt et al. 2019). Additionally, the play activities which the children engaged in during the observations that took place in this research are in line with the literature. Most of the children's play was: a) on their own, b) sedentary in nature (e.g., playing with electronic devices), c) took place in indoor settings and d) when at hospital was usually on the child's bed (Skar 2002; Lima and Santos 2015; Witt et al. 2019). These characteristics of the children's play can be due to their health conditions that leave children weakened, as highlighted in Chapter 2 and Chapter 3. Those contextual conditions can also be explained by the accessibility concept, further explained in 7.1.4-Accessibility to play resources.

Another impact of the LTC/LLC on children's play was the limited interaction between the children themselves, which was a major theme in the observational findings. This limitation restricted the level and amount of their social play and being with other children. Evidence confirms that occupations undertaken with others (e.g., participating in play with others), which are called co-occupations, are expected to be negatively influenced by disabilities (Pickens and Pizur-Barnekow 2009). However, there is evidence that participation in co-occupations has a positive impact on the individual's occupational performance (Pickens and Pizur-Barnekow 2009; Hammell 2017b).

One of the main issues highlighted with regard to the influence of the LTC/LLC in restricting the children's social play was the isolation precautions. Data generated from both investigative methods demonstrated that actual infection, and/or fear of infection, was a concern leading to the limitation of social play opportunities; a constraint found in terms of space and equipment to use, such as being unable: a) to join group activities or b) to share play equipment. The caregivers also disregarded the importance of pets; a view informed by the adults' concerns over potential infections the children might catch, particularly when considering their children's conditions. These findings corroborate previous evidence associated with the negative consequences of 'infection prevention' on children resulting in: a) the reduction of contact with their peers (Witt et al. 2019), b) their inability to participate in hospital play activities (Foster and Whitehead 2019), and c) their inability to use the playroom (Gibson et al. 2010). Nevertheless, some available guidelines permit siblings' use of the playroom in order to reduce chances of infection transmission (Ivany et al. 2016). Such restrictions can have a negative impact on the patients themselves as a consequence by restricting their play with their siblings. Although the ultimate goal of the healthcare facilities is promoting children's health and well-being, some precautionary practices can counteract this aim. When play is limited by isolation precautions, which are designed to promote or sustain the children's health, such a situation could be argued to be negatively rather than positively influencing their well-being. Thus, the issue of ‘infection prevention’ requires careful consideration of children’s physical health, while maintaining their mental health as well.

Despite the children’s needs of being with others, it has been reported that some inappropriate attitudes of the caregivers can lead to social isolation of the child in their care, when overprotecting their children by isolating them (Bioy and Wood 2012). Some parents have a fear of stigma; accordingly, they restrict any interaction other people might have with their children in case the issues of ‘death’ and ‘dying’ might be mentioned (Levetown et al. 2011; Strong et al. 2011; Bluebond-Langner et al. 2012; Mack and Liben 2012). Hence, the physical separation of the children could be related to stigma and discrimination attached to, or associated with, the children’s disease that could be present in those children’s communities (Bioy and Wood 2012). Mufti et al. (2015), who studied children between 8 to 12 years old with beta-thalassemia major, found that community discrimination negatively influenced children’s self-worth and led to high levels of school drop-out. This discrimination towards children with such conditions can indicate poor community attitudes as a factor of the social environment related to the issue of the children’s isolation.

However, the previously reported negative impact of stigma does not appear to be the case in this study. The data from the Q methodology showed that the caregivers in this research believed in the insignificant impact of the community’s perception towards their children’s play. This perception is likely because these caregivers already established the boundaries regarding who their children are allowed to speak to or interact with. Additionally, during their participation in this study in order to limit any chance of causing psychological harm to the caregivers, discussions in regard to their children’s condition or the possibility of death or of a child dying were reduced to minimum levels. This sensitive issue also influenced the careful consideration that was given to the title of this research and in the developed forms used with the participants (see Appendix F, H and I). All the discussions the researcher established was related to play in the hospital/hospice setting; the issues of dying or illness were avoided. This specific focus could be seen as the reason for the caregivers not linking the community’s negative or discriminatory attitudes to their children’s play. Therefore, the mismatch between literature and the current findings is worth further investigation, in order to study the surrounding community such affected children are allowed to interact with. Also, further studies could ask the caregivers more clearly about their child patients’ possibility of dying, and the relationship of that possibility to their children’s play activities and behaviour.

Regardless of the caregivers' viewpoints and the stigma attached to the disease, the physical isolation of the children leads to their social isolation which, in turn, frequently results in those affected children developing psychological problems. When compared to other children, some with LTC/LLC experience occupational deprivation, because their occupational opportunities are restricted due to the fear of infection. This inequality can be viewed as the result of infection prevention, but which unfortunately prevents equality in play from being achieved in this case. This deprivation therefore highlights the importance of considering equitable opportunities for the children to be able to play in such challenging situations. Equity is a state that needs to be achieved by considering universal designs for children living with serious illnesses, deteriorating conditions and the possibility of dying because of their condition. Equity in resource availability enables children with a variety of health conditions and disabilities to participate in their different life roles and occupations which, as a consequence, is a key factor to them developing their identity (Mandich and Rodger 2006; Hammell 2017a). Building opportunities for participation in preferred occupations can also be achieved through community awareness and acceptance of an individual's differences; thus limiting the children's feelings of isolation or their sense of inferiority (Hewitt-Taylor 2008; Mufti et al. 2015).

Physical factors limiting the social play experience

At the hospitals, the use of patient's individual rooms appeared to be one of the factors associated with the children not playing together; being located in separate rooms resulted in very limited interaction between the children. Despite the increasing trend towards using such types of rooms, several studies found those locations decreased the resident patients' sociability (Lambert et al. 2014b; Curtis and Northcott 2016). Children in these studies illustrated the advantages of shared rooms, over individual ones, when it came to: a) making new friends, b) allowing play with others and c) reducing or preventing boredom. This current study supports this finding that the participants gave little importance to having a private play space according to their Q sortings.

Furthermore, this limited interaction was also observed in shared spaces such as the playroom, despite the presence of other children. The playroom is frequently used as an example in this discussion because it is a shared space designed to support children's play. A possible explanation for this limited interaction could be the small number of shared places, in addition to the inappropriate or inadequate amount of time children were offered together. The playroom in Kuwait only opened during the morning; a time when most of the children were sleeping or had their medical procedures. In Kuwait, the working hours are between 7:30 in the morning to 1:30 in the afternoon, with the playroom opening at 8:00am and closing around 12:30pm. This means that after the working hours, where children do not have any other procedures, the playroom is closed. Accordingly, the children did not have sufficient opportunities to get together and get to know each other, although peer familiarity is crucial for children’s play (Rubin et al. 1983). Graham et al. (2018), who studied the play of children with disabilities, reported that peer familiarity can draw the child’s attention away from their conditions because their peers can accommodate the child’s difficulties. Moreover, it has been reported that friendship generally can foster children’s participation in various occupations (Burgman 2012).

In addition, the physical layout of the furniture within the setting can encourage/hinder different levels of interaction. Occasionally, in shared areas, children would choose a table that no one else was using. When it was one table, both the children’s direct interactions (e.g., suggesting colour for the other child to use) and indirect interactions (e.g., copying the other child’s drawings) were positively influenced.

Despite the children’s needs for social interaction, the current services are not designed for the degree of social connectivity that they should facilitate; rather, the focus is based on the physical space and equipment available. A study was conducted with child-life specialists to identify elements contributing to optimal hospital playrooms (Weinberger et al. 2017). All the identified features were physical factors, with the natural element (e.g., window) and colour and décor (e.g., multi-colour walls) being reported as the most important. None of the identified factors related to children’s social play or their association with children’s interactions with others. This outcome was despite the fact that the survey used in the study included social interaction aspects. In addition to that the participants were asked open-ended questions to identify any other important features of a playroom.

Possible explanations for the particular ways in which services are organised (i.e. little consideration of social connectivity) can be related to the universities’ educational programmes in relation to the issue of children’s play. A study was conducted with students who were on child-related major programmes (where there was an emphasis on play in their curricula) about their intention to utilise play in their practices (Jung et al. 2017). The results showed that the stronger perception of play did not correlate with the participants’ intentions to use play. This finding suggests there is minimal emphasis on the value of play in these curricula. Nevertheless, many of the professionals within the healthcare services are known to deal with children’s play, including: play specialists, child-life specialists, play therapists and art therapists. However, their utilisation of play is limited to its use as a medium to serve a variety of benefits for the child for instance coping with their illnesses, expressing themselves, dealing with underlying psychosocial issues such as stress and anxiety, and for psychological interventions (Child Life Council 2011; Myrick and

Green 2012; Burns-Nader and Hernandez-Reif 2016; Kihara and Yamamoto 2018). Consequently, such focus of professions is expected to lead to less attention on the focus of play for the sake of play itself. Occupational therapists, on the other hand, uniquely viewed play as an end goal to achieve given that their intervention practice is based on supporting the individual's participation in their occupations (Parham 2008; American Occupational Therapy Association 2014). However, occupational therapists are very limited in the services they offered with this particular group of patients, patients with LTC/LLC. This limitation can be correlated with the very small number of occupational therapists working in palliative and end-of-life care (Haig and Summerfield-Mann 2016). No occupational therapists were observed while the researcher was collecting the data for this study; they were neither available during the observation sessions nor employed in that setting. Professionals who engaged in play during the collection of data for this study were play specialists and teachers. It is crucial to mention that developing a supportive play environment requires interdisciplinary team work to address the child as a whole. The unique occupational therapy focus on play as an occupation is to suggest that an optimal environment can be achieved by input from a range of different perspectives.

The different levels of social participation in play

The presence of family members was important to children's play, as demonstrated in the Q methodology; however, when children were accompanied by their family members, those people rarely joined the children in their playing. This situation suggests that the children appreciated their family members' presence in itself, even without the family members' engagement in play. The appreciation of their presence may also link to the children's sense of security, as emphasised in attachment theory, where the attachment system is increasingly activated during the period of illness (Tsilika et al. 2015). Accordingly, the children's needs for the social experience associated with play are not limited to the direct active play interaction.

Understanding the different levels of social participation in play can also be applicable for the children with complex needs. Being surrounded by others, even when they seemed to an observer not to be interacting, it could be construed as parallel play for these children. It is noteworthy to reinforce that a feature of play is *engagement*, which can be physical engagement, psychological engagement, or both; in a form which might be of low intensity and as simple as watching others playing (Lynch and Moore 2016). Additionally, as illustrated in pragmatism (in Chapter 1), there is no one model of play that can fit all children's play; their differences need to be respected. However, the play patterns of children with LTC/LLC are frequently evaluated by comparison to their age-matched normally developing children.

Professionals working with children with LTC/LLC respect those children’s different communication modes (Hewitt-Taylor 2008; Liben 2011). Recommendations have been developed in how to address the communication difficulties that these children might have (Brown 2007). Thus, this acknowledgement needs to be extended to also recognise their differences in play. Their cooperative play might be as simple as using their eye brow as a way of communicating with the group. Thus, understanding the different levels of occupational engagement is crucial for children with LTC/LLC. Nevertheless, these children’s participatory abilities can vary greatly, due to the unpredictable nature of their conditions. Some children will experience progressive deteriorations in their skills, while the condition may fluctuate with others (Hynson 2012). Therefore, more work is needed in identifying play modes, in particular for cognitively impaired children in order to support their play; an initiative which can include new ways of classifying their play. Furthermore, play is a subjective experience; when play is being studied as an occupation, that occupation is also subjective and therefore cannot be understood other than from the individuals’ perspectives, in order to understand the children’s level of social participation (Morris and Cox 2017).

Peers and other playmates need to notice that the children with complex needs require their interactions to be able to communicate and continue the play situations. Literature in relation to children with severe intellectual and multiple disabilities suggest emotional recognition as an indicator to understand the child (Bulgarelli and Caprino 2018; Hollingshead et al. 2018). Recognition cues include facial expressions, emotions in voice, certain vocalisation (e.g., grinding teeth) and body posture. However, such cues are easily misinterpreted and were not always obvious when data were collected for this study. Knowing the child and helping others learn how to communicate with the child is essential to support the child’s play (Barron et al. 2017).

Children’s choices of their playmate

Being with others was a play need; however, the choices of the playmate depended on two aspects: 1) children’s preferences and 2) people’s availability and willingness to share play. As highlighted earlier, the family were commonly prioritised and this was also documented previously (Wilson et al. 2010; Angstrom-Brannstrom et al. 2013; Nabors and Liddle 2017; Nabors et al. 2018; Adistie et al. 2019; Nabors et al. 2019; Witt et al. 2019). However, the children had different preferences in their perceptions of a playmate’s age, gender and playing with pets.

It had been mentioned in the findings chapter that two different perspectives for the children emerged from the Q methodology but these were similar in the two countries. One of the viewpoints placed low importance on a playmate’s age and gender, whereas the other group believed they were important. The same perspective applied to play with pets. This view is despite the generalisation in the literature which suggests the tendency in middle childhood is to have same age and gender playmates (Hughes 2010; Robnett and Susskind 2010) and which views pets as an important factor for all the children (Foster and Whitehead 2019; Nabors et al. 2019). Differences cannot be suggested as culturally-bonded or age-related, as found from the data in this study; rather, they can be seen to represent: a) personal preferences, b) already established relationships and c) the ways in which children were parented and nurtured (Robnett and Susskind 2010; Lam et al. 2014). However, the case from the caregivers' perspective was different, and will be discussed in 7.1.5: Culture-related aspects.

Despite the common phenomenon of the children's needs of being with others, some of the differences in their preferences are expressions of individual differences. At the same time, these extreme personal preferences (e.g. factor 1 having pets as most important and factor 2 having them as most unimportant – see 6.2 Findings of the Q methodology) are worth further investigation. Pets are being used in hospices and hospitals in the UK currently, but not in Kuwait. The importance of this pet initiative cannot be ignored given the established benefits and high prioritisation among one group. Some people viewed pets as sentient beings, as valuable as humans and as a family member (Walsh 2009; Burgman 2012). Additionally, pets tended to be non-conditional in giving their time to play compared to humans. Kaminski et al. (2002) reported that pets can provide unconditional companionship to patients. In the situation as reported in this research pets can fulfil the role of friend with unconditional acceptance of the child's condition. This benefit is critical for children with impairment who experience peer rejection (Burgman 2012).

Accessing peer interaction and making friendships are difficult for children with health problems. These difficulties can be also interpreted as a factor for the group which highlighted the playmate age and gender as less important (in factor 1; see 6.2 Findings of the Q methodology). Children with LTC/LLC, due to their health conditions, develop cautious lifestyles, and experience fear and anxiety that their symptoms might be triggered or elevated (Brook et al. 2012; Mufti et al. 2015). It has been reported that children's inability to participate in active games, consequent to their health status, led to their feeling less normal and viewing themselves as disabled (Gibson et al. 2010; Mufti et al. 2015; Witt et al. 2019). Additionally, impairments negatively impacted how others treated children differently, resulting in those recipients experiencing feelings of exclusion (Burgman 2012; Mufti et al. 2015). The case is more complicated when the children's problems are not limited to physical disabilities, but also consist of cognitive difficulties and the challenges of facing death and dying. Peer rejection in such situations restricts the children's opportunities for expressing identities, enhancing belonging and being 'children', which in turn can limit the educational development of the children's inner well-being (Mandich and Rodger 2006; Burgman

2012). Increasing socialisation and communication with other children experiencing similar situations can positively enhance these children's self-esteem and self-image (Orloff and Jones 2011). The implications of this study (see 7.2 Implications of the study) drawn from its findings suggest several ways of enhancing the play interaction between the children within the hospital/hospice setting. Nevertheless, encouragement and motivation are two of the children's psychological needs for them to continue playing.

The caregivers in this study linked the healthcare professionals' play with the children primarily for providing the children with encouragement and support. This aspect was illustrated by Adistie et al. (2019) who found that one of the psychological needs of children with terminal illnesses was motivation which can result from engagement in entertainment activities and jokes. Professionals need to spend time talking to the children about their play as an issue that is important to those young patients. Furthermore, parents' and children's awareness is necessary in regard to what and how children can join play. The awareness should include utilising tips and techniques which could help in maintaining the children's play levels such as breathing techniques and other coping and adaptation strategies. As a consequence, this understanding to children's play could also mitigate the development of secondary conditions and psychological harm that might otherwise occur because of the children's inability to participate with their peers. Therefore, respecting differences and helping the children to find their own ways of engagement are important issues to work on.

7.1.3 Accommodation for children's limitations in play

<u>Children's frequent playmates</u>

Despite the differences in the children's preferences of playmates, it was observed that their choices of a playmate were mainly informed by others' availability and the 'chosen' individual's willingness to play. The children in this study seem to appreciate anyone who is willing to share play, i.e. a play specialist, clown, volunteer, musician or a member of the healthcare staff. The children's most frequent playmates were adults. This is in accordance with researchers who studied children with multiple and severe disabilities that focused on the children's needs for adults as play partners (Brodin 1999; Besio 2004; Hamm 2006; Caprino and Stucci 2017; Graham et al. 2018). Consistently, in their findings, Witt et al. (2019) demonstrated that most of children's play, during hospitalisation, is with adults. Possible explanations for the reasons for this trend are offered in the following section.

The point to make here is that having an adult as a frequent playmate is very different to having other children to play with. Middle childhood is an age that is characterised by developing friendships where a crucial portion of children's time is taken up with peer groups (Parham 2008). Furthermore, Maunder and Monks (2018) reported that peer relationships are essential meet the children's needs of belonging and developing inner well-being (Holder and Coleman 2015). However, what does play that is not with peers mean for the children? We cannot be sure whether such play with an adult meets the definition of play which the child holds, or whether it contributes to living a childhood. Playing with adults only might be a reason for children with serious illnesses to experience occupational alienation, where the children are disconnected and isolated from their childhood. This form of occupational injustice is in addition to their experience of the possibility of dying that adds to restricting their options of being with others. The experience of alienation can happen regardless of whether adults think it is enriching to play with the child; the significance of alienation can only be measured by its meaning to the affected children themselves (Townsend and Wilcock 2004).

The very little known about the children's experience of 'play occupation injustice' (i.e. whether play is occupational alienation, deprivation or imbalance) can be interpreted as a result of the poor focus on 'play as a child's occupation'. Despite the fact that the proposed occupational therapy relevant to the child patients focused on play as a childhood occupation, and as an outcome goal to achieve, literature highlighted a mismatch between the value occupational therapists placed upon 'play as occupation' and its restricted use as a medium for therapy intervention. This mismatch was noted within a variety of developed countries within Europe and North America (Miller Kuhaneck et al. 2013; Bambrick 2015; Lynch et al. 2018). Occupational therapy researchers highlighted that there is still a lack of interest in play within research, theories and interventions used (Lynch et al. 2018; MItchell et al. 2018). Furthermore, within the Middle Eastern countries, including Kuwait, there is a lack of research evidence regarding occupation generally, and very limited opportunities for postgraduate education that also promotes an understanding of play as an occupation.

For the children in this study, the doctor/nurse role was not one that involved play. The healthcare professionals were usually referred to, by the children, as always 'being busy' (which could well be true) and were perceived in their professional roles as healers, as the children reported during their Q sorting. This perception seems to be due to the universal norms and current practice where the healthcare professionals place less priority on children's play and more on their traditional medically related roles and duties. The healthcare staff interrupted the children's play frequently and their interaction with the children was limited to their medical care as highlighted in the previous chapter. Some of the children initially avoided the researcher in this study, and later on explained their avoidance was because of a fear of injection. The children were not expecting an adult at the hospital to play with them or to have any interest in their play.

Basically, the children associated non-family adults' presence with medical procedures. This connection is likely to be associated with their lack of experience of a non-judgemental adult who is engaging with them in play. This point was illustrated by Mandell (1991) who addressed the issue of 'the least-adult role', which is further emphasised in the following Chapter 8, section 8.1: Dimensions of addressed reflexivity.

The level of the staff interaction with the children in this study differentiates the nature of service provided by the children's hospice and hospital. The caregivers in this study, from both Kuwait and the UK, had contrasting views when they compared their experiences at the hospital and hospice. They primarily acknowledged the staff interaction with the children at the hospice as well as the different organised group activities. Such differences were expected due to the nature of the supportive service offered by the hospices and their aim to improve children's QoL by addressing their physical, emotional, social and spiritual needs (International Children's Palliative Care Network 2015). Given the suggested move towards the adoption of the biopsychosocial model in hospitals, in order to replace or supersede the traditional medical model (Lehman et al. 2017), the healthcare team style of interaction is expected to pay more attention to different aspects of the children's lives; all of which contributes to enhancing the children's well-being.

The right play challenge

All of the children required some degree of assistance from an adult to play (i.e. when it was play with non- electronic devices) and it was observed there were some adults playing for the children. This scenario of adults present in play was due to the children's capabilities being negatively affected by their physical and cognitive impairments. Skar (2002), who interviewed children with disabilities, found that adults' presence is essential for providing play opportunities. Hence, this requirement is related to the fact that the children, unfortunately, were not having play opportunities that matched their abilities to manage their play.

The lack of the right play challenge, because of the mismatch between the children's capabilities and the environmental demands, is negatively affecting the children's occupational (play) participation. This link is drawn from the flow theory by Csikszentmihalyi (1988), as highlighted in Chapter 2. The PEO model, a theoretical foundation of this study that was based on the flow theory, clearly illustrates this relationship. The individual will have a greater experience of participation when the challenges and context of an occupation are in harmony with their skills. When there is a poor fit (see the PEO model, Figure 2-3) between the individual's abilities and the environmental demands, such a dissonance can result in poor levels occupational performance (Csikszentmihalyi 1988; Strong et al. 1999). This outcome could be seen as occupational deprivation in this study, where children were precluded from using some of the play equipment.

Furthermore, the mismatch causes occupational imbalance where excessive time was spent on one play type; such as with electronic devices or only with adults.

Some of the caregivers in this study were aware of the need for types of play that matched their children's abilities; particularly the caregivers who loaded significantly on factor 2 in the Q methodology (e.g., importance given to toys with sounds and music for children with complex needs). Healey and Mendelsohn (2019) illustrated that play which matches the children's abilities is the best 'toy' or model. Additionally, in their review of the play of children with disabilities Graham et al. (2018) found that children felt there was lack of suitable equipment to facilitate playing; a conclusion in line with the studies reviewed in Chapter 3. The children in these studies complained about the limited availability of toys and the need for more appropriate play (Aldiss et al. 2009; Gibson et al. 2010; Kirk and Pritchard 2012; Lambert et al. 2014b, a; Lima and Santos 2015). The play tools might be available, as found in this research; however, the children's complains could be the lack of resources which match the children's abilities or the restricted accessibility to these resources (see 7.1.4: Accessibility to play resources).

Therefore, the lack of resources that match the children's abilities, as observed and noted in this study, emphasises the importance of considering environmental intervention with a view to decrease the challenges to enhance the children's performance. It is noteworthy that the proposed environment, which can support the children's play needs, should be adaptive and responsive to the changes in the children's abilities. This stipulation is because of what has been highlighted earlier about the nature of LTC/LLC; children can undergo progressive changes in their conditions, which sometimes are unpredictable (Hynson 2012). The changes in the children's conditions are expected to be accompanied by changes in their abilities to participate in play; the more severe the condition the less likely it is that they will be able to participate. Thus, the patterns of a child's play are never consistent; the same child's play can vary hugely in terms of their level or mode of participation. This factor complements the emphasised idea of pragmatism, in which there is no one truth. These changes in the children, as a consequence, demonstrates the requirement for a responsive environment with flexibility in resources for adaptation.

The stimulation of children's play

The disparity between the children's abilities and the environmental challenges they were facing (e.g., inappropriate play equipment or space to use) was overcome by the presence of the grown-ups in this research. This situation was also the case in the literature; researchers reflected on the important role of parents' presence during children's play; a presence able to overcome or compensate for their children's limited abilities (Brodin 1999; Caprino and Stucci 2017). One of the observed consequences of the mismatch between the children's abilities and the play resources was that the high levels of assistance received led to the grown-ups taking control over the children’s play. A clear example of this bias involved children with complex needs, where the adults were playing for them. Children were not able to have control over their play, in spite of the fact that the player’s control is one of the features that is used to define ‘play’ (see Chapter 1 – 1.2.1 Play). Play is also a method for the children to exercise a limited degree of control over their lives when they lose most of that control due to the nature of their condition. Play occupation can positively contribute to the children’s well-being, as well as to their occupational development when they engage in occupations in their own ways (Wiseman et al. 2005; Hammell 2008). The absence of the occupational right to exert autonomy in choosing what, where and how to participate in an occupation, such as playing, results in occupational marginalisation (Townsend and Wilcock 2004). Thus, children need to exercise their right to have choices as well as experiencing degrees of control over what they are doing (Hammell 2017b).

It is worth mentioning that this discussion is not intended to degrade the adults’ role in children’s play. It has been reported that adults playing for children who have disabilities can help those affected children to feel included when there is no-one else willing to play with them (Gibson et al. 2010; Mufti et al. 2015; Graham et al. 2018). However, balancing the level of assistance provided to children, in order to prevent interfering with the children’s autonomous play, is crucial. This goal could be achieved by understanding how to help children to play, while preserving the features of their play being self-controlled.

Hence, adults’ presence cannot be considered as the optimal solution to the issue of the lack of the most appropriate play; the lack of the right play challenge. Besides its negative influence on children’s autonomous play, as mentioned above, parents or other adult playmates were not always available for the child to play with. Moreover, as observed, adults did not seem to have the skills of adapting the play to the child’s level. Children frequently received maximum level of assistance when only minimal help was required to enable their successful participation in the play activity. This is in addition to the findings reported by Brodin (1999), who illustrated that some parents expressed their inability to play with their children if those children had severe or profound multiple disabilities. Graham et al. (2015) explained this adult/child problem by demonstrating the burden on caregivers to facilitate the play. The adults’ burden stemming from their children’s very challenging play skills and needs can be linked to parenting style. For example, Morozini (2015) emphasised the parents’ role in stimulating play and providing a stimulating environment. This concept seems to be related to good parenting; ability to supervise the children’s play was seen as important by the caregivers in this study. Accordingly, such play interaction and perceived responsibilities are placing the child’s play burden onto their caregivers.

However, play opportunities for children do not necessarily require stimulation, organised play or adults to join in that playing. This perspective was partly explained earlier when family members' presence was highlighted as important in itself, even without their engagement in playing with their children. There is a need to raise awareness and knowledge of the play requirements of children with LTC/LLC and how to support these needs to enable the children to play satisfactorily. This awareness could be also related to the need for education provided to children and their families on what and how children's play can be encouraged. Play that can fulfil its benefits needs to preserve its nature of being fun, as well as being directed and controlled by the players themselves. Play does not need to have a purpose, educational value or skills to improve. Playing is simply what the children viewed as enjoyable, regardless of their future which, for some, may be very limited. This enjoyment and subjective factor is particularly important for children living with the possibility of an imminent death, so they can fill their final days with meaningful experiences for themselves and for other people caring for those children. Ito et al. (2015), who investigated the factors leading to a 'good death' for children with cancer, found that both play and the opportunities to play freely were essential elements.

Children's playfulness

One of the negative consequences of having an adult as the children's playmate was the difficulties in measuring the children's experience of playfulness by observation; in particular for those with complex needs. The children were taking part in play behaviour but their subjective experience – their passion and meaning associated with that playing – was not guaranteed. This confusion is despite the fact that the meaning of play is a necessary element that differentiates play from non-play (Bundy 2011). The children's facial expressions for example, during the observation, did not indicate any of their body language. It can be argued that those who were playing for the children knew them very well and were attuned to their child's subtle behaviour changes. However, it was not always the case to be able to take and trust the caregivers' subjective viewpoint (i.e. when not only the parents are taking care of the child, but they are also sharing the responsibility with grandparents, or other guardians).

The difficulties in making judgements to evaluate the playfulness of children with complex needs are due, in particular, to the lack of guidance on how to understand the life-world of these children. There is some available guidance on how to assess these children's negative experiences such as pain, as shown through combative behaviour and biological plausibility (Liben 2011; Bausewein et al. 2016; Harrop et al. 2017); however, there is no evident guidance on how to assess their enjoyment levels. Most of the available outcome measures developed for this population, which targeted the QoL of children receiving palliative care, focused primarily on pain and other symptom management. These measures mainly drew account from the carers' views as the Palliative Care Outcome Scale (Hearn and Higginson 1999) and Paediatric Pain Profile (Institute of Child Health/University College London/Royal College of Nursing Institute 2003). These two instruments do not account for children's enjoyment levels although that issue is one of the most important aspects informing the child's QoL.

The lack of ways to measure children's playfulness also exists in professions concerned with children's play, as in occupational therapy. Bundy (2011), who is a pioneer in this field and constructed a playfulness approach and several play assessments (Skard and Bundy 2008), highlighted the difficulties in assessing play (e.g. how to recognise a child's intrinsic motivation) and the lack of a generally accepted gold standard to do so. Despite this problem, she suggested specific behaviours to look for; it can be argued that the more these behaviours are present the more playfulness and pleasure a child is experiencing. Bundy (2011) highlighted the following issues: 1) *intrinsic motivation*: the child enjoys themself, persists and does activities for process rather than product; 2) *internal control*: child decides, uses play objects well and feels safe; 3) *freedom*: uses things creatively; and 4) *framing*: gives and reads cues. However, in this current study some of these behaviours were difficult to observe for the play of children with palliative care, in particular from those children with complex needs. Behaviours like internal control and freedom might be different for children with palliative or end of life when their physical bodies are not performing as they used to, when they may not feel safe because of what is happening to their bodies. This suggests more work is needed in this field of understanding play. Focus should be upon gaining an understanding of play from the players themselves, as well as developing ways to investigate and understand the perspectives of children with cognitive impairments. In addition to the need to respect and acknowledge the differences in children with LTC/LLC in their communicating abilities, it is also important to include knowledge of the ways they express their intrinsic motivation and their levels of internal control to be able to judge the components of their play behaviour.

7.1.4 Accessibility to play resources

Importance of the accessibility factor

Although the importance of the accessibility factor in relation to the children's play between the UK and Kuwait was different (as mentioned in Chapter 6), the issue of access to play opportunities for children with LTC/LLC was not a highly important matter in either country. This finding is in accordance with the lack of studies investigating such children's access to play options (Gibson et al. 2010; Kirk and Pritchard 2012). Though, the lower importance to the accessibility concept is contradictory to the observations where the accessibility was a major barrier to play. The importance of age-appropriate and gender-appropriate play tools was highlighted by some of the participants in the Q methodology component of this study. However, the observational data showed that these specifications were unnecessary when compared to need for easy access to the play equipment.

The relatively small importance of the play option accessibility factor reported by the participants could be due to several reasons including: a) the considerable percentage of children's time which was taken up by playing with electronic devices (i.e. which are easy to control and use independently) and b) the high level of assistance children were already getting (i.e. when play did not involve electronic devices, the children had an adult playmate offering assistance). This latter situation was because of the children's inability to participate in play themselves; for example, it was difficult or impossible for the children in this study to handle the size of the Lego bricks or remove the lid of a colour pen.

It is acknowledged that there is no one universal environment that can accommodate all the children with LTC/LLC, or others with similarly demanding conditions, otherwise it might be too challenging for some and very easy for others (Lynch 2018); resulting in losing the playfulness experience for some children. Accordingly, a responsive environment to adaptation is a necessary requirement that utilises the universal designs, so allowing easy access to different play types for the different abilities of the children.

Accessibility to the use of electronic devices

Play with electronic devices was the most frequent play that children engaged in. It is notable that the increase in its use is not restricted to children with LTC/LLC in this study or children with disabilities, but also with normally developing children. The use of these devices has become a worldwide issue irrespective of ethnicity or economic status (Besio 2004; Holloway et al. 2013; Kabali et al. 2015; Dashti and Yateem 2018). This increase in their use could be a consequence of their accessibility and convenience; they can be played (with) everywhere and anywhere and do not necessarily need a playmate. This opinion is in line with Lima and Santos (2015), who illustrated that children at the hospital mostly used electronic devices as they can be easily manipulated/used in their own beds. Much evidence has demonstrated that this increase in the use of electronic devices as 'toys' is due to their portability, handheld small size and ease of use (i.e. such devices can be used independently by children as young as two years of age) (Michael Cohen Group 2011; Kabali et al. 2015; Paudel et al. 2017; Dashti and Yateem 2018). Such benefits could also illustrate why the children with very complex needs in this study were also able to use an electronic device over extended periods of time.

Regardless of the general negative consequences documented about the use of electronic devices (Suchert et al. 2015; Carson et al. 2016; Sisson et al. 2016) or their usefulness (Reid Chassiakos et al. 2016; Jurdi et al. 2018), what is crucial to consider here is the occupational imbalance created by users spending too much time on one specific activity. Such a focus is 'unhealthy' and might limit a child's optimal development when compared to the experiences children can have by engaging in a variety of play activities or occupations, rather than just one. This occupational imbalance not only negatively impacts a child's play; its influence could be extended to their other occupations. Auditing children's routines can be extremely significant when considering the occupations they value, as compared to the opportunities they have to participate in them.

However, despite the concerns society might have about screen time, recognising the evolution in technology and its use can indicate a likelihood that the established occupational balance is shifting and our view needs to evolve with it. Occupations, as mentioned previously, are very subjective; this controversial electronic device issue can shed light onto the current debate regarding the 'dark side' of an occupation; particularly with reference to play and playing. The 'dark side' of occupation is not to suggest bad or good occupations as Twinley (2017) pointed out; it does however refer to aspects of the topic of occupations that are not well explored, and which may not promote good health or well-being (Twinley 2012). The points to consider might be: a) anti-social, b) unproductive, c) harmful or d) addictive aspects of an occupation; a perspective which is in contrast to the traditional view of our understanding to what occupation is (Twinley 2012; 2017). Therefore, it is crucial to broaden our understanding of the unexplored aspects of an occupation, where the 'dark side' of it might bring the balance to individual's life (Twinley 2012) through appreciating people's subjective experience of an occupation. Not seeing the value or meaning of an occupation does not suggest ignoring it, or what such activities can bring to the children because occupations are both complex and multi-dimensional (Twinley 2017). Thus, this debate is not to suggest supporting occupations that are judged to be unhealthy; but to gain an understanding of the contributions these occupations can make, as well as finding possibilities to enhance each individual's well-being.

Value of the electronic devices

One of the unanticipated findings in this study was that despite the long hours observed of children using the electronic devices, neither the children nor the caregivers placed great importance on such play; with the exception of one device (i.e. personal tablets) in one group. This exception represents the caregivers in the UK in factor 2, whose children have complex needs and who demonstrated the use of personal tablets for generating auditory sounds.

It might be expected that caregivers place little importance on their children playing with electronic devices; however, it was surprising that none of the children's extracted factors in either country (Kuwait or UK) revealed this issue to be an important item for their play. This contradiction between the participants' viewpoints highlighting the low importance given to play with electronic devices and the long hours observed, can be explained by the prioritisation of the social play experience. An example of this point was when the researcher suggested alternative play for children who were engaged with electronic devices; all of them agreed. Additionally, the times the children were not playing with electronic devices was non-solitary play; they had someone to play with, so valuing the significance of rich social play. Thus, the data from this study suggests that the lack of having someone who was willing to play was responsible for the children spending much of their time on a specific type of play: an electronic device. Arcury et al. (2017) found a decrease in children's media use time in relation to the increase of number of people sharing the room. This disparity between the importance of an electronic device, and its use, again draws attention to the issue of occupational imbalance. Children were spending long hours on what they perceived is not very important when compared to other play, hence restricting the positive influence that preferred play can have on their QoL (Hammell 2017b).

It can also be suggested that the lower prioritisation of play with electronic devices can be due to the fact that the children were not using these devices as a form to play; instead, it was an available and accessible device to overcome their boredom as a medium to pass the time. This possibility was also evident from the participants' comments presented in Chapter 6. Another example was when children were eating while watching YouTube. These behaviours have been reported by some researchers as inappropriate media use that results in increased screen time (Conlon et al. 2015; Thompson and Tschann 2016).

When the children in this study were required to prioritise aspects related to their play, their selections were based on their perceptions of the meaning of play; with 'optimal' play being the highest ranked. Accordingly, it is important to understand children's reasons for playing and the meaning they carry for what play is before reaching a conclusion in regard to their play and their preferred types.

Opportunities for constructive play

Constructive play was the second most common type of play observed: primarily 'arts and crafts' play. This type of play was also prioritised as the highest by the participants in the Q methodology among the different groups, when compared to the other play types. The only group who provided a lower ranking was the caregivers of children with complex needs (in factor 2, see

Caregivers' group section in Chapter 6); however, they reported their children's use of constructive play in an adaptive way, as demonstrated in the findings.

While the children were choosing constructive play, the activities which were prepared by the adults were most frequently arts and crafts activities. This outcome could be because the play specialists, who facilitated most of the children's play, usually used arts and crafts activities; an orientation demonstrated by the participants in the study by Nabors and Liddle (2017). This preference could be because of their belief in the usefulness of arts and crafts to provide distraction and to allow the children to express their feelings (Nabors and Liddle 2017; Nabors et al. 2018; Adistie et al. 2019; Foster and Whitehead 2019). Another possible explanation for the use of arts and crafts suggested by Moore and Lynch (2015) is that the arrangement of play spaces within the hospitals encourages such types of play because of the restricted indoor space, hard floors, and the presence of tables and chairs. Furthermore, in the four settings included in this research, each of the four had a specified room or a corner for arts and crafts. For example, in Kuwait's hospice there was a 'messy room' for arts and crafts which was within a bigger play area. Hence, the adults' perceptions/values placed on arts and crafts play, together with the design of hospital/hospice settings that support such a play activity, could be the reason for restricting other forms of play. As a consequence, the children were rarely engaged in gross motor play. This arrangement within the settings can demonstrate the need to optimise the play environment to facilitate children's play; play that provides meaning and pleasure to themselves as participating children.

James et al. (1998) reported that the meaning of play for the children is different from adults' definitions of play. When adults talk about the benefits of play, it is likely to be linked to its educational benefits to the children because of the shift in the communities towards a more academically oriented approach, with increased time and weight given to schooling and education (Gray 2011; Milteer et al. 2012; Jasem and Delport 2019). This focus could be interpreted as a result of the future-oriented perspectives of adults for the children, as well as a lack of awareness of the significant role of play in both *being* and *becoming*. Thus, values given to the individuals' play in particular, and their other occupations, should be evaluated from the perspectives of the individuals themselves. When this evaluation does not happen, conflicts can occur; for instance, in relation to decision-making regarding therapy goals. For occupational therapists, the implementation of a client-centred, occupation-focused intervention is sometimes not possible, even though they are the core philosophical concepts of the profession. In their review Bushby et al. (2015) reported that occupational therapists experience conflict in upholding occupation-based practice, because of the tension with family members' goals or the caring organisation's rules. This conflict could be interpreted as a result of the lack of awareness of how the client-centred occupation-based practice can influence the individual's health and well-being. This issue is likely to be associated with the less obvious benefit outcomes of play to be measured when compared to the self-care or handwriting goals for instance, where it is easier to notice any improvements. Thus, the relationship between play and children's health and well-being needs to be made more obvious for the patients themselves, their caregivers, and the institutional systems.

Play space

It has been highlighted that the children in this study appeared less concerned with the specific play equipment in addition to play space than with social experience of the play. This discovery is despite what has been reported in the literature of the need for different play spaces for children with LTC/LLC (Aldiss et al. 2009; Coyne and Kirwan 2012; Lambert et al. 2014b; Verschoren et al. 2015). In addition, other studies which targeted hospitals' designs generally stressed the need for more play areas for their younger patients (Boztepe et al. 2017; Cartland et al. 2018). However, this discrepancy with the findings that emerged in this research is to be expected due to the prioritisation resulting from the Q methodology. Giving the different play spaces less importance means they are less important only when compared to other items providing richer social experiences. This prioritisation could be interpreted and understood from the link the participants made when they sorted the Q items. It could also be clarified by previous evidence where children highlighted corridors and waiting areas as important spaces since they often get pleasant social interaction with others in those locations (Verschoren et al. 2015).

The current study expanded the emphasis on play spaces and included focus on natural outdoor areas, including green and blue spaces. The data showed that the participants were not really concerned about having such areas; a finding which differs from previous evidence (Skar 2002; Reeve et al. 2017). However, some researchers found such outdoor areas were not efficiently used by the patients; an outcome which is similar to the participants' explanations in this study in terms of the reasons why outdoors is not important to them. The explanations included: a) the weather, b) children's limitations and c) inaccessibility to these spaces (Skar 2002; Sherman et al. 2005; Riet et al. 2014; Weerasuriya et al. 2018; Leite et al. 2019). Although the time of the year can create various assumptions about children's play, data were collected during good weather seasons. In Kuwait that season is between February and May (i.e. were the lowest temperature is around 15°C and the highest is 37°C) (Kuwait Government Online 2018) and in the UK between August and November. Furthermore, the participants in this study were asked about periods of good weather or if the areas were accessible with all the medical equipment the children were using, and they did not change their responses.

The low level of importance given to the topic of outdoor areas by the participants in this study is not to suggest the insignificance of such areas; rather, the availability of green and blue spaces was perceived as an unimportant factor to enhance children's participation in play from the participants' perspectives. 'Outdoors' might become a significant factor when children find their other needs (e.g., social play) are able to be met in such areas. However, this issue requires further investigation (see later in this chapter 7.4 Recommendations for future research) given that a positive relationship was established in previous studies between the nature of healthcare settings and patients' health, for children as well as for adults (Whitehouse et al. 2001; Sherman et al. 2005; Shepley and Song 2014; Blaschke et al. 2018; Marcus 2018). In addition, it is worth noting that it is difficult to provide some play opportunities unless it is the natural environment (Wiseman et al. 2005).

The reason the study's participants were not bothered about having access to outdoor areas could also be because of the norms and expectations associated with being hospitalised. Consequently, play for the sake of play is not particularly important to them when/if it is not linked to a positive impact on their health during the course of illness, or when it might negatively affect their health. This conclusion corroborates results detailed in the findings chapter regarding the participants' responses to these blue/green areas issues. These findings are also likely to be related to the patients' lack of views of the outdoor areas from inside the healthcare facility; a potential barrier to the use of these spaces, as suggested by Weerasuriya et al. (2018). Nevertheless, play activities that usually take place in outdoor settings (e.g., active play and ball games) were at similar ranks to these settings as found from the Q methodology data; accordingly, linking the spaces to the common features of children's play.

7.1.5 Culture-related aspects

Similarities across the cultures

It has been acknowledged in Chapter 2 (in section 2.4.2 Play in different cultures) that play varies across communities; a variation despite the fact that play is one of the most common elements of childhood across cultures (Rubin et al. 1983; Haight et al. 1999; Hughes 2010; Smith 2010; Roopnarine 2011). The findings of this study showed evident commonalities in regard to most of the children's play needs. These similarities can be suggested because children are first and foremost children who need to play. The commonality in the findings was in regard to the children's general play needs; the few points that emerged as culture-specific were more related to specific play types and playmates (elaborated in the next section). Moreover, countries nowadays are becoming more culturally diverse than at any time before; people young and old are both influencing and being influenced by their surroundings. In addition, the advancement in technology is another factor reshaping the world by building more connections and facilitating faster communications. An example of this development is that children were playing some ‘app’ games (e.g. subway surf) in both Kuwait and the UK when observed. The ‘global’ context of such playing can open a discussion designed to understand special features within a game that makes it popular across communities and cultures. Given the commonality in play needs, it is worth investigating play specifications that meet the children’s needs across cultures. This investigation would be for the purpose of finding possibilities of supporting the children’s participation in play and limiting any negative consequences that might result from occupational deprivation.

Differences in children’s play across the two cultures

The differences in the play environment were found to be secondary to the children’s primary play needs. The differences were neither essential play needs nor ranked as highly important /unimportant across the groups. In regard to the social environment, it was about the playmate. In Kuwait, most participants mentioned their relatives and cousins in their play talks; however, in the UK the children frequently mentioned their friends. Evidence supporting this preference in the UK was strengthened by the cards they were receiving from school friends since being hospitalised. These preferences can be seen as an influence of the culture of the community they were living in, particularly relating to peer familiarity (Rubin et al. 1983; Hughes 2010). Preferences in Kuwait might also result from the small size of the country (when compared to the UK), where families live closer together given that they usually live near to where they grew up; hence, making it easier to keep these connections. The culture of the communities also shaped a further few points. In Kuwait, the adults, including the parents and play specialists, rarely played with children compared to the situation in the UK. The Kuwait adults were more focused on preparing or suggesting play, rather than actual playing with the children. It is important to understand these aspects as they could have an impact on other issues related to the children’s play; for example accessibility to play resources and the people they share play with. This suggestion is informed by the fact that accessibility to play resources was more important in the UK than in Kuwait among both groups of participants: the children and their caregivers.

Regarding a playmate’s age and gender, only Kuwait’s caregivers in factor 1 placed high importance on age and gender aspects regarding the playmate and the appropriateness of the play equipment. The similarity of the second extracted factor of Kuwait’s caregivers to the UK data, by ranking these items lower, can be explained by the children’s complex needs. As a consequence, caregivers did not focus much on such cultural aspects. In addition, half of the participants who loaded significantly high on this factor in Kuwait, factor 2, were not Arab;

compared to factor 1 participants, who were all Arab. Such a finding strongly suggests the influence of cultural norms (Hartup 1983). Moreover, the need for age-appropriate and gender-appropriate toys was generally higher in Kuwait than in the UK. This preference suggests that the cultural norms within Kuwait are highly valued by, and important to, the participants. Therefore, for cultural competence it is crucial to consider individuals' differences. Some of these factors, despite being non-modifiable items, are important to understand when creating opportunities that are intended to enhance children's participation in play.

Another noted difference between the two participant groups was with regards to their play activities. Playing with blocks/Lego, puzzles, imaginative and pretend play was more important in Kuwait, whereas reading and/or listening to stories had higher importance in the UK. This finding could result from the variation in children's play across cultures and also the product of school curricula reflecting the aspects given most attention (Rubin et al. 1983; Hughes 2010). It is essential to understand these differences in order to provide children with play opportunities that respect their priorities and preferences. These issues are also discussed in the following section, where possible implications of the study's findings are demonstrated.

7.2 Implications of the study

The adopted framework of 'pragmatism' advocates minimising the differences that divide us insignificantly, whilst acknowledging the multiple realities (Rorty 1982; Tashakkori and Teddlie 1998; Rorty 1999). Consequently, such focus is essential when taking the findings of this study further and considering inpatient healthcare settings that are used by a diversity of populations; notably in contemporary multicultural communities. The aforementioned discussion confirmed the children's similar play needs and priorities.

Analysing and discussing the collected data shed light on several factors associated with this study which are discussed next. The most important issues are: a) creating opportunities for social play and b) respecting the differences in the patterns of the children's play.

Creation of social play opportunities: The current study's findings indicate that for children to play, creating social opportunities for all is a requirement, while also respecting the players' differences. Play activities does not necessarily have to be in the form of structured or organised group play; it is only about facilitating being with others, to be in one place at one time. This requirement could be just an initial medium for the children to get on with others. It is not restricted to play time or playroom, but also to other times during the day so the children get to meet and interact with each other, thus developing play interaction. For instance, the lunch time can be considered a perfect time of the day for this 'getting to know you' activity. Literature on the concept of hospice highlighted dining area designs as communal eating spaces (Niedzielski et al. 2016; Waldrop and McGinley 2018). Hyde et al. (2011) demonstrated that eating together in a hospice was positively acknowledged by the patients as a way of gaining access to social experience. In addition to the lunch time, any activities during the afternoon can be beneficial. In Kuwait late afternoon film-watching in the big screen suit the routine of most of the families; this is an example to consider the culture in selecting the activity to facilitate. It is preferable for such an activity to be located within the ward that children are admitted to, rather than other areas of the healthcare setting. In such a familiar location children can be assigned to specific roles to run that activity to facilitate interaction such as showing people to their seats and serving drinks and snacks for the afternoon film.

Although the children seemed to prefer playing with peers, they also appreciate being with anyone who is willing to share playtime with them. Accordingly, the role of the adults, including the whole healthcare team, is to adopt ways of engaging in play not only for encouragement but also to help children form their identities. The children need to be reassured and it needs to be acknowledged that each individual is unique in their abilities; thus, being different in their play mode is part of their identity that is to be respected.

Utilising the physical factors in supporting social interaction: Chairs on the wards/corridors represent a simple and easy physical change which children can utilise, which will allow contact with other patients as well as healthcare professionals. This option is preferable to the children spending most of the time in their rooms. In addition to considering the area of the play (e.g., within the ward as in the cinema example) the layout of the furniture arrangement is important in how it facilitates children’s interactions. Nevertheless, it might be challenging but it is recommended to balance the privacy of the patients with social interaction experiences when considering developing optimal environments. As described previously, there are tendencies to gravitate towards individuals’ rooms rather than searching out shared areas; thus, it may instead be helpful to consider addressing the provision of visible and easy access to shared areas from individual patients’ rooms. These opportunities can be openings to direct and indirect interactions; having shared areas in the middle and surrounding rooms is one such example.

Matching the needs, preferences and abilities of the children: Playing with electronic devices can present the possibility of finding a common language that most of the children speak as a way of initiating interaction between them. In one of the settings, children were able to borrow an Xbox for their rooms. What a great chance it would be to have such play equipment in shared areas where children can share and engage in challenges utilising these technologies; thereby using the play resources, play spaces and equipment to support the children’s play needs.

For so many children the Lego bricks provide good challenges for their cognitive skills but not their physical abilities. Hence, it is vital to consider both the physical and cognitive abilities of the children when suggesting/ providing a play tool. This point should include play-matching the children's prioritisation and skills with optimal degrees of challenge. This organisational challenge is particularly significant regarding children with complex needs, for whom play was provided without taking into consideration their perspectives and values. Nevertheless, it is important for the children to experience the control over their play when it is led by others; they need to have the choice over what to take part in and when, regardless of the assistance they are receiving.

Incorporating or creating environments that account for variations in children's preferences and abilities is crucial while providing choices, such as age-appropriate and gender-appropriate toys and equipment of specific play types; for example involving board/card games or imaginative/pretend play. An appropriate qualifying observation is the fact that the above issues were a secondary factor when the children's play was assessed. Most importantly, these suggested options should provide easy access for the children. This access can be organised in a simple directed way so the child can easily get whatever is needed. Moreover, it would be beneficial to have play spaces, in particular the playroom, open for longer periods and at the weekends. A specific cupboard, for play tools which are not safe for children to obtain by themselves, can be locked after working hours. Accordingly, the children will have access to a safe and nearby area just to make a change from being in their bed. Nevertheless, portable soft floor pads can be available to borrow and use, particularly in patient's rooms as an option which can get them out of their beds.

Professional intervention: The experience of 'play injustice' is a serious area that requires professional intervention. This need results from the negative consequences of the disruption of play on children's well-being and QoL (Law 2002; Hocking 2009; Gerlach et al. 2014; Law and King 2014). Accordingly, there is a need for professional intervention evaluating children's abilities and constructing play plans that support ways in which children's engagement levels in play can be enhanced. Occupational therapists can significantly contribute to this area of concern, since enabling people's participation in meaningful and purposeful occupations is the primary aim of occupational therapy (World Federation of Occupational Therapists 2010). This goal can be achieved though setting individualised play plans for each child suggesting how they can participate in their preferred play and other valued occupations in their own way. Such a plan should also include conversation techniques to account for each child's condition and its required precautions. Caregivers in particular need to be educated on how to support children's play, by helping their children to experience autonomy at the same time. This outcome depends, to a great extent, on the child's abilities; although this esoteric population is very different in their needs and capabilities from the needs that exist in the general population in either country. The professional play plan can guide the caregivers towards the most suitable possible ways that take into account any physical, intellectual, visual or hearing impairment of the patients they are caring for or dealing with. Suggestions touched on might include: a) invitation to play, b) physical guidance, c) maintaining their attention, d) simplifying play situations, e) encouraging, and f) also not interrupting the play on some occasions.

Optimise the environment that supports children's occupations: Play occupation needs to be considered as an outcome goal and not only as a medium. The children's daily routine is one of the areas that needs more focus within the healthcare settings. Despite all the resources, people, spaces and equipment being available, the observational findings suggested that children were deprived from fully living their lives. Effective proactive modifications in children's routines are important to consider the different types of play; in particular the active play since it was the play model which children engaged in the least. Thus, it is crucial to encourage a variety of play types rather than merely arts and crafts. This initiative is suggested in order to ensure optimal development in order to improve each child's health and well-being.

Creative ideas for enabling enjoyable occupational participation could be considered, whilst also taking into considerations the precautions and consequences of the children's health conditions. Hammell (2017a) illustrated the crucial aspect of striving for equity rather than focusing on equality in the resources, which is also a focus that pragmatists advocate (Rorty 1999). This goal is particularly appropriate for this current study, given that the healthcare settings are used by very different populations and the children with LTC/LLC vary in their abilities.

Taking the findings further: It is worth mentioning that the presented findings with their clear description of the contexts and participants, in addition to the process of data collection and analysis, can facilitate translating these findings to other cultures and settings (Graneheim and Lundman 2004); particularly as most of what was found was applicable in both the Kuwait and UK cultures. However, this might necessitate further investigation.

7.3 Strengths and limitations of the study

7.3.1 Strengths of the study

The discovery in this research contributed to the literature on children's play in hospital/hospice contexts generally, and more specifically for children living with LTC/LLC. The research methods employed in this study allowed the children's voices to be heard, and the finding strongly suggest that these children were able to express what is important to them. Additionally, the investigation into the caregivers' perspectives greatly enhanced understanding of the studied phenomenon.

The collected data has been provided by participants from two different cultures, Kuwait and the UK. The number of the participants in both countries and settings was similar, suggesting an equal balance in the findings from both countries. Although the children's ages were taken into consideration during the analysis, the findings did not indicate any strong link that could be related to age as a factor.

The method of participation used in this study (i.e. both the Q methodology and observation) also suggested a possible nature of research that can limit or add only a minimal burden onto the participants' routines and which can facilitate a high response rate. Most of the participants who were approached, both children and caregivers, agreed to participate as they mentioned that they have nothing to do and so responding could, if nothing else, be a relief to their boredom. Nevertheless, the way the Q methodology looks, like a fun game-like instrument, made a positive impression on the gatekeepers for gaining ethical approval to carry out the research; a positive perception which was also noted by the participants

The extracted factors from the Q sortings explained more than 35% of the study variance (see Appendix O) which can guarantee a solid outcome for a Q methodology study (Watts and Stenner 2012). In addition, the observation was triangulated with the mixed-methods data identified in the Q methodology findings, suggesting potential explanations for the novel findings relating to the play needs of this particular population. The observation can be considered comprehensive because it covered children with different abilities and health conditions who were observed carrying out different activities in a variety of different areas with different people.

The Q methodology, besides its usefulness in accessing data to meet the study's aim, also enabled the participants to understand and express their emotions during their responses to the Q set; quite an eye opener for some of the participants. An example of this 'unexpected' dimension was a child who reported before she started that: '*all of them (the Q items) will be unimportant.'* Interestingly, this child considered only four cards out of 27 as '*unimportant*' when she initially classified the Q items into the three groups; important, neutral and unimportant.

7.3.2 Limitations of the study

Although the sample in this study was recruited from two different cultures at two different healthcare settings, there were unequal sizes of the samples from the hospitals and hospices, so restricting comparison between these two healthcare settings (i.e. less participants were recruited from the hospice). Furthermore, the data being skewed towards patients with palliative care needs, rather than end-of-life needs, tended to reduce the sample; a circumstance representing a further limitation of this study. According their conditions' severity, none of the children was within the red category and few were classified in the amber group. Another issue within the sample is regarding the less homogeneity of the participants in terms of their chronological age and cognitive abilities. Despite these differences were helpful in finding shared viewpoints, it might worth performing subgroup analyses on those with limited cognitive abilities versus those who did not have these disabilities.

A main limitation of this study is the under-representation of the play needs and the prioritisation of children with complex needs which could be compensated for by incorporating those children's perspectives in the Q methodology. Despite their caregivers providing rich information, their voices also need to be considered. Additionally, for these children it was also not easy to decide whether some of the observed behaviours were actual play or were not play, so making very difficult to understand any influences coming from the associated environmental factors.

The researcher also acknowledged that for the observational data, her presence affected the collected data, despite the marginal role she was adopting. This influence can be noted especially with the adults present who were encouraging their children to engage with different toys or those caring for children with complex needs. It seems that the researcher's presence made them keep the children busy by playing both with and for them.

Not only were the participants themselves influenced by the researcher's presence, but the different research phases are also expected to have been influenced by the researcher. This expectation is informed by the researcher's central role in the construction of the knowledge, which is the nature of most qualitative studies, given that the researcher was the research instrument used to collect the data (Robson 2002; Lichtman 2014). In spite of the fact that this research was a mixed-methods study, heavy emphasis was placed on the qualitative aspect. It is therefore possible that the study's findings could be influenced by a researcher with a particular background, training and working experience, alongside the more general cultural and societal factors. All of these factors are likely to impact the researcher's perspective in the analysis. However, this situation can be regarded as both a strength and a limitation; an issue which is further discussed in the next chapter (Chapter 8).

With regards to limitations within the Q methodology, the children's voices were not incorporated in terms of selecting the Q items; those voices could have been included by using greater 'patient public involvement' strategies. However, the children did influence the development of the Q set to some extent through the piloting process (see 4.3.2 Piloting section) where few aspects were changes in accordance to the children's feedback. Another limitation within this method was related to two of the Q items representing two different things on one card. This was a trial to cover the concept broadly in the children's sample; a) electronic devices having videogames and tablets in the children's set (item #25) and b) another card which showed a clown and a musical man as people to entertain the child (item #4) (see Table 4-3). Some children had two different opinions about the two items on a card. However, to overcome this issue, the researcher tried to understand from the participant which item they were referring to, and why not the other. All these data were recorded in their discussion by the use of the audio-recorder and were considered in the analysis. There were also a few cards that did not add much to the findings; particularly cards relating to the weather, cooking/baking and time for free play, which the researcher in hindsight would not have included.

Another issue within the Q methodology was with the ranking scale of the Q matrix. Some of the participants used around two-thirds of the columns for the important cards. For further explanations, the participants believed that some of the cards which were under the neutral columns were important as, for example, '-1' and sometimes '-2' columns. Accordingly, some of the participants' *important* rankings were analysed as *neutral*. The same issue occurred with the unimportant items, in particular the Q sorts which represented caregivers of children with very complicated needs, by having unimportant cards under *neutral* to *important* columns. This situation was due to the use of a fixed sorting model. In addition, some of the participants reported that it was 'challenging' for them to choose. It is also worth mentioning that the lack of interest by many participants in the outdoor cards might be due to their psychological wellbeing; it would be very beneficial if a screening tool were to be used for measuring this aspect.

7.4 Recommendations for future research

The findings of this study reinforce knowledge about the experience of children living with LTC/LLC, with particular reference to the issues of play occupation deprivation and injustice. The research raises two important points to consider for future research. Firstly, the current play provision in hospitals and hospices is not designed based on children's needs of social interactions; rather that provision is focused on, as well as informed by, equipment availability and individual health outcomes. Secondly, it is important to account for the needs of children with cognitive difficulties and complex needs, as represented in this research. Accordingly, it is crucial to focus on evaluating the environmental changes and the children's level of participation in play, together with their well-being, in addition to developing various media in order to understand the playfulness experience of children with complex needs.

Play and well-being: Future studies can investigate how universal designs can be incorporated within healthcare settings in order to support children's play. More research could potentially focus on the issue of play deprivation within healthcare settings and its influence such deprived children's well-being. This suggestion is informed by the lack of studies that clarify the effect of occupational deprivation on children and more specifically children living with LTC/LLC. Thus, outcomes confirming this association between enabling play and that activity's positive impact on the children's health and well-being are required. Trials can also help in establishing the relationship between nourishing play environments within the healthcare settings and the children's QoL in the long term, as well as highlighting the play benefits that match the healthcare institution's vision. This investigation could also include measuring play's effect on the caregivers. Studies can be also extended to other settings, such as children's homes and schools, to determine other ways to support and enrich children's play.

Despite the fact that the focus of this study was not on the siblings of children living with LTC/LLC, their well-being seems to be a major area of concern, as they may also be experiencing play/occupational deprivation as a result of their sibling's condition. Issue related to the siblings of children with chronic illnesses were previously noted; a study by Knecht et al. (2017) elaborated on such siblings having difficult emotional, social, personal experiences and having other unmet needs. Accordingly, there is a need for further research with more focus on the play provision for the child-patient's siblings to allow the latter to voice their needs.

The positive experience that the children need: The resulting contradiction in findings of children's play needs, including the issues of: a) outdoor play and b) playing with pets requires further in-depth investigation. It might also be worth considering investigating the meaning of play which is expected to carry other connotations different from those associated with traditional forms of play. The ongoing research studies on play usually rely on the theoretical established meaning of play, which might be different for children nowadays. A contemporary definition should include children's voices but also address the different perspectives of parents, teachers, healthcare professionals and other stake holders.

Virtual reality technology is a promising area for the children with complex needs which may enable them to participate in play. However, before this initiative is developed, there is a need to find a way to measure their 'playfulness' levels in order to guarantee that their play using the virtual reality or any other technology is contributing in a positive way to the playfulness experience. Nevertheless, it is important to understand the play mode of children living with LTC/LLC; particularly those with complex health care needs. Therefore, more attention should be paid to developing different media for assessing children' positive experiences. It would also be helpful to include enjoyment and pleasure, besides pain and symptom issues, as dimensions of measurement when evaluating children's QoL.

Possibilities of social play: More studies are required to identify the possible options of getting children to play together. Outcome measuring tools need to be used to evaluate the appropriateness of this potential outcome. It would also be beneficial if future research could address playing with electronic devices in particular. Communication technologies can open up many possibilities, though these possibilities need to be wisely used if the occupational balance is to be maintained for children with LTC/LLC. This proviso is necessary because the rapid and huge progress in technology use by the new generations cannot be changed; however, that technology can be adapted to create an extraordinarily rich play experience. The possible explanations for the increased use of electronic devices can be also used as cues and guidance in creating other play opportunities.

Using assistive technology can be of great benefit for the children with complex needs; however, the use of such a resource requires much consideration. In particular, assistive technology should be developed in a way that is easy for the children to be able to use independently. The observed use of technologically assisted required staff training and significant preparation before the child could start using such a resource. These technologies can also assist the children's communication, which in turn enhances their social play by allowing them to feel included in, as well as part of, the group.

The physical isolation due to infection prevention and community discrimination experienced by children with LTC/LLC is an area that requires further investigation. Studies should be designed to find out how the infection can be controlled to reduce the negative influence of isolation on children's play. Additionally, further research can assess how the stigma, noted within the two societies involved in this study, is impacting play negatively, with a goal of controlling such negative influences.

Children's occupations: Despite the fact that evaluating occupational rights was not the focus of this study, it seems, from the collected data, that the children are experiencing occupational injustice including deprivation, imbalance and alienation in their play. Research focusing on play as children's occupation is recommended to acknowledge and investigate this injustice. Additionally there is a need to look at the children's other occupations, given that it was not only the play occupation that was negatively impacted. One such example that requires attention is the long hours of staying in bed, when the child has the ability to move. Thus, more in-depth studies are called for on children's routines both at hospital, hospice and home in order to find out what is involved in a typical day at home/ward; information that can be used to identify and audit what might be identified as ‘occupational injustice’. As a consequence, developing tools is a requirement to facilitate the assessment of the children’s occupational deprivation within a variety of settings, including inpatient healthcare settings. This development initiative is for the purpose of generating meaningful outcomes for children experiencing palliative care. When looking at children’s other occupations, it is worth considering the issue of the green and blue outdoor areas for further investigation in relation to the children’s other occupations and those areas apparent lack of perceived importance to the participants.

Importantly, research needs to account for the children with complex needs by finding ways of employing participatory research with them, since they are still an under-researched group. This relative empirical neglect was also the case in this particular study, as the children’s voices were under-represented in the Q methodology. Additionally, given that the data collected for this study did not adequately address the challenging issue of children with end-of-life needs, such a population requires further research with different designs that can study their play as well as their other occupations.

7.5 Summary of the chapter

Given that children living with LTC/LLC experience less play than their unaffected peers, it can be confirmed that the children’s conditions, as well as environmental factors, are placing restrictions on their play. This study is the first to explore play, and the social and physical environmental factors associated with their play, from the perspective of children living with LTC/LLC, and their caregivers, within inpatient healthcare settings. Despite the participants valuing some of the play resources such as play equipment and spaces, these resources were primarily intended to create a rich social play experience for those children. Having an optimal challenge is crucial for children to experience playfulness. Since this was not usually the case, both play occupation imbalance and deprivation were identified. These findings were discussed in relation to previous literature leading to recommending implementation of some of the key findings, while taking into account the limitations present in this study. Creating opportunities of being with others whilst matching the children’s needs and preferences will bring great benefits to the children. Future studies can be built upon these findings by evaluating the effectiveness of such implications on children’s well-being and the experience of positive occupations despite their illnesses. Even after the limitations within the current study are acknowledged, the findings make a novel contribution to the issue studied. Accordingly, the novelty of this study will be the emphasis in the Conclusion Chapter (Chapter 9). Prior to Chapter 9, the researcher’s reflexivity will be documented in the next chapter (Chapter 8).

Chapter 8 Reflexivity

In this chapter, reflexivity on the research process is demonstrated. This is achieved by illustrating the researcher's position in the different stages of the study and in doing research with children, in particular.

As a researcher, I kept a research diary throughout the research phases. Its use encouraged me to reflect on my own thoughts, feelings, assumptions and experiences. Noteworthy was that the balance between the nature of LTC/LLC and play was not easy to manage. Whereas play can be extremely positive and bring a huge amount of joy, the children's conditions on the other hand brought severe pain. I experienced, with the children, moments filled with happiness but also lived through other tough times where a child passed away. I kept all that in my diary in addition to the audit trail and had a continuous discussion with my academic supervisors which all helped me during my research journey in understanding the influence I personally had on the research data.

8.1 Dimensions of addressed reflexivity

Reflexivity can be understood as acknowledging the researcher's role in constructing the knowledge (Pillow 2003). Despite the fact that this definition is sometimes inadvertently used interchangeably with critical reflection (D'cruz et al. 2007) it, however, moves beyond the description comprising more immediate and dynamic self-awareness to deconstruct the researcher positionality (Finlay 2003; Graham et al. 2016). Reflexivity is about the researcher examining their own self and recognising their position within the research throughout the research phases (Berger 2015; Thurairajah 2019). This is by considering the actual potential and effect of the researcher's social position, the power dynamics differences with the participants and its impact on the data including collection, analysis and interpretation (Pillow 2003; Berger 2015; Thurairajah 2019). Recognising these influences and their implications on the findings was a major strategy for ensuring the accuracy and trustworthiness of this research (Pillow 2003; Berger 2015). This was not by eliminating subjectivity, but in order to manage it, since the research was undertaken from a critical ontological position where the researcher was central to the construction of the knowledge.

8.1.1 Insider/outsider researcher

Social differences are what gives the researcher the insider or outsider position in any research (Finefter-Rosenbluh 2017). For the participants, I seemed to be an 'insider'. This can be expected from the participants in Kuwait but not in the UK because of my race, language and the way I dress that is generally different to the population in the UK. However, the multi-cultural professionals the patients and their families were dealing with, in the UK, enabled them to see me as an insider. Also, I reached those participants through the principal investigators who were introducing me to the participants as one of the team. This is in addition to the fact that during the period of data collection, I tried to be visible for the people so they got used to see me in that setting. Nevertheless, I talked to the participants about a very important issue (most of them had not had the chance to talk to someone about it) which is play. All this influenced the participants in seeing me as an insider and also facilitated the establishment of rapport and the recruitment process (Blythe et al. 2013).

However, personally, I felt like an 'outsider'. Despite my professional background and previous experience of working at a hospital with children and children with complex needs, the settings where I collected the data were new to me. I have not had the experience before of working with children with palliative care needs. I have no children and have not cared for a child with illness. I did not share with participants' characteristics or roles that were studied (Blythe et al. 2013). Thus, doing the research as an outsider and studying an unfamiliar situation was somehow helpful in detaching me from the phenomenon and assisted in maintaining degrees of objectivity (Arber 2006).

8.1.2 Communication

As highlighted before on the data quality in Chapter 4, to maintain trustworthiness, I kept a consistent recruitment procedure and way of communication. For each participant, I made my role clear, as a researcher, and helped them to determine the responses they needed to give. Being an occupational therapist and having the required communication skills made it easy to communicate with the families. This was in addition to the research topic and the way I approached the participants, joining children in play (detailed further next in 8.1.4 Power-relationship). During the interactions with the participants, I paid attention to my body language: I was open, looked relaxed and smiling (Glasper 2010); however, this was not always easy. Acting as if comfortable despite the inner anxiety and stressful feelings required considerable effort. This was in particular during the initial days of my data collection within each setting. Although I was looking forward to beginning the data collection, I was also anxious for the process to start. I tried my best to think about the details and be prepared for it. Therefore, I started each setting by building relations among the clinicians, engaging in general discussions and volunteered for many organised activities. This further helped in building social trust. I became used to the routine within the settings where I collected the data more quickly than I expected. The team I worked with in Kuwait and the UK at both settings were very cooperative, thereby facilitating the collection of the data.

8.1.3 Participants' rights and confidentiality

During the data collection, I was oriented to carefully considering any distress that may occur among the participants in addition to clarifying to them their rights including whether to participate or the fact that they could withdraw at any time (see Chapter 5 – 5.2 Informed consent). One of the children who was taking part in the Q methodology appeared uncomfortable while participating; accordingly, I asked him if he wanted to stop and he agreed to do that. Additionally, to ensure the participants' rights were upheld, for the observations which were conducted on two different days, I began the second day by reiterating the overview of the study and getting the child's/legal guardian's consent verbally, despite the fact that it was obtained on the first day.

Occasionally, the participation was interrupted due to some medical procedures. Johnston et al. (2016) had also highlighted this point because of the nature of the hospital settings. In such cases, I was guided by the participants over whether they preferred to stop until that person left or to continue carrying on. This consequently sometimes affected the participant's privacy. In addition, when the healthcare staff had a discussion relating to the child's case, I used to stop the recorder when it was recording, all of which was to achieve a safe research practice environment for the participants.

8.1.4 Power-relationship

Despite my intention to be as friendly as possible, there is always an imbalance in power weighted towards the researcher (Finefter-Rosenbluh 2017). Achieving symmetrical power is essential to ensure the quality of the data. Therefore, I introduced myself with my first name followed by my interest in children's play. I also introduced myself as a researcher; however, when participants asked about my professional background, I informed them I am an occupational therapist but without elaborating because I did not want that to influence their answers or change their responses during my presence (Johnson and Onwuegbuzie 2004; Arber 2006). However, one of the challenges was that the participants, both the children and their caregivers, repeatedly asked during the Q sorting if what they were doing was correct. This can be expected as some people may give answers that do not represent their true perspectives; rather, they say what they think the researcher wants to hear. I replied by assuring them there are no right or wrong answers (explained in Chapter 4 – 4.3.3 Data collection). Furthermore, I clearly stated to the participants that I was interested in knowing what matters in relation to children's play from their perspectives.

Participatory research with children has been proposed to facilitate managing the power relationship between children and researchers (Mandell 1991). Therefore, in addition to my use of participatory research, I also adopted several methods to empower the children. Initially, I engaged with them in the joint action of play which had a role in showing how I, as a researcher, value children's abilities and in building rapport with them. I explained the research in a comprehensive fashion appropriate for the children's level of understanding. When I met the child for the first time, I talked to both the child as well as the caregiver at the same time distributing my eye contact between both. I gave the children the specially designed children's information sheet based on their age and obtained consent (Appendix H and Appendix I) from the children themselves. I offered the children different colours to choose to use in completing their assent forms. I went over each point with each to fill the form (for those who wanted to fill one in). I also used to recruit the child before the caregiver when both were willing to take part in the study. Most importantly, the children's choices were respected in regards to their willingness to participate or not over the legal guardians' wishes (example given in Chapter 5 – 5.2 Informed consent on respecting children's decisions).

Any tool which I used during the data collection, I initially introduced to the child and showed what it was and how it worked including the Q methodology cards and Q matrix mat, the audio-recorders and the camera. When one of the children saw the camera he felt fearful as he was not sure what it was or how it was used. Children saw their photos and deleted the ones which they did not like, and some of them took some pictures as well, all of which was to ensure that the children's voices, images and perspectives were presented in this study; thus, this contributed to contextualising the interpretations of the data (Phelan and Kinsella 2013).

Furthermore, in order to decrease the power imbalance, children were given the choice as to where they wanted to do the Q methodology; some of them did it on their beds, some in the playroom, and others on floor. At all times, I was at the child's level, slightly leaning toward the child (Glasper 2010). Moreover, when they finished sorting the Q methodology, they were asked if they were happy with their sorting or, if they wanted to make any changes, to feel free to do that. Some caregivers occasionally tried to influence the child's choices during the Q methodology by intervening. I responded by reminding the child about what they thought and politely asked the caregivers not to. I also reminded the caregivers that they can take part in the study and offer their perspectives as well if they wish. During the observation, because of the approach adopted, children were given the right to do whatever they wanted and be wherever they wanted to do the tasks, all of which helped to give the child having a sense of control over the research process.

8.1.5 Feeling comfortable

In order to help the children to feel comfortable, I carried my research bag with me in which I had a number of toys, colouring pens and papers. I played with the children before or after the data collections when I was in the field.

I used to ask the participants during their participation for further clarifications questions; occasionally I found some of them feeling troubled. A typical example was when they were given the extra card at the end of their Q sorting. The participants' reactions showed that they felt they had to use it although most of them did not add any. In such cases I reassured them that it was okay if they did not know and I re-directed them to move on.

Phelan and Kinsella (2013), however, highlighted that feeling too comfortable can create vulnerability and risk to the participants. Despite the fact that I kept the relationships which we built very professional, the families got attached easily as I noticed following the initial days (e.g., when children showed big smiles when they saw me or asked about me around the setting). Thus, I realised that it would not be easy to leave. Therefore, I tried to make my role even clearer to the participants and stated that I would only be available in the setting for a limited period.

I did not intentionally try to participate in the role of a child for the purpose of making the children more comfortable which Mandell (1991) called 'least-adult role'. It was the methods of interactions which I adopted (detailed earlier in 8.1.4 Power-relationship) minimising differences and making the children to feel that. Being friendly, building rapport, getting children's consent, attaining their trust and trust of other adults whom the children have confidence in (Mandell 1991; Randall 2012b) were initiated from my ethical and professional obligation to protect the participants and to be able to get representative data from the children rather than what they think the researcher wants to hear. This as a consequence assisted in creating a role of adult-as friend.

8.2 Summary of the chapter

Although this reflexivity cannot completely remove the researcher's influence on the research data and process, acknowledging its potential impact is crucial. The awareness of this enabled the researcher to look for alternative explanations in the data and be open to different possibilities. Being an insider researcher facilitated getting on with participants; however, the researcher's feeling of being an outsider assisted in detaching herself from the studied phenomenon. The communication style and adopted methods of interaction helped in balancing the power relationship between the researcher and the participants, particularly the participatory approach and engaging in participation in play style. These were important to participants' right to feel at ease during their participation. Accordingly, this can confirm the collection of rigorous data and build confidence in the conclusion of this research, to be presented in the next chapter.

Chapter 9 Conclusion

9.1 Summary of the research topic

Play is synonymous with childhood and integral to children's experience of childhood (James et al. 1998). It is unfortunately a fact that living with LTC/LLC negatively affects children's play, changing the way they live their childhood (Chapter 3). Less attention is usually paid to the needs of play of vulnerable children living with LTC/LLC, and this is despite the fact that the role and value of play may be of increased importance for these children (Burkhardt et al. 2011; Boucher et al. 2014; Amery 2016). Given that it is the primary childhood occupation, it is an occupational determinant of health and can contribute to children's well-being (Gerlach et al. 2014; Moore and Lynch 2018). Accordingly, the parallel planning, due to the nature of LTC/LLC as characterised by prognostic uncertainty, requires including play (Chapter 2).

This study was taken from an occupational therapist angle in investigating children's play and the environment to play. The aim of this study was to explore the environmental factors that contribute to a supportive play environment for children with LTC/LLC. The environment was explored considering the social and physical environmental factors that act on supporting/limiting children's participation in play while receiving inpatient healthcare services. The cultural aspect was also considered by collecting data from Kuwait and the UK.

The data were generated using Q methodology and observation utilising parallel mixed-methods study design. The data were collected from children (n= 58) with LTC/LLC between the ages of 5-11 years and their caregivers (n=39). The participants were recruited from children's hospitals and hospices (Chapter 4). High research standards were employed to ensure safe research practice where ethical issues were precisely addressed (Chapter 5).

The collected data were presented (Chapter 6) and discussed (Chapter 7) suggesting implications for practice and future research. Limitations in the study were also acknowledged and the researcher's role in constructing the knowledge was demonstrated recognising the reflexivity (Chapter 8). As a consequence, this contributed to the area of children's play and living with LTC/LLC and makes novel contributions to this growing field.

9.2 Novel contributions of the research

The key contributions that this research has made to the existing knowledge and evidence base are summarised next. Specifically it considers contributions to: research with children with

LTC/LLC; occupational science; research methodologies – in particular Q methodology; and key messages for practice.

Contribution to the knowledge: This study is the first to target play in depth for children living with LTC/LLC as a children's occupation which contributes to the field of occupational science as well as palliative care. It explored their everyday play and investigated the environmental factors within inpatient healthcare comparing two countries, Kuwait and the UK. Particular in the case of Kuwait, to the best of our knowledge, no previous study has included children with LTC/LLC.

This study has generated new knowledge showing that most of the children's play needs are very similar across the two cultures, regardless of the differences between and within communities. Crucially, the evidence contributes towards an explanation of children's prioritisation of the social play experience over the physical factors of play resources. They were mostly important in a way that supports being with others. The data also stressed the importance of understanding the playfulness experience for children with complex needs and acknowledging and respecting their differences.

The study design and used methods: The study design (mixed-methods research design) used in this research supported a greater understanding of the phenomenon. This study illustrated how a mixed-methods study approach was used and data were triangulated from several aspects: participants' generational groups, methods, settings and cultures. A major strength of this research is the representation of the findings from the children's perspectives themselves; the inclusion of children through the adoption of methods that assisted accounting for their voice in a fun and non-threatening atmosphere. Furthermore, participation was not restricted to specific abilities; it enabled the inclusion of all children – those with physical impairments as well as intellectual disabilities.

Q methodology and children: It is worth mentioning that the way Q methodology looks, suggesting fun and play, facilitated the recruitment process as well as obtaining ethical approval. This is particularly important to consider for research studies with vulnerable populations.

This method has not been used before with children with LTC/LLC or in comparing children from different communities. This thesis set out clearly how it can be used for such situations taking into consideration the participants' abilities, ages and language, and the cross-cultural aspects. The challenges and opportunities of using Q methodology across different cultures were also discussed.

Taking findings further: The adopted comparison tool between the cultures allows better implications of the study's findings and taking this knowledge further; however, this must be undertaken with caution. Crucially, the need is to create opportunities for social play experience utilising the physical factors in matching children's abilities and finding their preferences. Nevertheless, using the findings of this study, future research should extend the understanding of the relationship between play and the well-being of the children as well as that of their families. This is in addition to evaluating the appropriateness of social play opportunities on children's engagement. It is also important to understand the play modes and patterns of children with complex needs. Besides that, to understand their playfulness experiences in order to be able to support their participation in play that carries the meaning, features and benefits of play. This is for the purpose of filling children's lives with meaningful experiences, however these may be short lives.

9.3 Recommendations for meeting children's play needs

Based on this study's findings and its novel contributions, it is suggested that there is a need for improvement in the training programmes offered to professionals who work with children (e.g., occupational therapists, play specialists, nurses and doctors) to incorporate a greater focus on play. This applies specifically to university courses and to continuing education such as professional workshops and study days. The courses and workshops should focus on the value of play on children's being and becoming, their well-being and development, and how to consider their needs to ensure that optimal care is provided for them.

Practitioner occupational therapists can place focus of their interventions to support children's participation in play by targeting the environment and/or the task or activity rather than attempting to change children or their play needs. As highlighted in Chapter 2, in the discussion of the PEO model and the targeting of environmental interventions, it is important to consider other factors surrounding the child which are associated with their occupational (play) participation. Studies showing outcome measure as the context-therapy approach (Darrah et al. 2011; Anaby et al. 2016) could provide therapists a guidance in targeting the task or the environment and its effectiveness in getting adaptive responses/ better occupational performance with children.

9.4 Concluding remarks

It is every child's right to play regardless of their abilities and health conditions. This study contributed to the current body of knowledge on the topic and suggested possible ways to enhance children's participation in play which in turn can have an influence on their well-being. It is our professional responsibilities to create opportunities of joy for the children themselves as well as their families and loved ones and assist in drawing and painting wonderful memories no matter what the future holds.

Appendix A Overview of the thesis

	Literature review	Methods		Integration of the findings	Discussion
		Q methodology	Observation		
Aim/ question	What is known about the nature of the everyday play of children between the ages 5-11 living with LTC/LLC?	Explore the physical and social environmental factors that contribute to a supportive play environment for children with LTC/LLC while receiving inpatient healthcare services in Kuwait and the UK.		Synthesise the findings and achieve ultimate understanding of the phenomenon	Identify the related factors for the purpose of having a supportive play environment
Design	Scoping review	Parallel mixed-methods		Integrated analytic approach	Triangulation
Method	Search in electronic databases, Grey literature, and reference lists and manual searches	Integrated mixed-method collected in person	Qualitative observation using marginal participant	Parallel design of analysing and interpreting mixed-methods research	
Guidelines	Aveyard (2014) and Peters et al. (2015) guidelines	Watts and Stenner (2012)	Developed observational schedule (Appendix R)	Moran-Ellis et al. (2006) and O'Cathain et al. (2010)	Pragmatism approach, Occupational Science literature and Person-Environment-Occupation model

Participants/ materials	16 studies	66 participants (27 children and 39 caregivers)	31 children	Findings of the Q methodology and observation	The integrated findings and previous literature
Inclusion criteria	-Arabic and English written papers -Published between the years 1990 to March 2019 in any country -Discussed the daily play of children with LTC/LLC covering the ages 5-11 years	Child or caregiver of a child: -Diagnosed with LTC/LLC -Admitted to either a children’s hospice or a hospital ward. -Was 5–11 years old at the time of the study. -Judged by a responsible clinician to be medically stable -Have the mental capacity to participate (specific to Q methodology)			
Data analysis	Thematic analysis	Factor analysis (using PQ method software) and card content analysis (using NVivo software)	Content analysis (using NVivo software)	Following a thread	

Appendix B Manual search

Manual searches have been done in the following journals

- Journal of Social Work in End-of-Life & Palliative Care
- International Journal of Palliative Nursing
- Palliative medicine
- American Journal of Hospice & Palliative Medicine
- End of Life Journal
- BMJ Supportive and Palliative Care
- Journal of Child Health Care
- European Journal of Palliative Care
- Health Environments Research and Design Journal
- Journal of Healthcare Interior Design
- Design Studies
- Architectural Engineering and Design Management

Appendix C Approach for using Boolean operators and search symbols

Boolean operators		Approach for using AND and OR and no NOT
AND	Used	It searches for all search terms. Thus each result will contain all the search terms and hence limits the search to literature contain all the keywords.
OR		Using it will result in ensuring that each result contains at least one of the search terms. Thus, it will expand the results by finding any of the keywords. Therefore, it widens the search and good to using for synonyms.
NOT	Not used	It is used to show results that do not contain the specified terms which will reduce the number of results found. Not using “NOT” and the broad search terms yielded a vast number of papers, although, it was important to review all the possible studies for inclusion.
Approaches for using truncation symbols and inverted commas		
*	Used	Using the asterisk (*) allows broadening the search by retrieving varying endings of the search terms
“ ”	Used	Using the quotations assists to have the words to appear next to each other, with no other significant words between them to limit the search to relevant concepts

Appendix D Number of studies found in each database with the searching terms

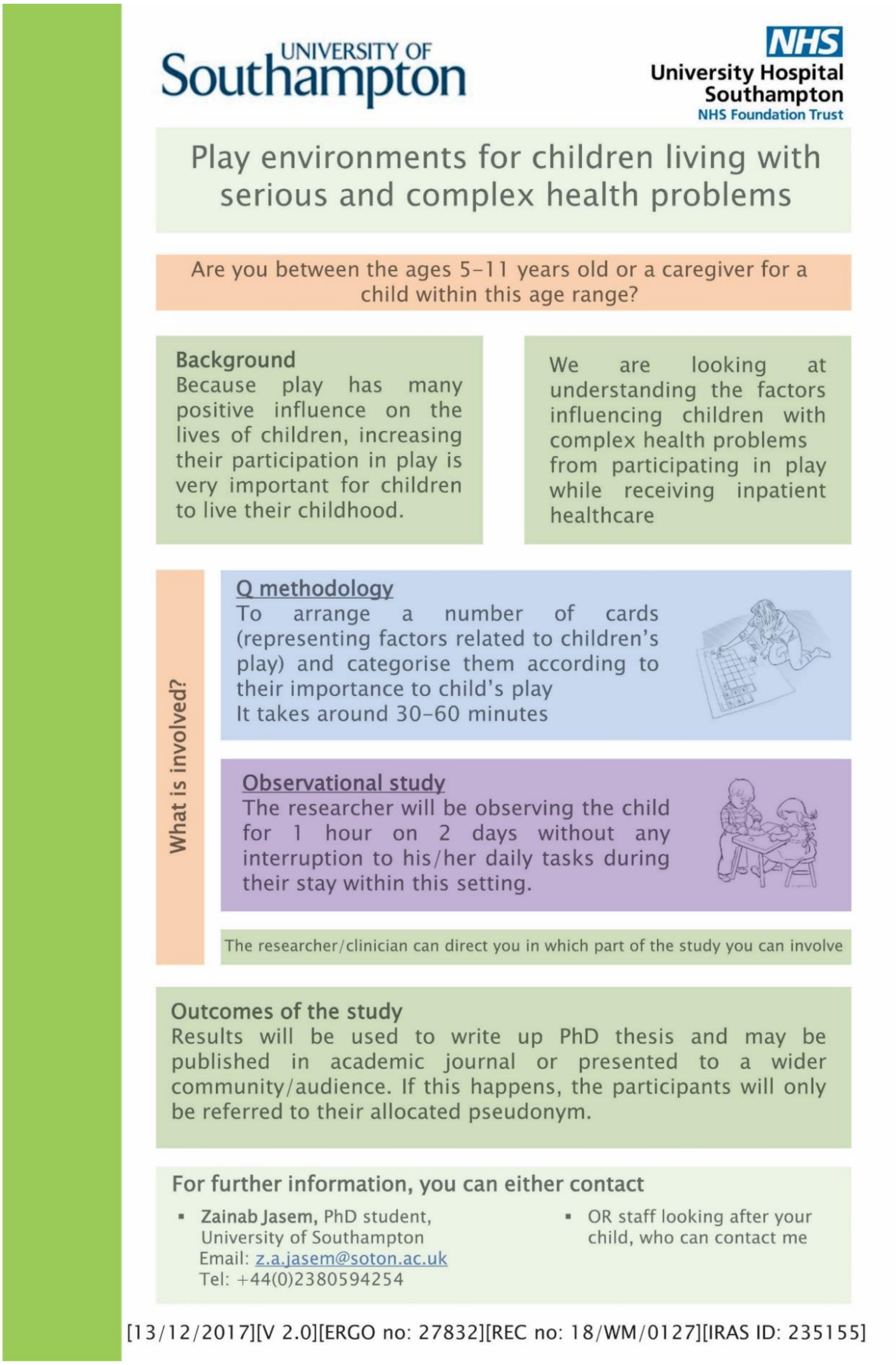
Search term		Articles found in each database								
		AMED	CINAHL	PsycINFO	Medline	EMBASE	Web of Science	Scopus	ASSIA	Cochrane Library
1	Child	11,938	432,756	396,045	1,455,420	401,543	1,235,886	1,793,292	70,281	5,915
2	Play	4,456	74,634	168,623	901,692	342,912	2,824,797	1,807,280	49,621	783
3	LTC/LLC	8,789	40,321	58,919	285,798	115,150	200,477	334,883	15,082	8,287
4	1 AND 2 AND 3	16	230	602	1960	464	1,040	1,539	196	223

Appendix E Examples of reviewed questionnaires to be used for data collection

Questionnaire	Purpose
Participation and Environment Measure for Children and Youth (Coster et al. 2012)	To evaluate children’s participation within different settings alongside environmental factors within each setting.
Pediatric Interest Profiles (Henry 2000)	To evaluate children’s interest and participation in a variety of play and leisure activities
Test of Playfulness (Skard and Bundy 2008)	To evaluate free play by measuring children’s internal control, intrinsic motivation and freedom to suspend reality.
Test of Environmental Supportiveness (Skard and Bundy 2008)	To evaluate the role of different variables of a particular environment in supporting children’s play.

Appendix F Poster

F.1 English poster



UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Play environments for children living with serious and complex health problems

Are you between the ages 5-11 years old or a caregiver for a child within this age range?

Background
Because play has many positive influence on the lives of children, increasing their participation in play is very important for children to live their childhood.

We are looking at understanding the factors influencing children with complex health problems from participating in play while receiving inpatient healthcare

What is involved?

Q methodology
To arrange a number of cards (representing factors related to children's play) and categorise them according to their importance to child's play
It takes around 30-60 minutes

Observational study
The researcher will be observing the child for 1 hour on 2 days without any interruption to his/her daily tasks during their stay within this setting.

The researcher/clinician can direct you in which part of the study you can involve

Outcomes of the study
Results will be used to write up PhD thesis and may be published in academic journal or presented to a wider community/audience. If this happens, the participants will only be referred to their allocated pseudonym.

For further information, you can either contact

- **Zainab Jasem**, PhD student,
  University of Southampton
  Email: z.a.jasem@soton.ac.uk
  Tel: +44(0)2380594254
- OR staff looking after your child, who can contact me

[13/12/2017][V 2.0][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

F.2 Arabic poster

UNIVERSITY OF Southampton

توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

هل يتراوح عمرك بين 5 إلى 11 سنة أو ترعى طفل في هذا العمر؟

فكرة البحث

بينت الدراسات أن مشاركة الأطفال في اللعب لها فوائد إيجابية متعددة تنعكس على حياتهم و صحتهم..

لذا نسعى من خلال هذا البحث إلى فهم العوامل التي تؤثر على مشاركتهم في اللعب.

الهدف من البحث

دراسة العوامل التي تؤثر سلبا أو إيجابا على الأطفال ذوي الرعاية الخاصة من المشاركة باللعب وذلك لتوفير بيئة لعب تناسب احتياجاتهم خلال فترة وجودهم في المراكز العلاجية المتخصصة.

ماذا سيترتب على مشاركتنا؟

فرز «بطاقات كيو»

كل بطاقة من بطاقات كيو تمثل واحدة من العوامل التي من الممكن أن يكون لها تأثير على لعب الأطفال اليومي خلال فترة وجودهم في المركز العلاجي/ المشفى. سيتطلب من المشارك فرز و ترتيب هذه البطاقات حسب أهميتها، و سيستغرق ذلك في حدود 30 إلى 60 دقيقة.

دراسة المشاهدة

سيقوم الباحث بمشاهدة طفلك و الأنشطة المختلفة التي يقوم بها على مدار ساعة على يومين، و هذا لأجل فهم أعمق لاحتياجات الأطفال في فترة وجودهم في المركز العلاجي/ المشفى.

سيوجهك الباحث (أو أحد أفراد الطاقم الطبي المشرفين على الحالة) لأي هذه الدراسات يمكنك المشاركة بها

نتائج البحث

سيقوم الباحث بجمع و تحليل البيانات لكاتبة أطروحة الدكتوراه ، و من المحتمل أن ينشر البحث في إحدى المجلات العلمية مع مراعاة عدم وجود أي معلومات تتعلق بشخصية المشارك.

لمزيد من المعلومات و التواصل:

- **زينب عبدالعزيز جاسم** (الباحث)
  طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
  ايميل: z.a.jasem@soton.ac.uk
  رقم الهاتف: +965 9927 2248
- ابلاغ المرض/الطبيب المسؤول عن طفلك و هو بدوره سيتواصل معنا

[6/10/2017] [V 1.0]

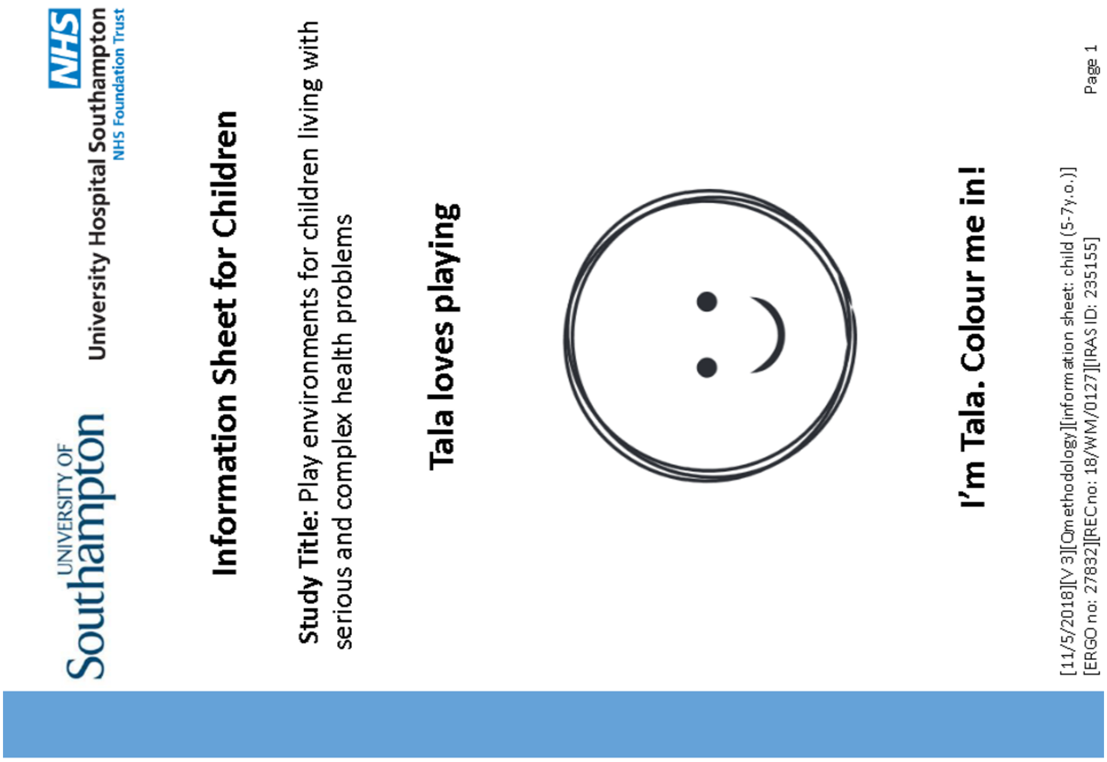
[ERGO no: 27832]

Appendix G The developed consent and participant information sheets

Methods and versions	Q methodology		Observation	
	English version	Arabic version	English version	Arabic version
Child	1. Information sheet (see Appendix H.1 and H.2) 3. Assent form (see Appendix I.1)	2. Information sheet (see Appendix H.3) 4. Assent form (see appendix I.2)	13. Information sheet (see Appendix H.8 and H.9) 15. Assent form (see Appendix I.7)	14. Information sheet (see Appendix H.10) 16. Assent form (see Appendix I.8)
Legal guardian	5. Information sheet (see Appendix H.4) 7. Consent form (see Appendix I.3)	6. Information sheet (see Appendix H.5) 8. Consent form (see Appendix I.4)	17. Information sheet (see Appendix H.11) 19. consent form (see Appendix I.9)	18. Information sheet (see Appendix H.12) 20. Consent form (see Appendix I.10)
Caregiver	9. Information sheet (see Appendix H.6) 11. Consent form (see Appendix I.5)	10. Information sheet (see Appendix H.7) 12. Consent form (see Appendix I.6)		

Appendix H Information sheet

H.1 Children information sheet, Q methodology (English version), for 5-7 ages



UNIVERSITY OF Southampton

University Hospital Southampton NHS Foundation Trust

Information Sheet for Children

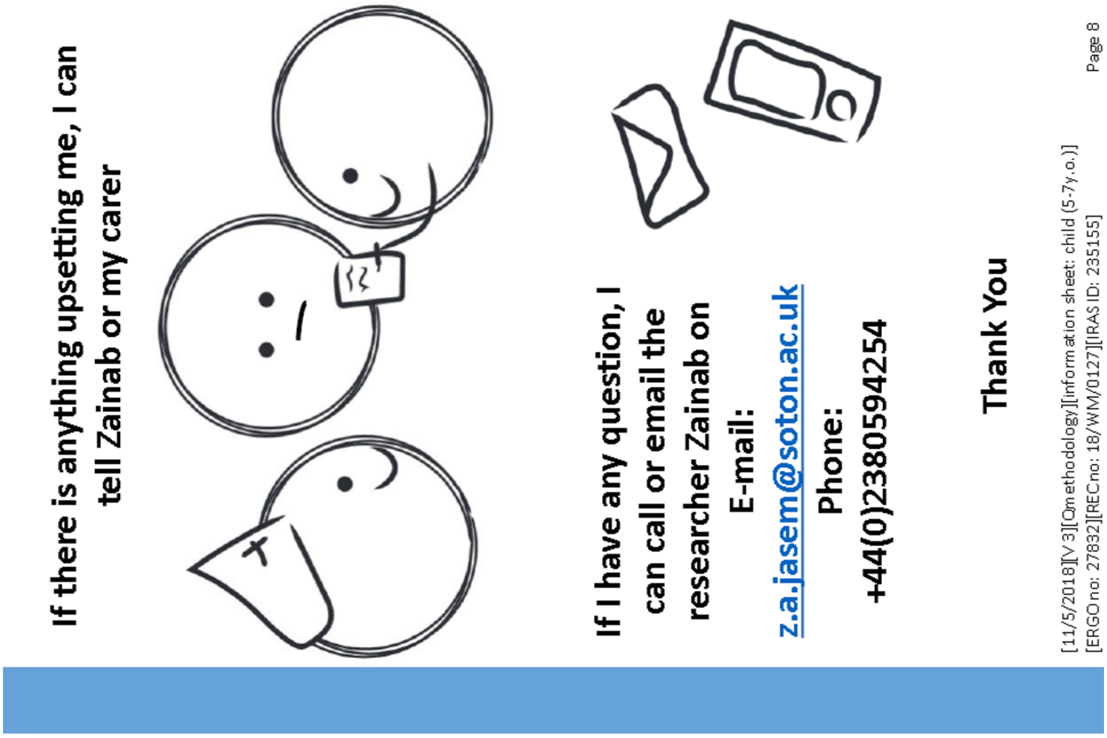
Study Title: Play environments for children living with serious and complex health problems

Tala loves playing

I'm Tala. Colour me in!

[11/5/2018][V 3][Qmethodology][information sheet: child (5-7y.o.)]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

Page 1



If there is anything upsetting me, I can tell Zainab or my carer

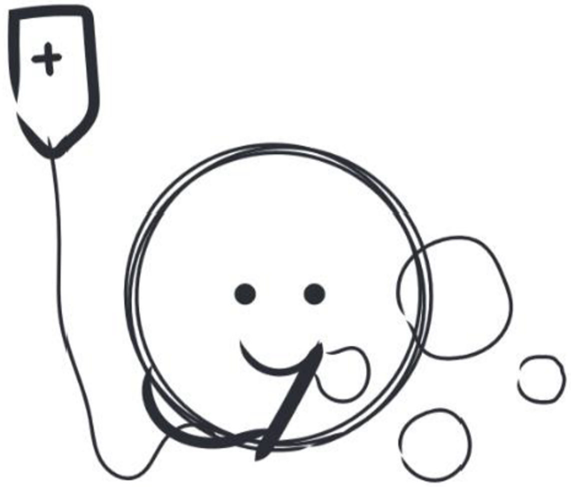
If I have any question, I can call or email the researcher Zainab on
E-mail:
z.a.jasem@soton.ac.uk
Phone:
+44(0)2380594254

Thank You

[11/5/2018][V 3][Qmethodology][information sheet: child (5-7y.o.)]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

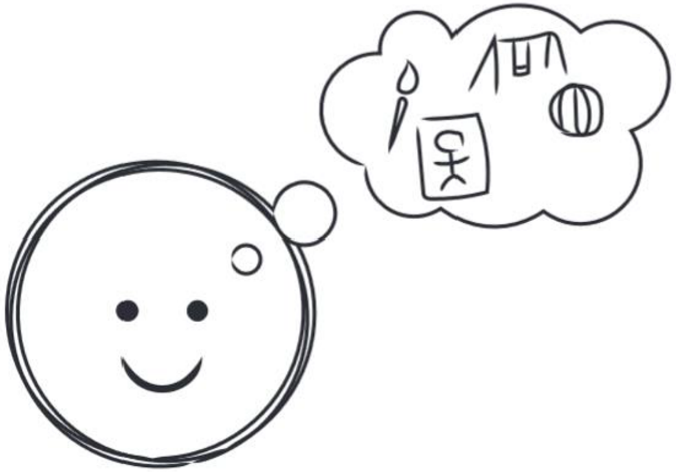
Page 8

I like to play

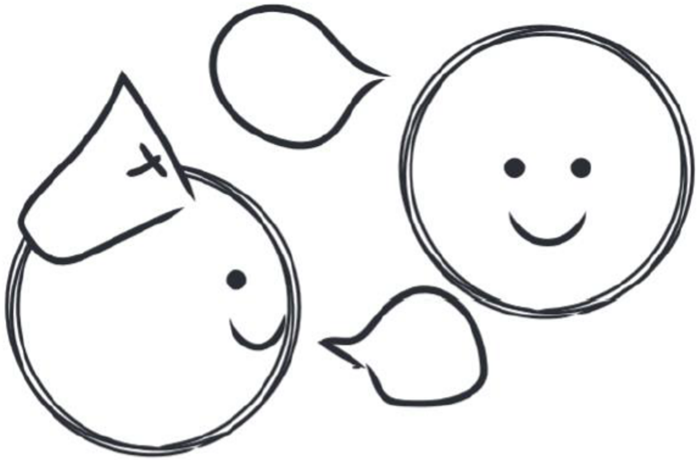


Zainab (the researcher) wants to know how I play

Zainab will write about how we play, so we can tell everyone what we need to enjoy play



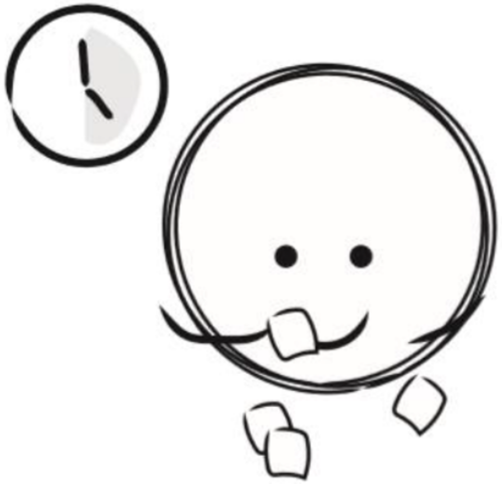
The doctor/nurse looking after me will know I'm taking part



I can also tell anyone I want

[11/5/2018][V 3][Qmethodology][information sheet: child (5-7y.o.)]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155] Page 6

I will play a game with Zainab which may take half an hour



[11/5/2018][V 3][Qmethodology][information sheet: child (5-7y.o.)]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155] Page 3

It's fun!

I will arrange cards in a triangle and the researcher will record my voice

If I feel uncomfortable, I'll use the stop sign and Zainab will stop

H.2 Children information sheet, Q methodology (English version), for 8-11 ages

UNIVERSITY OF Southampton

NHS University Hospital Southampton NHS Foundation Trust

Information Sheet for Children

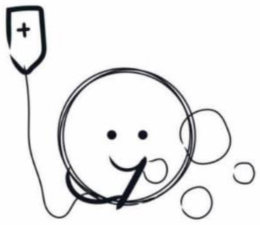
Study Title: Play environments for children living with serious and complex health problems

Would you like to take part in our study?

It is about your play
Before deciding, we will look at this information sheet with you and you can ask anything you like.

Why are we doing this research?

We know play is important to children and that it can be difficult to play in some places, or if you feel unwell. We want to know more about how children play when they are in a hospital or being cared for by doctors and nurses.



What happens when the study stops?

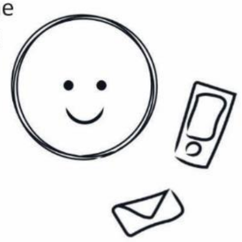
We will write about what we did in this study and share that with other people using your research name so no one will know that you took part. We will also write a summary of the results for you to read if you would like.

What if there is a problem?

If you are unhappy about anything we do or say please, tell your carer. They have been told who to contact.

If you want to ask any questions about the study or need more information, please call or email the primary researcher, Zainab Jasem

E-mail: z.a.jasem@soton.ac.uk
Phone: +44(0)2380594254



Thank you

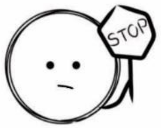
Why me?

We have been invited to take part because you are being looked after by doctors and nurses here in the hospital. We're interested in hearing about what are the important things for you to be able to play while being in the hospital.

What will happen if I take part?

1. We will ask you and your mum, dad or carer to write your names on a form to say you would like to take part.
2. We will play a game arranging cards in a triangle. This will take around 30 minutes during which, Zainab, the researcher, will record your voice.

Do I have to take part?



No, you don't. Talk to your mum, dad or carer before you decide. You can always change your mind.

If you do not want to take part, just say no. You will still have the same care as usual at the hospital.

What is good about taking part in the study?

We hope it will be fun! Taking part will really help us to learn more about children's play when they are in the hospital, so we can tell everyone what you and other children need to enjoy play.

Will anything about the research upset me?

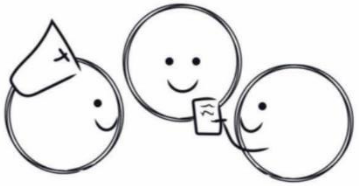
This study has been checked to make sure you will be safe. Sometimes it can feel uncomfortable to talk about your play, we are here to listen, if you feel you want to stop you can.

What do I do if I don't want to take part in the study anymore?

Just tell the researcher or your carer that you'd like to stop. You can still stop any time, even if we have started the study.

Will other people know I am doing this study?

The doctor/nurse looking after you will know you are taking part. You can tell anyone you want. Nobody else will know, unless there are something we are worried about your safety or the safety of another child, so that we can help.



Will anyone know what I have did in the study?

We will not tell anyone what we have seen in the study. We will store all your information privately.

H.3 Children information sheet, Q methodology (Arabic version)

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إرشادات المشاركة (للأطفال)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة
اسم الباحث: زينب جاسم

هل تود المشاركة في هذا البحث؟
يتعلق البحث بلعب الأطفال.. قبل إدلائكم بالموافقة على المشاركة، يرجى منكم فهم هذه الإرشادات المكتوبة. كما أن الباحث يرحب بالإجابة على جميع تساؤلاتكم.

ماهو الهدف من إجراء هذا البحث؟
من خلال هذا البحث نود التعرف أكثر على طبيعة اللعب عند الأطفال خلال فترة وجودهم في المشفى، حيث أنه من الممكن وجود بعض المعوقات التي تحد إمكانية مشاركتهم في اللعب كبقية الأطفال.

لماذا تم اختياري؟
لأن عمرك يتراوح مابين 5 إلى 11 سنة و تتلقى الرعاية من أحد المراكز العلاجية المتخصصة.

ماذا يجب علي أن أفعل؟
سنلعب لعبة "فرز بطاقات كيو" و هي عبارة عن ترتيب البطاقات بشكل مثلث حسب أهميتها. سيقوم الباحث بتسجيل صوتي للحديث أثناء ترتيب هذه البطاقات و ذلك سيستغرق حوالي نصف ساعة.

هل تجب علي المشاركة؟
لا، فمشاركتك إختيارية و ليست إجبارية، و يمكنك الوقف عن المشاركة في لعبة الفرز متى ما أردت دون الحاجة لشرح الأسباب.

هل هناك ما يمكنه أن يضايقني إن شاركت؟
لا.. و لكن إن شعرت بأي ضيق فنحن مستعدون لسماعك و فهم ما يزعجك، كما أنه يمكنك كما ذكرنا التوقف عن المشاركة في أي وقت.

هل هناك أي فائدة من مشاركتي؟
نتمنى أن تكون لعبة الفرز ممتعة! كما أن مشاركتك في هذا اللعبة ستساعدنا على فهم احتياجات الأطفال و إخبار المختصين برعاية الأطفال بما يحتاجونه ليستمتعوا بوقتهم أكثر.

من الذي يقوم بعمل هذا البحث؟
زينب؛ طالبة دكتوراه في جامعة ساوثهامبتون في بريطانيا و هي من يقوم بهذا البحث.

من سيكون لديه علم بمشاركتي؟
الممرض/الطبيب المشرف على حالتك. يمكنك إخبار من تود و لكن "زينب" لن تخبر أحدا إلا بموافتك.

ماذا سيحدث بعد الإنتهاء من البحث؟
سنقوم بكتابة النتائج و من المحتمل نشرها و مناقشتها مع الأشخاص المختصين بتوفير الرعاية للأطفال، و لكننا حريصون على مراعاة عدم ذكر أي معلومات تتعلق بشخصيتكم مباشرة.

قام مجموعة من المختصون بمراجعة البحث للتأكد من أنه لا يوجد أي خطورة على الأطفال الذين يودون المشاركة.

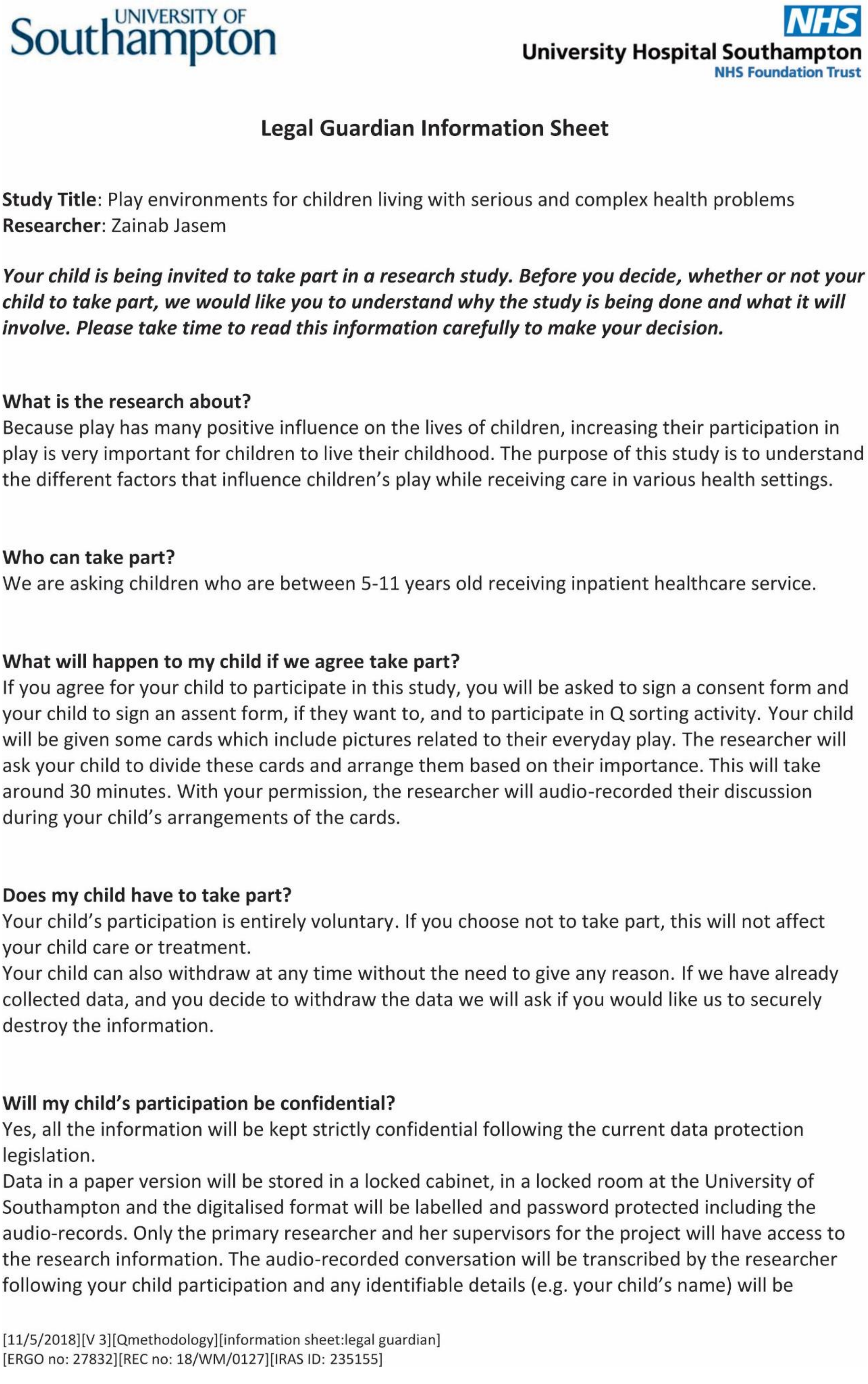
لمزيد من المعلومات و التواصل:

زينب عبدالعزيز جاسم (الباحث)
طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: z.a.jasem@soton.ac.uk
رقم الهاتف: +965 9927 2248

د. دنكان راندال (باحث مشرف)
أستاذ في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: D.C.Randall@soton.ac.uk
رقم الهاتف: +44(0)23 8059 7960

[13/12/2017] [V 2.0] [Q methodology] [information sheet: child][ERGO no: 27832]

H.4 Legal guardian information sheet, Q methodology (English version)



UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Legal Guardian Information Sheet

Study Title: Play environments for children living with serious and complex health problems
Researcher: Zainab Jasem

Your child is being invited to take part in a research study. Before you decide, whether or not your child to take part, we would like you to understand why the study is being done and what it will involve. Please take time to read this information carefully to make your decision.

What is the research about?
Because play has many positive influence on the lives of children, increasing their participation in play is very important for children to live their childhood. The purpose of this study is to understand the different factors that influence children's play while receiving care in various health settings.

Who can take part?
We are asking children who are between 5-11 years old receiving inpatient healthcare service.

What will happen to my child if we agree take part?
If you agree for your child to participate in this study, you will be asked to sign a consent form and your child to sign an assent form, if they want to, and to participate in Q sorting activity. Your child will be given some cards which include pictures related to their everyday play. The researcher will ask your child to divide these cards and arrange them based on their importance. This will take around 30 minutes. With your permission, the researcher will audio-recorded their discussion during your child's arrangements of the cards.

Does my child have to take part?
Your child's participation is entirely voluntary. If you choose not to take part, this will not affect your child care or treatment.
Your child can also withdraw at any time without the need to give any reason. If we have already collected data, and you decide to withdraw the data we will ask if you would like us to securely destroy the information.

Will my child's participation be confidential?
Yes, all the information will be kept strictly confidential following the current data protection legislation.
Data in a paper version will be stored in a locked cabinet, in a locked room at the University of Southampton and the digitalised format will be labelled and password protected including the audio-records. Only the primary researcher and her supervisors for the project will have access to the research information. The audio-recorded conversation will be transcribed by the researcher following your child participation and any identifiable details (e.g. your child's name) will be

[11/5/2018][V 3][Qmethodology][information sheet:legal guardian]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

masked. Each participant will be given an individual code and a pseudonym, so your child's actual name will not be attached to the information collected about your child. Thus, information will be anonymised and will not be recognisable to anyone outside of the study.
The identifiable data will be retained until 2020 to produce the thesis and the anonymised data will be retained for 10 years following completion of the study. Then they will be securely destroyed.

What are the benefits of my child taking part?
We cannot promise that this study will have direct benefits for your child. It is hoped that the information will help us to understand what is important to the play of children living with serious and complex health problems. This is important to inform services supporting the play needs of children.

Are there any risks involved?
We appreciate that talking about their play for some children can be uncomfortable. Please do let us know if you or your child feel uncomfortable.
If an issue has raised about your child's condition following your participation in this study, Sue Wilkins is happy to offer support either by phone (01962760555) or email (sue.wilkins@naomihouse.org.uk).
If we find something that may affect your child's health during the study, we will immediately discuss this with you. But we may discuss your child's care with others to make sure your child and other children are safe.

What we need to do if my child wants to take part?
If you are interested in taking part in the study you can either:

- Discuss with staff looking after your child, who can contact me
- Or email the researcher on z.a.jasem@soton.ac.uk
- Or telephone the researcher on +44(0)2380594254

What will happen to the results of the research?
This research project is being conducted in part fulfilment of the award of Doctorate of Philosophy (PhD) programme at the Faculty of Health Sciences at the University of Southampton. Thus, when the study is completed, it will be written up to produce a thesis demonstrating the findings and will be submitted to the University of Southampton.
The study findings are also likely to be published in a scientific journal and presented at scientific conferences to a wider community. If this happens, the participants will only be referred to their allocated pseudonym.
We will supply all participants who would like with a copy of the findings. If you are interested in receiving a copy, you can let us know by writing down your email or postal address on the paper which you will be asked to fill your demographic data.

Who is organising and funding this study?

The study is organised and sponsored by University of Southampton and funded by Kuwait Cultural Office.

Who has reviewed the study?

This study has been reviewed by the Ethics and Research Governance committee of the Faculty of Health Sciences at University of Southampton (ERGO number: 27832) and it was also reviewed by the Black Country Research Ethics Committee (REC no: 18/WM/0127) and other appropriate ethical research committees.

What happens if something goes wrong?

If you have any concern or complaint about this study or the research team, you can contact:

- the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk). If you remain unhappy and wish to complain formally, the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.
- the Patient Advice and Liaisons Service. (Address: Patient support services, C level, Centre Block, Southampton General Hospital; Email: patientsupportservices@uhs.nhs.uk or contact them by phone: 023 8120 6325).

Thank you for considering your involvement in this study

Further information and contact details

Zainab Jasem	**Dr Duncan Randall**
PhD student, University of Southampton	Principal Teaching Fellow, RGN, RSCN, RHV
Email: z.a.jasem@soton.ac.uk	Email: D.C.Randall@soton.ac.uk
Tel: +44(0)2380594254	Tel: +44(0)23 8059 7960

H.5 Legal guardian information sheet, Q methodology (Arabic version)

UNIVERSITY OF Southampton

إرشادات المشاركة (ولي أمر الطفل المشارك)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

عزيزي المشارك..
يرجى قراءة هذه الإرشادات قبل الإدلاء بالموافقة على مشاركة طفلكم في هذا البحث، و يرحب الباحث بالإجابة على جميع التساؤلات من خلال التواصل عبر الهاتف أو البريد الإلكتروني الموضح أدناه.

ماهو الهدف من هذا البحث؟
بينت الدراسات أن مشاركة الأطفال في اللعب لها فوائد إيجابية متعددة تنعكس على حياتهم و صحتهم، لذا نسعى من خلال هذا البحث إلى فهم العوامل التي تؤثر على مشاركتهم في اللعب من خلال دراسة العوامل التي تؤثر -سلبا أو إيجابا- على الأطفال ذوي الرعاية الخاصة من المشاركة باللعب لتوفير بيئة لعب تناسب احتياجاتهم خلال فترة وجودهم في المراكز العلاجية المتخصصة.

لماذا تم اختيار طفلي للمشاركة في هذا البحث؟
تمت دعوة طفلك للمشاركة في هذا البحث لأن عمره يتراوح ما بين 5 إلى 11 سنة و هو يتلقى الرعاية من أحد المراكز العلاجية المتخصصة.

ماذا سيترتب على مشاركة طفلي في البحث؟
في حالة موافقتك على مشاركة طفلك في البحث سيطلب منك تعبئة نموذج اقرار مستنير و كذلك من طفلك (إن أحب ذلك)، و من ثم فرز "بطاقات كيو". كل بطاقة من بطاقات كيو تمثل واحدة من العوامل التي من الممكن أن يكون لها تأثير على لعب طفلك اليومي خلال فترة وجوده في المشفى. سيطلب الباحث من طفلك فرز و ترتيب هذه البطاقات حسب أهميتها بالنسبة له، بالإضافة إلى أن الباحث سيقوم بتسجيل صوتي للطفل أثناء ترتيب هذه البطاقات و لن يحتوي ذلك على أي معلومات تتعلق بشخصية المشارك، و ذلك لن يستغرق أكثر من 30 دقيقة.

ماهي فائدة المشاركة في هذا البحث؟
على الرغم من عدم وجود فوائد مباشرة في حال مشاركة طفلك، إلا أن مشاركته مهمة جدا و ستساهم في دعم البحث العلمي في فهم احتياجات الأطفال مما سيكون له أثر ايجابي في تحسين بيئة المشفى للأطفال الذين يعانون من نفس التحديات الذي يعاني منها طفلك.

ماهي النتائج السلبية المترتبة على مشاركة طفلي؟
لا توجد أي تكاليف أو خطورة جراء المشاركة، كما أن البحث لا يتضمن أية أدوية أو فحوصات.
إذا لاحظ الباحث خلال البحث وجود أي مؤشر يمكن أن يكون له أي خطورة على طفلك ، سيوضحه لك.

كيف ستراعى سرية المعلومات؟
ستحفظ جميع المعلومات بسرية تامة لدى الباحث شخصيا و لا يصلها غيره في ملفات مغلقة لضمان الخصوصية، و لن يتم تداولها خارج إطار البحث.

ماذا علينا أن نفعل في حال موافقتنا على المشاركة ؟
إن أحببتم المشاركة في هذا البحث فيمكنكم ابلاغ الممرض المسؤول عن طفلك و هو بدوره سيعلمنا أو التواصل مباشرة مع الباحث عن طريق الهاتف(+965 9927 2248) أو البريد الإلكتروني(z.a.jasem@soton.ac.uk) .

هل تجب على طفلي المشاركة؟
مشاركة طفلك إختيارية و ليست إجبارية، و له الحرية بالانسحاب في أي وقت دون الحاجة إلى بيان الأسباب، و لن يؤثر ذلك على الرعاية الصحية التي يتلقاها.

ماذا عن نتائج البحث؟
سيقوم الباحث بجمع و تحليل البيانات لكتابة أطروحة الدكتوراه حيث أن هذا البحث متطلب للحصول على هذه الدرجة. و من المحتمل أن ينشر البحث في إحدى المجلات العلمية مع مراعاة عدم وجود أي معلومات تتعلق بشخصية المشارك.
إذا كنتم تودون معرفة النتائج و الإطلاع عليها، فيرجى إبلاغ الباحث حتى يستطيع التواصل معكم بعد تحليل النتائج.

[13/12/2017] [V2.0][Qmethodology][information sheet: legal guardian][ERGO no: 27832]

UNIVERSITY OF
Southampton

ماذا إن حدثت أية مشكلة خلال مشاركة طفلي في البحث؟
إذا طرأت أي مشكلة فيمكنكم التواصل مع الباحث أو الممرض المسؤول و سيقومون بحل المشكلة.
إن شعر طفلك ببعض الضيق تلو مشاركته، يمكنكم الاتصال على مركز الإنماء الاجتماعي و هم مستعدون لتوفير الإستشارة.
بإمكانكم التواصل معهم على الهاتف (+965 22402409 / +965 22402407) أو البريد الالكتروني
(contact@sdo.gov.kw) أو زيارة مركزهم الكائن في منطقة المرقاب في مدينة الكويت.

تم الحصول على موافقة إجراء هذا البحث من قبل جامعة ساوثهامبتون في المملكة المتحدة و اللجنة الدائمة لتنسيق البحوث الطبية و الصحية في وزارة الصحة في دولة الكويت.

لمزيد من المعلومات و التواصل:

زينب عبدالعزيز جاسم (الباحث)
طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: z.a.jasem@soton.ac.uk
رقم الهاتف: +965 9927 2248

د. دنكان راندال (باحث مشرف)
أستاذ في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: D.C.Randall@soton.ac.uk
رقم الهاتف: +44(0)23 8059 7960

H.6 Caregiver information sheet, Q methodology (English version)

UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Participant Information Sheet (Caregiver)

Study Title: Play environments for children living with serious and complex health problems
Researcher: Zainab Jasem

Your are being invited to take part in a research study. Before you decide, whether or not to take part, we would like you to understand why the study is being done and what it will involve. Please take time to read this information carefully to make your decision.

What is the research about?
Because play has many positive influence on the lives of children, increasing their participation in play is very important for children to live their childhood. The purpose of this study is to understand the different factors that influence children's play while receiving care in various health settings.

Who can take part?
We are asking caregivers of children who are between 5-11 years old receiving inpatient healthcare service.

What will happen if I agree to take part?
If you agree to participate in this study, you will be asked to sign a consent form and to participate in Q sorting activity. You will be given some cards which include statements related to your child's everyday play. You need to arrange the cards in order of importance to your child's play. This should take less than 60 minutes to complete. With your permission, the researcher will audio-recorded your discussion during the arrangements of the cards.

Do I have to take part?
Your participation is entirely voluntary. If you choose not to take part, this will not affect your child care or treatment.
You can also withdraw at any time without the need to give any reason. If we have already collected data, and you decide to withdraw the data we will ask if you would like us to securely destroy the information.

Will my participation be confidential?
Yes, all the information will be kept strictly confidential following the current data protection legislation.
Data in a paper version will be stored in a locked cabinet, in a locked room at the University of Southampton and the digitalised format will be labelled and password protected including the audio-records. Only the primary researcher and her supervisors for the project will have access to the research information. The audio-recorded conversation will be transcribed by the researcher following your participation and any identifiable details (e.g. your child's name) will be masked.

[11/5/2018][V 3][Q methodology][information sheet: caregiver]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

Each participant will be given an individual code and a pseudonym, so your actual name will not be attached to the information collected about you. Thus, information will be anonymised and will not be recognisable to anyone outside of the study.

The identifiable data will be retained until 2020 to produce the thesis and the anonymised data will be retained for 10 years following completion of the study. Then they will be securely destroyed.

What are the benefits of taking part?

We cannot promise that this study will have direct benefits for your child. It is hoped that the information will help us to understand what is important to the play of children living with serious and complex health problems. This is important to inform services supporting the play needs of children.

Are there any risks involved?

We appreciate that talking about your child's play for some people can be uncomfortable. Please do let us know if you feel uncomfortable.

If an issue has raised about your child's condition following your participation in this study, Sue Wilkins is happy to offer support either by phone (01962760555) or email (sue.wilkins@naomihouse.org.uk).

If we find something that may affect your child's health during the study, we will immediately discuss this with you. But we may discuss your child's care with others to make sure your child and other children are safe.

What should I do if I want to take part?

If you are interested in taking part in the study you can either:

- Discuss with staff looking after your child, who can contact me
- Or email the researcher on z.a.jasem@soton.ac.uk
- Or telephone the researcher on +44(0)2380594254

What will happen to the results of the research?

This research project is being conducted in part fulfilment of the award of Doctorate of Philosophy (PhD) programme at the Faculty of Health Sciences at the University of Southampton. Thus, when the study is completed, it will be written up to produce a thesis demonstrating the findings and will be submitted to the University of Southampton.

The study findings are also likely to be published in a scientific journal and presented at scientific conferences to a wider community. If this happens, the participants will only be referred to their allocated pseudonym.

We will supply all participants who would like with a copy of the findings. If you are interested in receiving a copy, you can let us know by writing down your email or postal address on the paper which you will be asked to fill your demographic data.

Who is organising and funding this study?
The study is organised and sponsored by University of Southampton and funded by Kuwait Cultural Office.

Who has reviewed the study?
This study has been reviewed by the Ethics and Research Governance committee of the Faculty of Health Sciences at University of Southampton (ERGO number: 27832) and it was also reviewed by the Black Country Research Ethics Committee (REC no: 18/WM/0127) and other appropriate ethical research committees.

What happens if something goes wrong?
If you have any concern or complaint about this study or the research team, you can contact:

- the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk). If you remain unhappy and wish to complain formally, the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.
- the Patient Advice and Liaisons Service. (Address: Patient support services, C level, Centre Block, Southampton General Hospital; Email: patientsupportservices@uhs.nhs.uk or contact them by phone: 023 8120 6325).

Thank you for considering your involvement in this study

Further information and contact details

Zainab Jasem
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Email: z.a.jasem@soton.ac.uk
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H.7 Caregiver information sheet, Q methodology (Arabic version)

UNIVERSITY OF Southampton

إرشادات المشاركة (رعاة الأطفال/ الحاضنين)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة
اسم الباحث: زينب جاسم

عزيزي المشارك..
يرجى قراءة هذه الإرشادات قبل الإدلاء بالموافقة على مشاركة طفلكم في هذا البحث، و يرحب الباحث بالإجابة على جميع التساؤلات من خلال التواصل عبر الهاتف أو البريد الإلكتروني الموضح أدناه.

ماهو الهدف من هذا البحث؟
بينت الدراسات أن مشاركة الأطفال في اللعب لها فوائد إيجابية متعددة تنعكس على حياتهم و صحتهم، لذا نسعى من خلال هذا البحث إلى فهم العوامل التي تؤثر على مشاركتهم في اللعب من خلال دراسة العوامل التي تؤثر -سلبا أو إيجابا- على الأطفال ذوي الرعاية الخاصة من المشاركة باللعب لتوفير بيئة لعب تناسب احتياجاتهم خلال فترة وجودهم في المراكز العلاجية المتخصصة.

لماذا تم اختياري للمشاركة في هذا البحث؟
تمت دعوتك للمشاركة في هذا البحث لرعايتك لطفل يتراوح عمره ما بين 5 إلى 11 سنة هو يتلقى الرعاية من أحد المراكز العلاجية المتخصصة.

ماذا سيترتب على موافقتي بالمشاركة؟
في حالة موافقتك على المشاركة.. سيطلب منك تعبئة نموذج اقرار مستنير بموافقتك على المشاركة، و من ثم فرز "بطاقات كيو". كل بطاقة من بطاقات كيو تمثل واحدة من العوامل التي من الممكن أن يكون لها تأثير على لعب طفلك اليومي خلال فترة وجوده في المشفى. سيتطلب منك ذلك فرز و ترتيب هذه البطاقات حسب أهميتها، بالإضافة إلى أن الباحث سيقوم بتسجيل صوتي لحديثكم أثناء ترتيب هذه البطاقات و لن يحتوي ذلك على أي معلومات تتعلق بشخصية المشارك، و ذلك لن يستغرق أكثر من ساعة 60 دقيقة من وقتك.

ماهي فائدة المشاركة في هذا البحث؟
على الرغم من عدم وجود فوائد مباشرة في حال مشاركتك، لكن مشاركتكم مهمة جدا و ستساهم في دعم البحث العلمي مما سيكون له أثر ايجابي في تحسين بيئة المشفى للأطفال الذين يعانون من نفس التحديات التي يعاني منها طفلك.

ماهي النتائج السلبية المترتبة على مشاركتي؟
لا توجد أي تكاليف أو خطورة جراء المشاركة، كما أن البحث لا يتضمن أي أدوية أو فحوصات.
إذا لاحظ الباحث خلال البحث وجود أي مؤشر يمكن أن يكون له أي خطورة على طفلك ، سيوضحه لك.

كيف ستراعى سرية المعلومات؟
ستحفظ جميع المعلومات بسرية تامة لدى الباحث شخصيا و لا يصلها غيره في ملفات مغلقة لضمان الخصوصية، و لن يتم تداولها خارج إطار البحث.

ماذا علي أن أفعل إن أردت المشاركة ؟
إن أحببت المشاركة في هذا البحث فيمكنك ابلاغ الممرض المسؤول عن طفلك و هو بدوره سيعلمنا أو التواصل مباشرة مع الباحث عن طريق الهاتف(+965 9927 2248) أو البريد الإلكتروني(z.a.jasem@soton.ac.uk).

هل تجب علي المشاركة؟
مشاركتك اختيارية و ليست اجبارية، و لك الحرية بالانسحاب في أي وقت دون الحاجة إلى بيان الأسباب، و لن يؤثر ذلك على الرعاية الصحية التي يتلقاها طفلك.

ماذا عن نتائج البحث؟
سيقوم الباحث بجمع و تحليل البيانات لكتابة أطروحة الدكتوراه حيث أن هذا البحث متطلب للحصول على هذه الدرجة. و من المحتمل أن ينشر البحث في إحدى المجلات العلمية مع مراعاة عدم وجود أي معلومات تتعلق بشخصية المشارك.
إذا كنت تود معرفة النتائج و الإطلاع عليها، فيرجى إبلاغ الباحث حتى يستطيع التواصل معك بعد تحليل النتائج.

[13/12/2017] [V 2.0][Q methodology][information sheet: caregiver] [ERGO no: 27832]

ماذا إن حدثت أية مشكلة خلال مشاركتي في البحث؟
إذا طرأت أي مشكلة فيمكنك التواصل مع الباحث أو الممرض المسؤول و سيقومون بحل المشكلة.
إن شعرت ببعض الضيق تلو مشاركتك، يمكنك الاتصال على مركز الإنماء الاجتماعي و هم مستعدون لتوفير الإستشارة. يمكنك التواصل معهم على الهاتف (+965 22402409 /+965 22402407) أو البريد الالكتروني (contact@sdo.gov.kw) أو زيارة مركزهم الكائن في منطقة المرقاب في مدينة الكويت.

تم الحصول على موافقة إجراء هذا البحث من قبل جامعة ساوثهامبتون في المملكة المتحدة و اللجنة الدائمة لتنسيق البحوث الطبية و الصحية من وزارة الصحة في دولة الكويت.

لمزيد من المعلومات و التواصل:

زينب عبدالعزيز جاسم (الباحث)
طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: z.a.jasem@soton.ac.uk
رقم الهاتف: +965 9927 2248

د. دنكان راندال (باحث مشرف)
أستاذ في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: D.C.Randall@soton.ac.uk
رقم الهاتف: +44(0)23 8059 7960

H.8 Children information sheet, Observation (English version), for 5-7 ages

UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

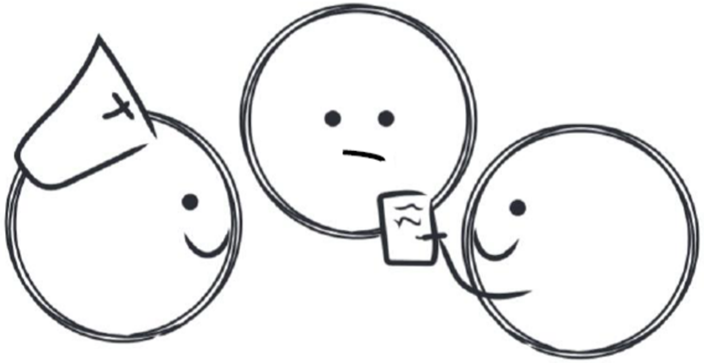
Information Sheet for Children

Study Title: Play environments for children living with serious and complex health problems

Tala loves playing

I'm Tala. Colour me in!

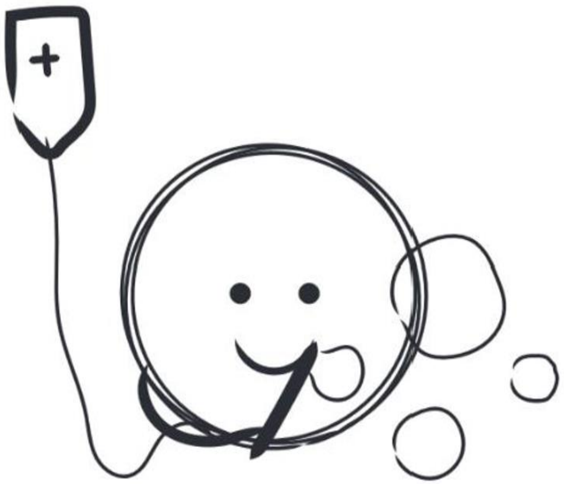
If there is anything upsetting me, I can tell Zainab or my carer



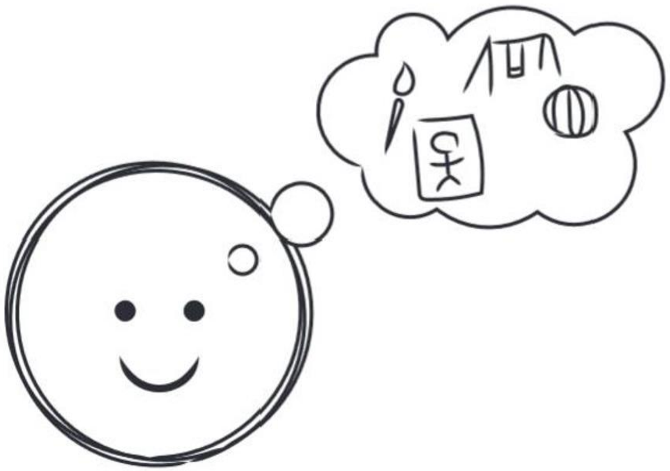
If I have any question, I can call or email the researcher Zainab on
E-mail:
z.a.jasem@soton.ac.uk
Phone:
+44(0)2380594254

Thank You

I like to play



Zainab will write about how we play, so we can tell everyone what we need to enjoy play



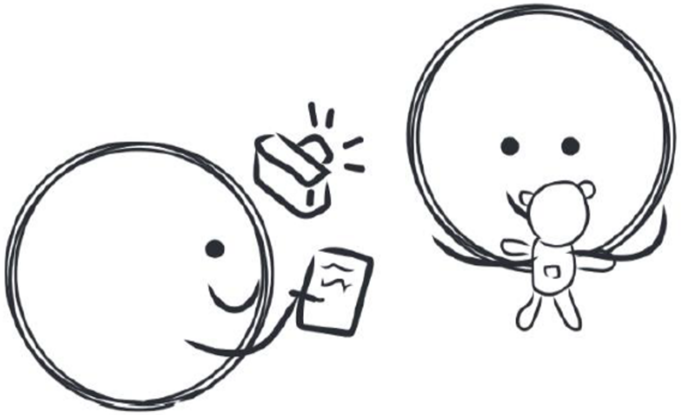
Sometimes it can feel funny having someone watching you

But if I feel uncomfortable, I'll use the stop sign and Zainab will stop

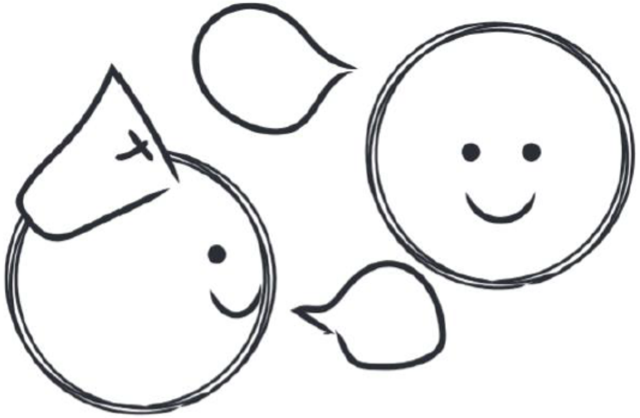
Zainab (the researcher) wants to know how I spend my time while in the hospital

She will spend 1 hour with me today and another 1 hour tomorrow

Zainab is writing some notes and may take some photos



The doctor/nurse looking after me will know I'm taking part



I can also tell anyone I want

H.9 Children information sheet, Observation (English version), for 8-11 ages

University of Southampton

University Hospital Southampton NHS Foundation Trust

NHS

Information Sheet for Children

Study Title: Play environments for children living with serious and complex health problems

Would you like to take part in our study?

It is about your play

Before deciding, we will look at this information sheet with you and you can ask anything you like.

Why are we doing this research?

We know play is important to children and that it can be difficult to play in some places, or if you feel unwell. We want to know more about how children play when they are in a hospital or being cared for by doctors and nurses.

What happens when the study stops?

We will write about what we did in this study and share that with other people using your research name so no one will know that you took part. We will also write a summary of the results for you to read if you would like.

What if there is a problem?

If you are unhappy about anything we do or say please, tell your carer. They have been told who to contact.

If you want to ask any questions about the study or need more information, please call or email the primary researcher, Zainab Jasem

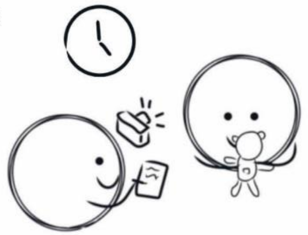
E-mail: z.a.jasem@soton.ac.uk
Phone: +44(0)2380594254

Thank you

Why me?

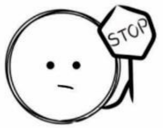
We have been invited to take part because you are being looked after by doctors and nurses here in the hospital. We're interested in hearing about what are the important things for you to be able to play while being in the hospital.

What will happen if I take part?



1. We will ask you and your mum, dad or carer to write your names on a form to say you would like to take part.
2. There is nothing special you need to do. Zainab (the researcher) will be watching you for about 1 hour on 2 days. She may also take some photo if you are happy to.

Do I have to take part?



No, you don't. Talk to your mum, dad or carer before you decide. You can always change your mind.

If you do not want to take part, just say no. You will still have the same care as usual at the hospital.

What is good about taking part in the study?

Taking part will really help us to learn more about how children play when they are in the hospital, so we can tell everyone what you and other children need to enjoy play.

Will anything about the research upset me?

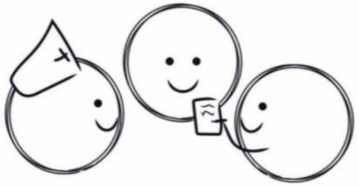
This study has been checked to make sure you will be safe. Sometimes it can feel funny having someone watching you but we hope that you will not notice Zainab after a few moments.

What do I do if I don't want to take part in the study anymore?

Just tell the researcher or your carer that you'd like to stop. You can stop using your stop and go sign. You can still stop any time, even if we have started the study.

Will other people know I am doing this study?

The doctor/nurse looking after you will know you are taking part. You can tell anyone you want. Nobody else will know, unless there are something we are worried about your safety or the safety of another child, so that we can help.



Will anyone know what I have did in the study?

We will not tell anyone what we have seen in the study. We will store all your information privately.

H.10 Children information sheet, Observation (Arabic version)

UNIVERSITY OF Southampton

إرشادات المشاركة (للأطفال)

عنوان البحث: بيئة اللعب المناسبة لاحتياجات الأطفال المصابين بأمراض مزمنة
اسم الباحث: زينب جاسم

هل تود المشاركة في هذا البحث؟
يتعلق البحث بلعب الأطفال.. قبل إدلائكم بالموافقة على المشاركة، يرجى منكم فهم هذه الإرشادات المكتوبة. كما أن الباحث يرحب بالإجابة على جميع تساؤلاتكم.

ماهو الهدف من إجراء هذا البحث؟
من خلال هذا البحث نود التعرف أكثر على طبيعة اللعب عند الأطفال خلال فترة وجودهم في المشفى، حيث أنه من الممكن وجود بعض المعوقات التي تحد إمكانية مشاركتهم في اللعب كبقية الأطفال.

لماذا تم اختياري؟
لأن عمرك يتراوح مابين 5 إلى 11 سنة وترقد حاليا في هذا المشفى.

ماذا يجب علي أن أفعل؟
لا شيء.. سيقوم الباحث ببساطة بمشاهدتك لفهم كيفية قضائك لوقتك خلال فترة وجودك في المشفى على مدار ساعة خلال يومين.
إن كنت لا تمانع، سيقوم الباحث بالتقاط بعض الصور خلال ذلك الوقت بينما تلعب.

هل تجب علي المشاركة؟
لا، فمشاركتك اختيارية و ليست اجبارية، و يمكنك الوقف عن المشاركة في متى ما أردت دون الحاجة لشرح الأسباب.

هل هناك ما يمكنه أن يضايقني إن شاركت؟
لا.. و لكن إن شعرت بأي ضيق فنحن مستعدون لسماعك و فهم ما يزعجك، كما أنه يمكنك كما ذكرنا التوقف عن المشاركة في أي وقت.

هل هناك أي فائدة من مشاركتي؟
نتطلع من خلال مشاهدتك على فهم احتياجات الأطفال و إخبار المختصين برعاية الأطفال بما يحتاجونه ليستمتعوا بوقتهم أكثر.

من الذي يقوم بعمل هذا البحث؟
زينب طالبة دكتوراه في جامعة ساوثهامبتون في بريطانيا و هي من يقوم بهذا البحث.

من سيكون لديه علم بمشاركتي؟
الممرض/الطبيب المشرف على حالتك. يمكنك إخبار من تود و لكن زينب لن تخبر أحدا إلا بموافتك.

ماذا سيحدث بعد الانتهاء من البحث؟
سيقوم الباحث بكتابة النتائج و من المحتمل نشرها و مناقشتها مع الأشخاص المختصين بتوفير الرعاية للأطفال و لكننا حريصون على مراعاة عدم ذكر أي معلومات تتعلق بشخصيتكم مباشرة.

قام مجموعة من المختصون بمراجعة البحث للتأكد من أنه لا يوجد أي خطورة على الأطفال الذين يودون المشاركة في هذا البحث.

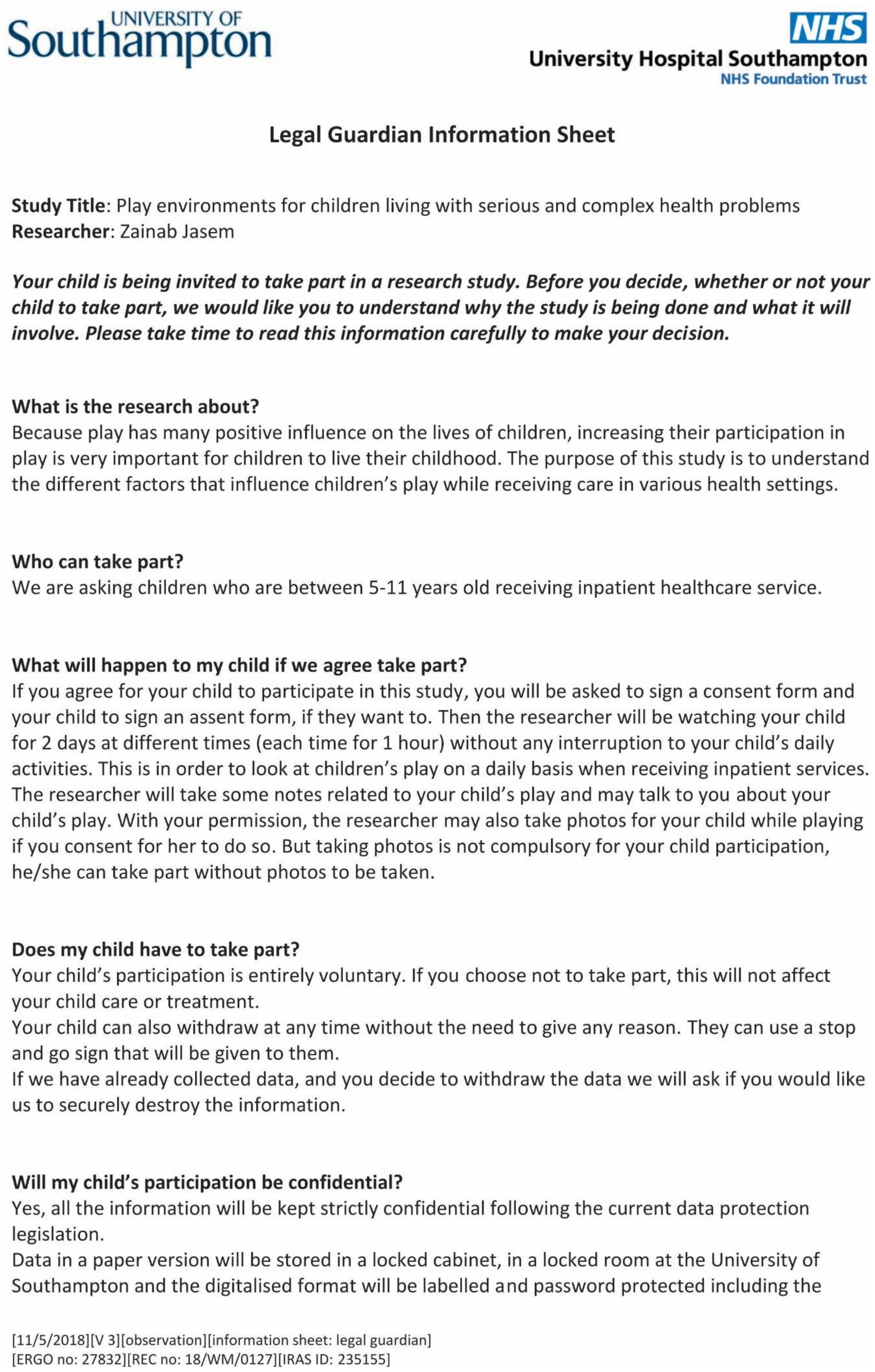
لمزيد من المعلومات و التواصل:

زينب عبدالعزيز جاسم (الباحث)
طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: z.a.jasem@soton.ac.uk
رقم الهاتف: +965 9927 2248

د. دنكان راندال (باحث مشرف)
أستاذ في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: D.C.Randall@soton.ac.uk
رقم الهاتف: +44(0)23 8059 7960

[13/12/2017] [V 2.0][observation][information sheet: child] [ERGO no: 27832]

H.11 Legal guardian information sheet, Observation (English version)



UNIVERSITY OF
Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Legal Guardian Information Sheet

Study Title: Play environments for children living with serious and complex health problems
Researcher: Zainab Jasem

Your child is being invited to take part in a research study. Before you decide, whether or not your child to take part, we would like you to understand why the study is being done and what it will involve. Please take time to read this information carefully to make your decision.

What is the research about?

Because play has many positive influence on the lives of children, increasing their participation in play is very important for children to live their childhood. The purpose of this study is to understand the different factors that influence children's play while receiving care in various health settings.

Who can take part?

We are asking children who are between 5-11 years old receiving inpatient healthcare service.

What will happen to my child if we agree take part?

If you agree for your child to participate in this study, you will be asked to sign a consent form and your child to sign an assent form, if they want to. Then the researcher will be watching your child for 2 days at different times (each time for 1 hour) without any interruption to your child's daily activities. This is in order to look at children's play on a daily basis when receiving inpatient services. The researcher will take some notes related to your child's play and may talk to you about your child's play. With your permission, the researcher may also take photos for your child while playing if you consent for her to do so. But taking photos is not compulsory for your child participation, he/she can take part without photos to be taken.

Does my child have to take part?

Your child's participation is entirely voluntary. If you choose not to take part, this will not affect your child care or treatment.

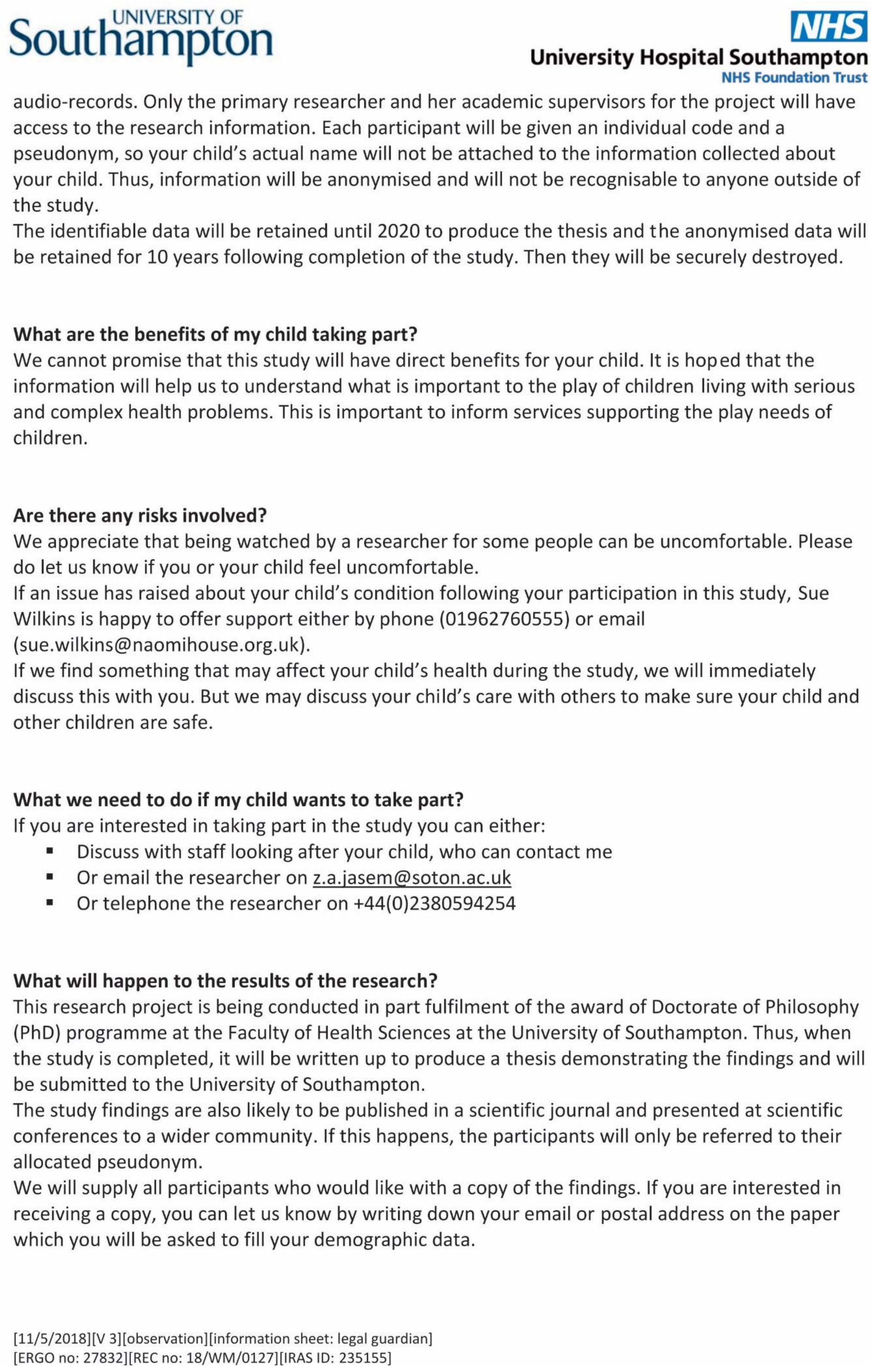
Your child can also withdraw at any time without the need to give any reason. They can use a stop and go sign that will be given to them.

If we have already collected data, and you decide to withdraw the data we will ask if you would like us to securely destroy the information.

Will my child's participation be confidential?

Yes, all the information will be kept strictly confidential following the current data protection legislation.

Data in a paper version will be stored in a locked cabinet, in a locked room at the University of Southampton and the digitalised format will be labelled and password protected including the



audio-records. Only the primary researcher and her academic supervisors for the project will have access to the research information. Each participant will be given an individual code and a pseudonym, so your child's actual name will not be attached to the information collected about your child. Thus, information will be anonymised and will not be recognisable to anyone outside of the study.

The identifiable data will be retained until 2020 to produce the thesis and the anonymised data will be retained for 10 years following completion of the study. Then they will be securely destroyed.

What are the benefits of my child taking part?

We cannot promise that this study will have direct benefits for your child. It is hoped that the information will help us to understand what is important to the play of children living with serious and complex health problems. This is important to inform services supporting the play needs of children.

Are there any risks involved?

We appreciate that being watched by a researcher for some people can be uncomfortable. Please do let us know if you or your child feel uncomfortable.

If an issue has raised about your child's condition following your participation in this study, Sue Wilkins is happy to offer support either by phone (01962760555) or email (sue.wilkins@naomihouse.org.uk).

If we find something that may affect your child's health during the study, we will immediately discuss this with you. But we may discuss your child's care with others to make sure your child and other children are safe.

What we need to do if my child wants to take part?

If you are interested in taking part in the study you can either:

- Discuss with staff looking after your child, who can contact me
- Or email the researcher on z.a.jasem@soton.ac.uk
- Or telephone the researcher on +44(0)2380594254

What will happen to the results of the research?

This research project is being conducted in part fulfilment of the award of Doctorate of Philosophy (PhD) programme at the Faculty of Health Sciences at the University of Southampton. Thus, when the study is completed, it will be written up to produce a thesis demonstrating the findings and will be submitted to the University of Southampton.

The study findings are also likely to be published in a scientific journal and presented at scientific conferences to a wider community. If this happens, the participants will only be referred to their allocated pseudonym.

We will supply all participants who would like with a copy of the findings. If you are interested in receiving a copy, you can let us know by writing down your email or postal address on the paper which you will be asked to fill your demographic data.

Who is organising and funding this study?

The study is organised and sponsored by University of Southampton and funded by Kuwait Cultural Office.

Who has reviewed the study?

This study has been reviewed by the Ethics and Research Governance committee of the Faculty of Health Sciences at University of Southampton (ERGO number: 27832) and it was also reviewed by the Black Country Research Ethics Committee (REC no: 18/WM/0127) and other appropriate ethical research committees.

What happens if something goes wrong?

If you have any concern or complaint about this study or the research team, you can contact:

- the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk). If you remain unhappy and wish to complain formally, the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.
- the Patient Advice and Liaisons Service. (Address: Patient support services, C level, Centre Block, Southampton General Hospital; Email: patientsupportservices@uhs.nhs.uk or contact them by phone: 023 8120 6325).

Thank you for considering your involvement in this study

Further information and contact details

Zainab Jasem
PhD student, University of Southampton
Email: z.a.jasem@soton.ac.uk
Tel: +44(0)2380594254

Dr Duncan Randall
Principal Teaching Fellow, RGN, RSCN, RHV
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H.12 Legal guardian information sheet, Observation (Arabic version)

UNIVERSITY OF Southampton

إرشادات المشاركة (ولي أمر الطفل المشارك)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة
اسم الباحث: زينب جاسم

عزيزي المشارك..
يرجى قراءة هذه الإرشادات قبل الإدلاء بالموافقة على مشاركة طفلكم في هذا البحث، و يرحب الباحث بالإجابة على جميع التساؤلات من خلال التواصل عبر الهاتف أو البريد الإلكتروني الموضح أدناه.

ماهو الهدف من هذا البحث؟
بينت الدراسات أن مشاركة الأطفال في اللعب لها فوائد إيجابية متعددة تنعكس على حياتهم و صحتهم، لذا نسعى من خلال هذا البحث إلى فهم العوامل التي تؤثر على مشاركتهم في اللعب من خلال دراسة العوامل التي تؤثر -سلبا أو إيجابا- على الأطفال ذوي الرعاية الخاصة من المشاركة باللعب لتوفير بيئة لعب تناسب احتياجاتهم خلال فترة وجودهم في المراكز العلاجية المتخصصة.

لماذا تم اختيار طفلي للمشاركة في هذا البحث؟
تمت دعوة طفلك للمشاركة في هذا البحث لأن عمره يتراوح ما بين 5 إلى 11 سنة و هو يتلقى الرعاية من أحد المراكز العلاجية المتخصصة.

ماذا سيترتب على مشاركة طفلي في البحث؟
في حالة موافقتك على مشاركة طفلك في البحث سيطلب منك تعبئة نموذج إقرار مستنير و كذلك من طفلك (إن أحب ذلك). لن يتطلب من طفلك القيام بأي عمل، سيقوم الباحث ببساطة بمشاهدة طفلك و متابعة الأنشطة المختلفة التي يقوم بها على مدار ساعة على يومين، و هذا من أجل فهم أعمق لاحتياجات الأطفال. سيقوم الباحث بأخذ بعض الملاحظات خلال مشاهدته لطفلك و بعض الصور (التقاط الصور ليس أمرا ملزما فهو مقرون بموافقتكم) المتعلقة بمشاركته باللعب.

ماهي فائدة المشاركة في هذا البحث؟
على الرغم من عدم وجود فوائد مباشرة في حال مشاركة طفلك، إلا أن مشاركته مهمة جدا و ستساهم في دعم البحث العلمي في فهم احتياجات الأطفال مما سيكون له أثر ايجابي في تحسين بيئة المشفى للأطفال الذين يعانون من نفس التحديات الذي يعاني منها طفلك.

ماهي النتائج السلبية المترتبة على مشاركة طفلي؟
لا توجد أي تكاليف أو خطورة جراء المشاركة، كما أن البحث لا يتضمن أية أدوية أو فحوصات.
إذا لاحظ الباحث خلال البحث وجود أي مؤشر يمكن أن يكون له أي خطورة على طفلك ، سيوضحه لك.

كيف ستراعى سرية المعلومات؟
ستحفظ جميع المعلومات بسرية تامة لدى الباحث شخصيا و لا يصلها غيره في ملفات مغلقة لضمان الخصوصية، و لن يتم تداولها خارج إطار البحث. في حالة استخدام الصور (مقرون بموافقتكم) فيمكنكم تحديد كيفية استخدامها عبر ملئ إقرار مستنير.

ماذا علينا أن نفعل في حال موافقتنا على المشاركة ؟
إن أحببتم المشاركة في هذا البحث فيمكنكم ابلاغ الممرض المسؤول عن طفلك و هو بدوره سيعلمنا أو التواصل مباشرة مع الباحث عن طريق الهاتف(+965 9927 2248) أو البريد الإلكتروني(z.a.jasem@soton.ac.uk) .

هل تجب على طفلي المشاركة؟
مشاركة طفلك إختيارية و ليست إجبارية، و له الحرية بالانسحاب في أي وقت دون الحاجة إلى بيان الأسباب، و لن يؤثر ذلك على الرعاية الصحية التي يتلقاها.

ماذا عن نتائج البحث؟
سيقوم الباحث بجمع و تحليل البيانات لكتابة أطروحة الدكتوراه؛ حيث أن هذا البحث متطلب للحصول على هذه الدرجة. و من المحتمل أن ينشر البحث في إحدى المجلات العلمية مع مراعاة عدم وجود أي معلومات تتعلق بشخصية المشارك.
إذا كنتم تودون معرفة النتائج و الإطلاع عليها فيرجى إبلاغ الباحث حتى يستطيع التواصل معكم بعد تحليل النتائج.

[13/12/2017] [V 2.0][observation][information sheet: legal guardian] [ERGO no: 27832]

ماذا إن حدثت أية مشكلة خلال مشاركة طفلي في البحث؟

إذا طرأت أي مشكلة فيمكنكم التواصل مع الباحث أو الممرض المسؤول و سيقومون بحل المشكلة.
إن شعر طفلك ببعض الضيق تلو مشاركته، يمكنكم الاتصال على مركز الإنماء الاجتماعي و هم مستعدون لتوفير الإستشارة.
بإمكانكم التواصل معهم على الهاتف (+965 22402409 / +965 22402407) أو البريد الالكتروني
(contact@sdo.gov.kw) أو زيارة مركزهم الكائن في منطقة المرقاب في مدينة الكويت.

تم الحصول على موافقة إجراء هذا البحث من قبل جامعة ساوثهامبتون في المملكة المتحدة و اللجنة الدائمة لتنسيق البحوث الطبية و الصحية في وزارة الصحة في دولة الكويت.

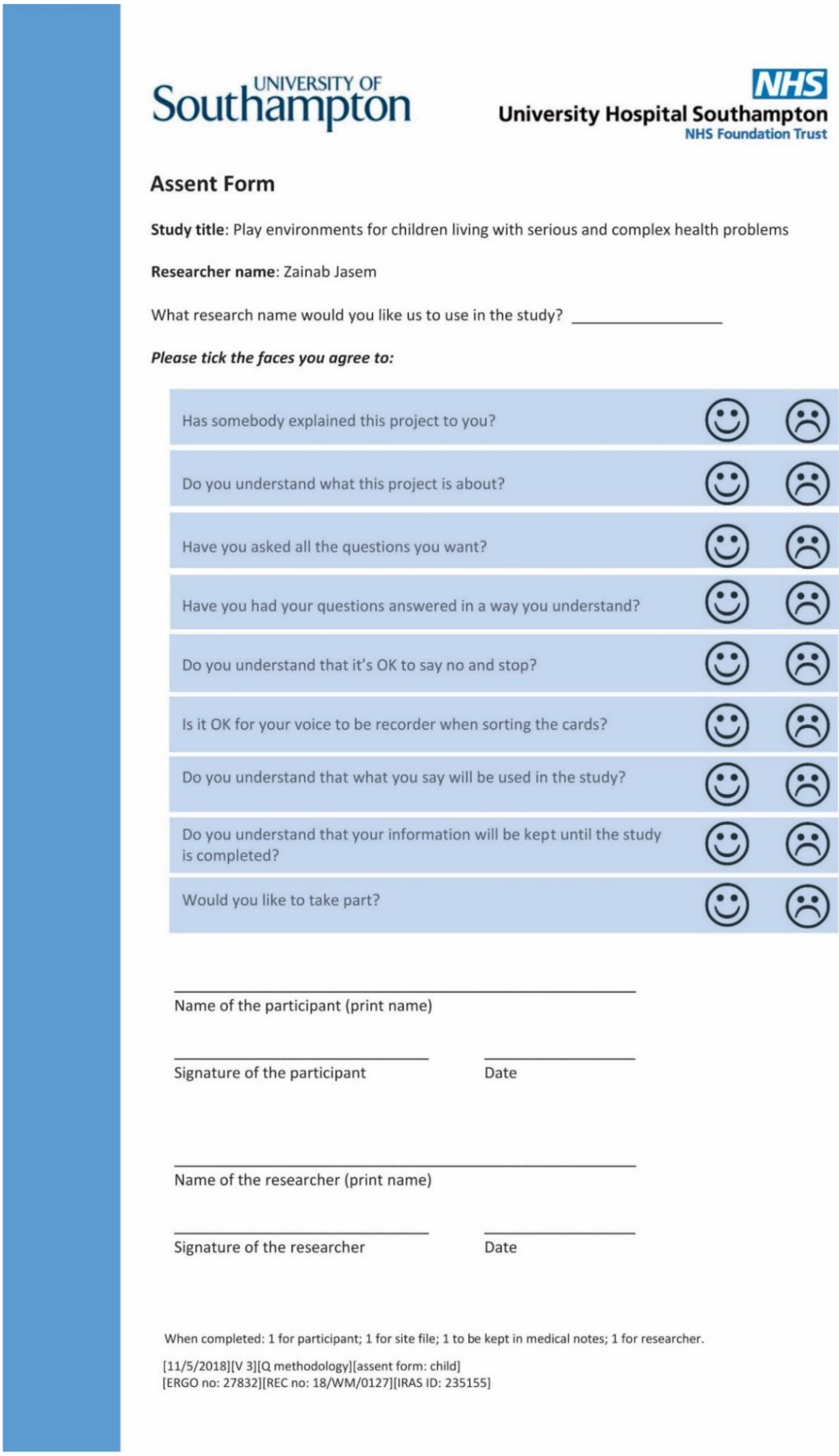
لمزيد من المعلومات و التواصل:

زينب عبدالعزيز جاسم (الباحث)
طالبة دكتوراه في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: z.a.jasem@soton.ac.uk
رقم الهاتف: 2248 9927 965+

د. دنكان راندال (باحث مشرف)
أستاذ في جامعة ساوثهامبتون (المملكة المتحدة)
ايميل: D.C.Randall@soton.ac.uk
رقم الهاتف: 7960 8059 23(0)44+

Appendix I Informed consent

I.1 Children’s Q methodology Assent form (English version)



UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Assent Form

Study title: Play environments for children living with serious and complex health problems

Researcher name: Zainab Jasem

What research name would you like us to use in the study? ________________

Please tick the faces you agree to:

Has somebody explained this project to you?	☺	☹
Do you understand what this project is about?	☺	☹
Have you asked all the questions you want?	☺	☹
Have you had your questions answered in a way you understand?	☺	☹
Do you understand that it’s OK to say no and stop?	☺	☹
Is it OK for your voice to be recorder when sorting the cards?	☺	☹
Do you understand that what you say will be used in the study?	☺	☹
Do you understand that your information will be kept until the study is completed?	☺	☹
Would you like to take part?	☺	☹

____
Name of the participant (print name)

______________________ ______________
Signature of the participant Date

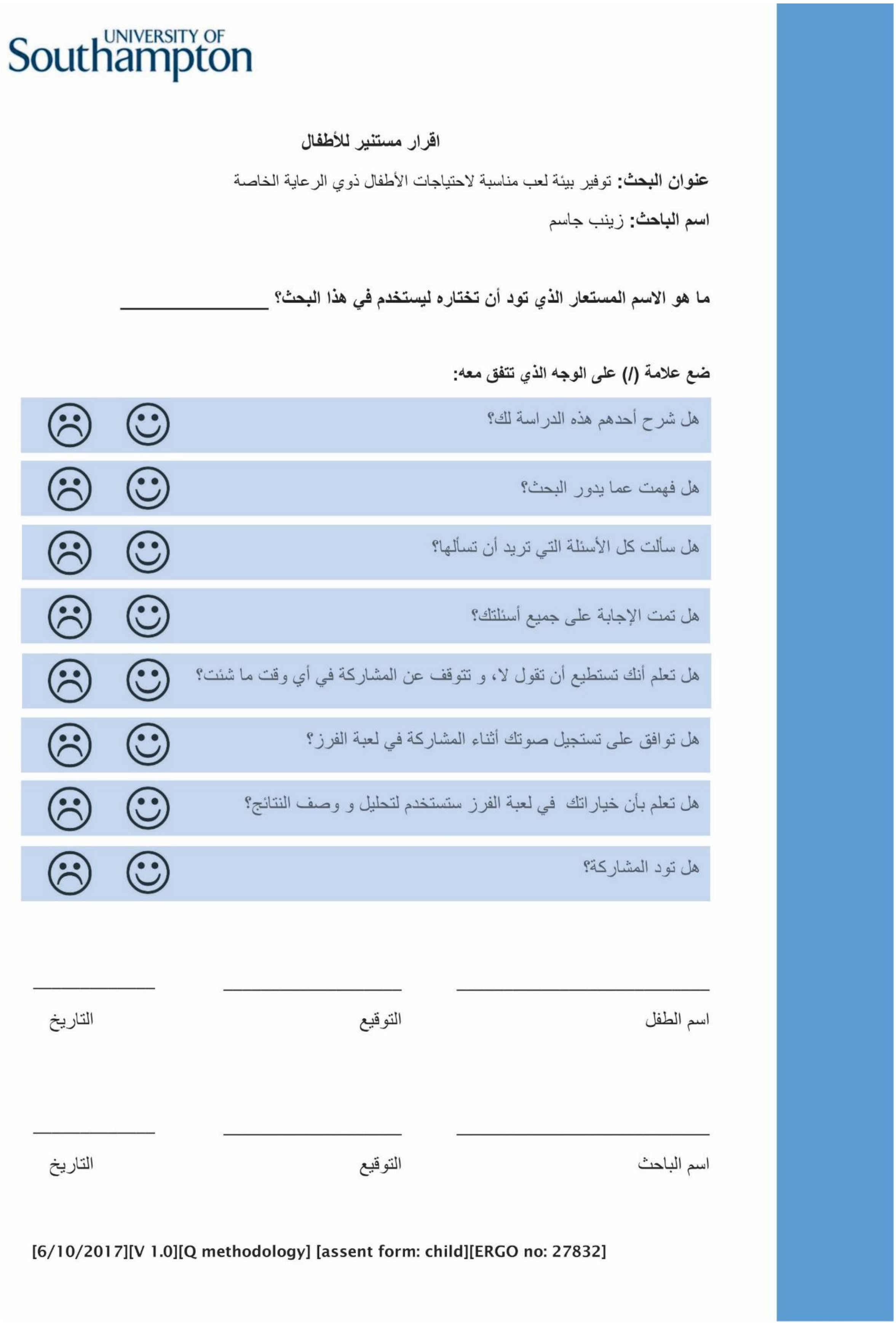
____
Name of the researcher (print name)

______________________ ______________
Signature of the researcher Date

When completed: 1 for participant; 1 for site file; 1 to be kept in medical notes; 1 for researcher.

[11/5/2018][V 3][Q methodology][assent form: child]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

I.2 Children’s Q methodology Assent form (Arabic version)



UNIVERSITY OF Southampton

اقرار مستنير للأطفال

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

ما هو الاسم المستعار الذي تود أن تختاره ليستخدم في هذا البحث؟ ________________

ضع علامة (/) على الوجه الذي تتفق معه:

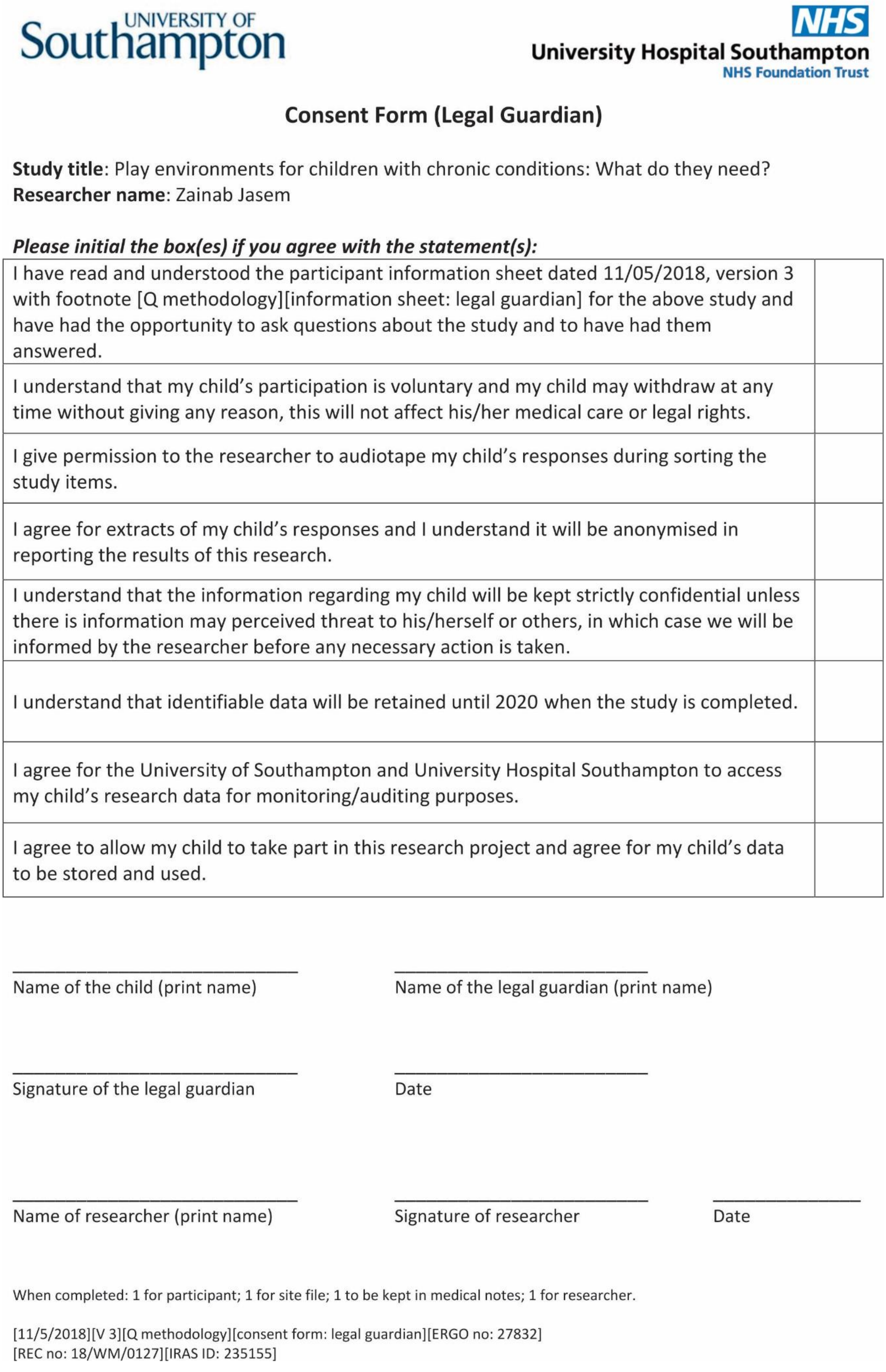
هل شرح أحدهم هذه الدراسة لك؟	☺	☹
هل فهمت عما يدور البحث؟	☺	☹
هل سألت كل الأسئلة التي تريد أن تسألها؟	☺	☹
هل تمت الإجابة على جميع أسئلتك؟	☺	☹
هل تعلم أنك تستطيع أن تقول لا، و تتوقف عن المشاركة في أي وقت ما شئت؟	☺	☹
هل توافق على تستجيل صوتك أثناء المشاركة في لعبة الفرز؟	☺	☹
هل تعلم بأن خياراتك في لعبة الفرز ستستخدم لتحليل و وصف النتائج؟	☺	☹
هل تود المشاركة؟	☺	☹

اسم الطفل ____________ التوقيع ____________ التاريخ ____________

اسم الباحث ____________ التوقيع ____________ التاريخ ____________

[6/10/2017][V 1.0][Q methodology] [assent form: child][ERGO no: 27832]

I.3 Legal guardian Q methodology consent form (English version)



UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Consent Form (Legal Guardian)

Study title: Play environments for children with chronic conditions: What do they need?
Researcher name: Zainab Jasem

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet dated 11/05/2018, version 3 with footnote [Q methodology][information sheet: legal guardian] for the above study and have had the opportunity to ask questions about the study and to have had them answered.	
I understand that my child's participation is voluntary and my child may withdraw at any time without giving any reason, this will not affect his/her medical care or legal rights.	
I give permission to the researcher to audiotape my child's responses during sorting the study items.	
I agree for extracts of my child's responses and I understand it will be anonymised in reporting the results of this research.	
I understand that the information regarding my child will be kept strictly confidential unless there is information may perceived threat to his/herself or others, in which case we will be informed by the researcher before any necessary action is taken.	
I understand that identifiable data will be retained until 2020 when the study is completed.	
I agree for the University of Southampton and University Hospital Southampton to access my child's research data for monitoring/auditing purposes.	
I agree to allow my child to take part in this research project and agree for my child's data to be stored and used.	

Name of the child (print name)

Name of the legal guardian (print name)

Signature of the legal guardian

Date

Name of researcher (print name)

Signature of researcher

Date

When completed: 1 for participant; 1 for site file; 1 to be kept in medical notes; 1 for researcher.

[11/5/2018][V 3][Q methodology][consent form: legal guardian][ERGO no: 27832]
[REC no: 18/WM/0127][IRAS ID: 235155]

I.4 Legal guardian Q methodology consent form (Arabic version)

UNIVERSITY OF Southampton

اقرار مستنير للبالغين كاملي الأهلية (ولي أمر الطفل المشارك)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

الرجاء وضع الحرف الأول من اسمك في المربعات المقابلة للجمل التي تتفق معها:

لقد قمت بقراءة و فهم إرشادات المشاركة المؤرخة ب6/10/2017 (نسخة 1) المذيلة بـ **[Q methodology][information sheet: legal guardian]** كما تمت الإجابة على جميع تساؤلاتي	
أعلم بأن مشاركة طفلي في هذا البحث اختيارية، و لنا الحرية بالانسحاب في أي وقت دون الحاجة إلى إدلاء الأسباب، و لن يترتب على ذلك أي ضرر على طفلي	
لا أمانع من التسجيل الصوتي لطفلي خلال مشاركته	
أنا على علم بأن المعلومات التي يتم جمعها من خلال مشاركة طفلي في هذه الدراسة سوف يتم تخزينها بسرية تامة.	
في حال ملاحظة الباحث وجود أي مؤشر يمكن أن يكون له أي خطورة على طفلي أو على الآخرين سيقوم الباحث بإخباري قبل المضي بأي خطوة	
أوافق على مشاركة طفلي في هذا البحث	

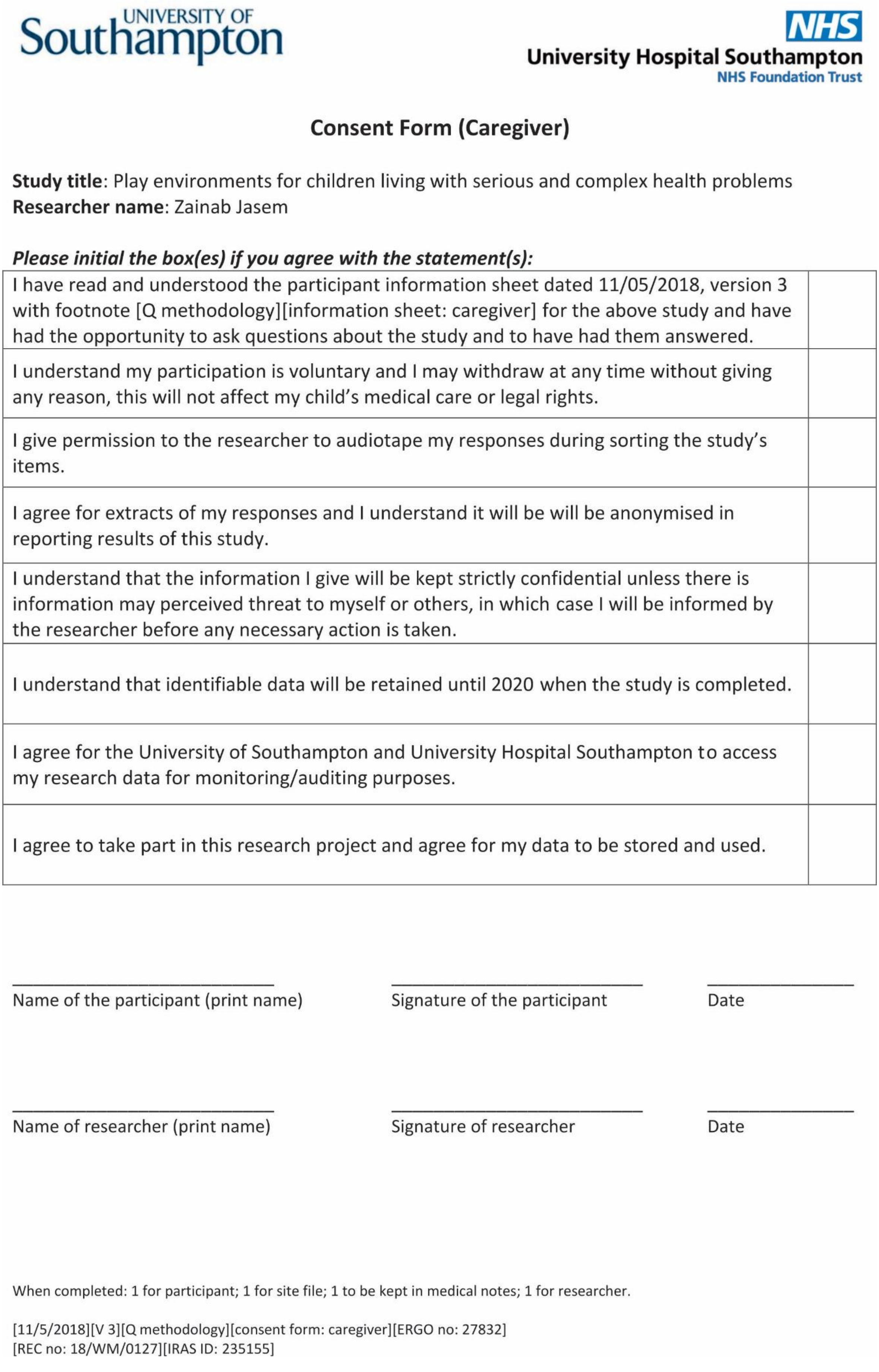
اسم الطفل ______________________________ اسم ولي أمر الطفل ______________________________

التوقيع ______________________________ التاريخ ______________________________

اسم الباحث ______________________________ التوقيع ____________________ التاريخ ______________

[6/10/2017][V 1.0][Q methodology] [consent form: legal guardian][ERGO no: 27832]

I.5 Caregivers’ Q methodology consent form (English version)



UNIVERSITY OF Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Consent Form (Caregiver)

Study title: Play environments for children living with serious and complex health problems
Researcher name: Zainab Jasem

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet dated 11/05/2018, version 3 with footnote [Q methodology][information sheet: caregiver] for the above study and have had the opportunity to ask questions about the study and to have had them answered.	
I understand my participation is voluntary and I may withdraw at any time without giving any reason, this will not affect my child’s medical care or legal rights.	
I give permission to the researcher to audiotape my responses during sorting the study’s items.	
I agree for extracts of my responses and I understand it will be will be anonymised in reporting results of this study.	
I understand that the information I give will be kept strictly confidential unless there is information may perceived threat to myself or others, in which case I will be informed by the researcher before any necessary action is taken.	
I understand that identifiable data will be retained until 2020 when the study is completed.	
I agree for the University of Southampton and University Hospital Southampton to access my research data for monitoring/auditing purposes.	
I agree to take part in this research project and agree for my data to be stored and used.	

____________________________ ___________________________ ________________
Name of the participant (print name) Signature of the participant Date

____________________________ ___________________________ ________________
Name of researcher (print name) Signature of researcher Date

When completed: 1 for participant; 1 for site file; 1 to be kept in medical notes; 1 for researcher.

[11/5/2018][V 3][Q methodology][consent form: caregiver][ERGO no: 27832]
[REC no: 18/WM/0127][IRAS ID: 235155]

I.6 Caregivers’ Q methodology consent form (Arabic version)

UNIVERSITY OF Southampton

اقرار مستنير للبالغين كاملي الأهلية (رعاة الأطفال/ الحاضنين)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

الرجاء وضع الحرف الأول من اسمك في المربعات المقابلة للجمل التي تتفق معها:

لقد قمت بقراءة و فهم إرشادات المشاركة المؤرخة ب6/10/2017 (نسخة 1) المذيلة بـ **[Q methodology][information sheet: caregiver]** كما تمت الإجابة على جميع تساؤلاتي.	
أعلم بأن مشاركتي بهذا البحث اختيارية، و لي الحرية بالانسحاب في أي وقت دون الحاجة إلى إدلاء الأسباب، و لن يترتب على ذلك أي ضرر علي أو على طفلي.	
لا أمانع من التسجيل الصوتي.	
أنا على علم بأن المعلومات التي يتم جمعها من خلال مشاركتي في هذه الدراسة سوف يتم تخزينها بسرية تامة.	
في حال ملاحظة الباحث وجود أي مؤشر يمكن أن يكون له أي خطورة علي أو على الآخرين سيقوم الباحث بإخباري قبل المضي بأي خطوة.	
أوافق على المشاركة في هذا البحث.	

اسم المشارك ____________________ التوقيع ________________ التاريخ ____________

اسم الباحث ____________________ التوقيع ________________ التاريخ ____________

[6/10/2017][V 1.0][Q methodology] [consent form: caregiver][ERGO no: 27832]

I.7 Children's observation assent form (English version)

University of Southampton

NHS
University Hospital Southampton
NHS Foundation Trust

Assent Form

Study Play environments for children living with serious and complex health problems
Researcher name: Zainab Jasem

What research name would you like us to use in the study? ____________________

Please tick the faces you agree to:

Has somebody explained this project to you?	☺	☹
Do you understand what this project is about?	☺	☹
Have you asked all the questions you want?	☺	☹
Have you had your questions answered in a way you understand?	☺	☹
Do you understand that it's OK to say no and stop?	☺	☹
Do you understand Zainab will take notes and they will be used in the study?	☺	☹
Do you understand that your information will be kept until the study is completed?	☺	☹
Would you like to take part?	☺	☹

Optional permission for taking photos - please tick the faces you agree to:

Are you happy for photos to be taken for you?	☺	☹
Is it OK for your picture to be shown to other people when we talk about the study?	☺	☹
Is it OK to show your face?	☺	☹

____
Name of the participant (print name)

__________________________________ ____________________
Signature of the participant Date

____
Name of the researcher (print name)

__________________________________ ____________________
Signature of the researcher Date

When completed: 1 for participant; 1 for site file; 1 to be kept in medical notes; 1 for researcher.

[18/4/2018][V 3][observation][assent form: child]
[ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

I.8 Children’s observation assent form (Arabic version)

UNIVERSITY OF Southampton

اقرار مستنير للأطفال

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

ما هو الاسم المستعار الذي تود أن تختاره ليستخدم في هذا البحث؟ ________________

ضع علامة (/) على الوجه الذي تتفق معه:

هل قام أحدهم بشرح هذه الدراسة لك؟	☺	☹
هل فهمت عما يدور البحث؟	☺	☹
هل سألت كل الأسئلة التي تريد أن تسألها؟	☺	☹
هل تمت الإجابة على جميع أسئلتك؟	☺	☹
هل تعلم أنك تستطيع أن تقول لا، و تتوقف عن المشاركة في أي وقت ما شئت؟	☺	☹
هل انت موافق على ان يقوم الباحث بمشاهدتك خلال مشاركتك بالانشطة المختلفة و أخذ بعض الملاحظات؟	☺	☹
هل تود المشاركة؟	☺	☹

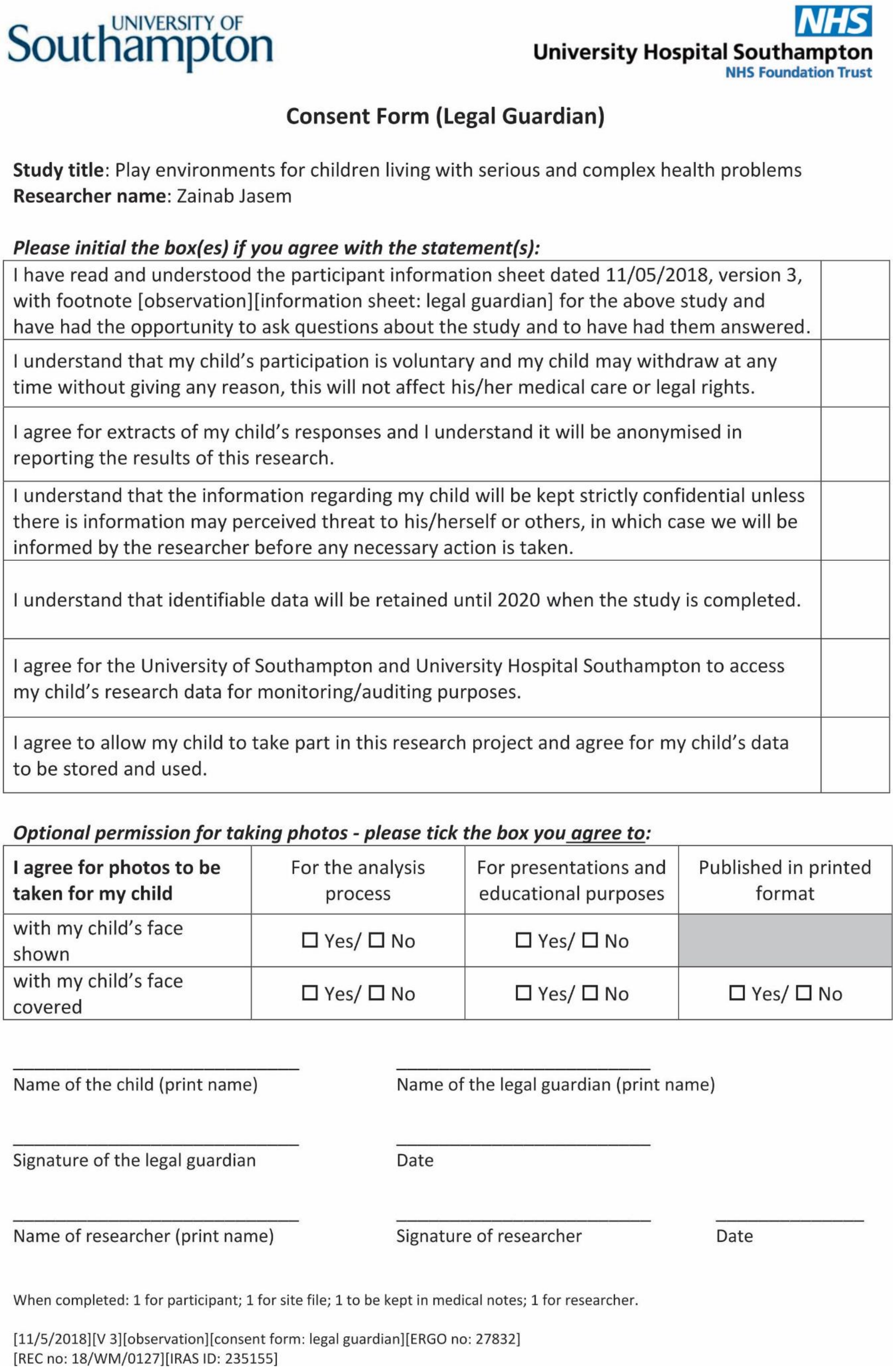
<u>التقاط الصور (اختياري)</u> ضع علامة (/) على الوجه الذي تتفق معه:

هل أنت موافق على أن يتم أخذ بعض الصور لك؟	☺	☹
هل أنت موافق على أن يتم تداول الصور بين فريق البحث؟	☺	☹
هل أنت موافق على إظهار وجهك في الصور؟	☺	☹
هل أنت موافق على أن يتم استخدام صورك في وصف نتائج البحث؟	☺	☹
هل أنت موافق على أن يتم وضع صور على الانترنت؟	☺	☹

____________________	______________	__________
اسم الطفل	التوقيع	التاريخ
____________________	______________	__________
اسم الباحث	التوقيع	التاريخ

[6/10/2017][V 1.0][Observation][assent form: child][ERGO no: 27832]

I.9 Legal guardian observation consent form (English version)



UNIVERSITY OF Southampton

NHS University Hospital Southampton NHS Foundation Trust

Consent Form (Legal Guardian)

Study title: Play environments for children living with serious and complex health problems
Researcher name: Zainab Jasem

Please initial the box(es) if you agree with the statement(s):

I have read and understood the participant information sheet dated 11/05/2018, version 3, with footnote [observation][information sheet: legal guardian] for the above study and have had the opportunity to ask questions about the study and to have had them answered.	
I understand that my child’s participation is voluntary and my child may withdraw at any time without giving any reason, this will not affect his/her medical care or legal rights.	
I agree for extracts of my child’s responses and I understand it will be anonymised in reporting the results of this research.	
I understand that the information regarding my child will be kept strictly confidential unless there is information may perceived threat to his/herself or others, in which case we will be informed by the researcher before any necessary action is taken.	
I understand that identifiable data will be retained until 2020 when the study is completed.	
I agree for the University of Southampton and University Hospital Southampton to access my child’s research data for monitoring/auditing purposes.	
I agree to allow my child to take part in this research project and agree for my child’s data to be stored and used.	

Optional permission for taking photos - please tick the box you agree to:

I agree for photos to be taken for my child	For the analysis process	For presentations and educational purposes	Published in printed format
with my child’s face shown	☐ Yes/ ☐ No	☐ Yes/ ☐ No	
with my child’s face covered	☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No

______________________________ Name of the child (print name)

______________________________ Name of the legal guardian (print name)

______________________________ Signature of the legal guardian

______________________________ Date

______________________________ Name of researcher (print name)

______________________________ Signature of researcher

________________ Date

When completed: 1 for participant; 1 for site file; 1 to be kept in medical notes; 1 for researcher.

[11/5/2018][V 3][observation][consent form: legal guardian][ERGO no: 27832]
[REC no: 18/WM/0127][IRAS ID: 235155]

I.10 Legal guardian observation consent form (Arabic version)

UNIVERSITY OF Southampton

اقرار مستنير للبالغين كاملي الأهلية (ولي أمر الطفل المشارك)

عنوان البحث: توفير بيئة لعب مناسبة لاحتياجات الأطفال ذوي الرعاية الخاصة

اسم الباحث: زينب جاسم

الرجاء وضع الحرف الأول من اسمك في المربعات المقابلة للجمل التي تتفق معها:

لقد قمت بقراءة و فهم إرشادات المشاركة المؤرخة ب6/10/2017 (نسخة 1) المذيلة بـ **[observation][information sheet: legal guardian]** كما تمت الإجابة على جميع تساؤلاتي.	
أعلم بأن مشاركة طفلي في هذا البحث اختيارية، و لنا الحرية بالانسحاب في أي وقت دون الحاجة إلى إدلاء الأسباب، و لن يترتب على ذلك أي ضرر على طفلي.	
أنا على علم بأن المعلومات التي يتم جمعها من خلال مشاركة طفلي في هذه الدراسة سوف يتم تخزينها بسرية تامة.	
في حال ملاحظة الباحث وجود أي مؤشر يمكن أن يكون له أي خطورة على طفلي أو على الأخرين سيقوم الباحث بإخباري قبل المضي بأي خطوة.	
أوافق على مشاركة طفلي في هذا البحث.	

<u>التقاط الصور (اختياري)</u> الرجاء وضع الحرف الأول من اسمك في المربعات المقابلة للجمل التي تتفق معها:

أوافق على التقاط صور لطفلي	لتحليل نتائج البحث	في وصف نتائج البحث في المؤتمرات العلمية	في وصف نتائج البحث المنشورة على الانترنت	في وصف نتائج البحث المطبوعة كأوراق علمية
دون ظهور وجه طفلي				
لا أمانع من ظهور وجه طفلي				

اسم الطفل ____________________

اسم ولي أمر الطفل ____________________

التوقيع ____________________

التاريخ ____________________

اسم الباحث ____________________

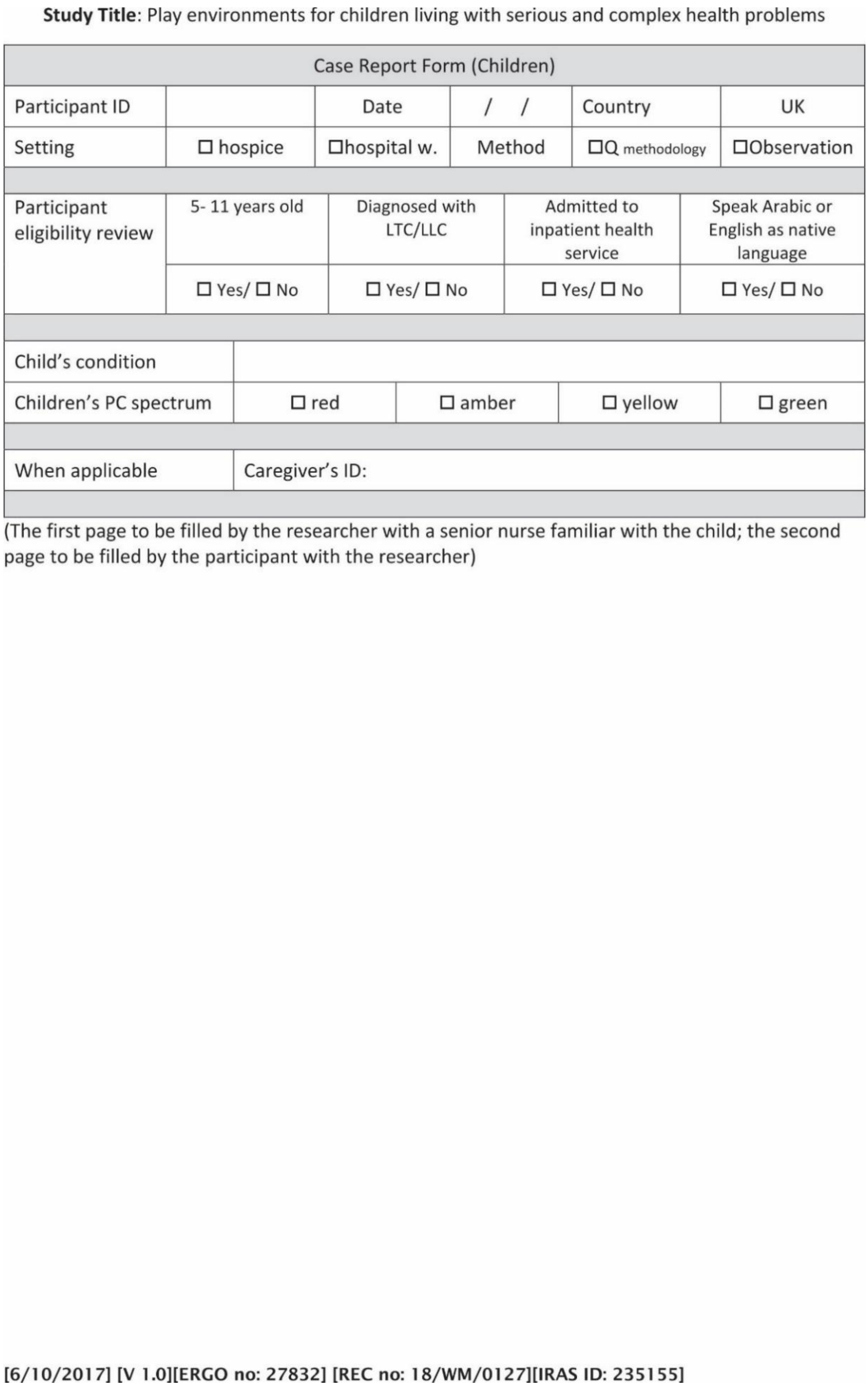
التوقيع ____________________

التاريخ ____________

[6/10/2017][V 1.0][Observation][consent form: legal guardian][ERGO no: 27832]

Appendix J Case report form

J.1 Children’s case report form (English version)



Study Title: Play environments for children living with serious and complex health problems

Case Report Form (Children)					
Participant ID		Date	/ /	Country	UK
Setting	☐ hospice	☐hospital w.	Method	☐Q methodology	☐Observation
Participant eligibility review	5- 11 years old	Diagnosed with LTC/LLC	Admitted to inpatient health service	Speak Arabic or English as native language	
	☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No	
Child’s condition					
Children’s PC spectrum	☐ red	☐ amber	☐ yellow	☐ green	
When applicable	Caregiver’s ID:				

(The first page to be filled by the researcher with a senior nurse familiar with the child; the second page to be filled by the participant with the researcher)

[6/10/2017] [V 1.0][ERGO no: 27832] [REC no: 18/WM/0127][IRAS ID: 235155]

Appendix J

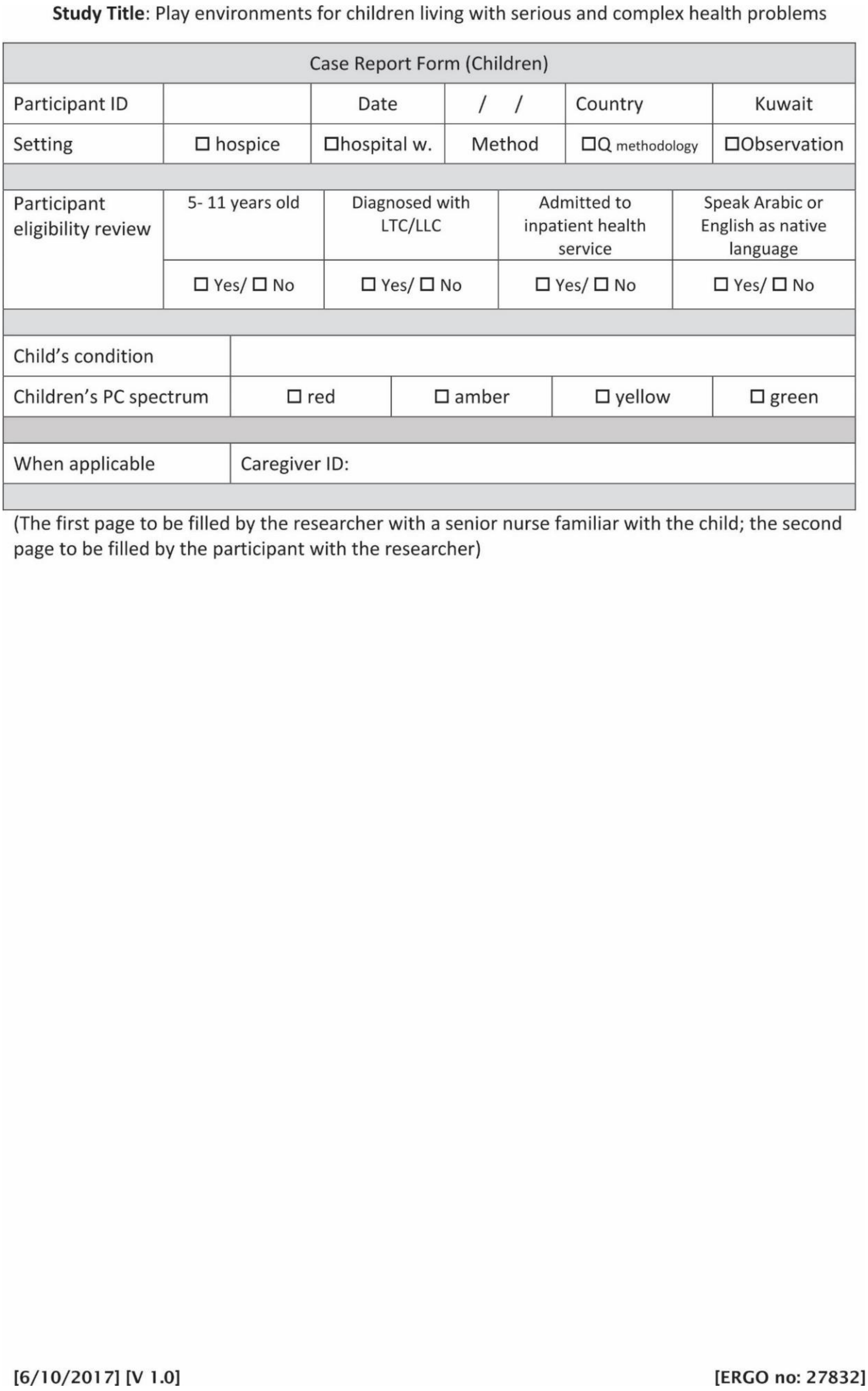
Child’s demographic data				
Participant name			Pseudonym	
Gender	☐ male	☐ female	DOB:	/ /
Ethnicity	☐ White ☐ Asian ☐ Black		☐ Chinese ☐ Mixed ☐ Other (specify): ____________________	
Genogram				

- -

Copy of the findings
If you are interested in having a copy of the findings, please let us know your email or postal address to which we can send the copy of the findings
☐ email address: ____ ☐ postal address: ____ ☐ other (specify): ____

[6/10/2017] [V 1.0][ERGO no: 27832] [REC no: 18/WM/0127][IRAS ID: 235155]

J.2 Children's case report form (Arabic version)



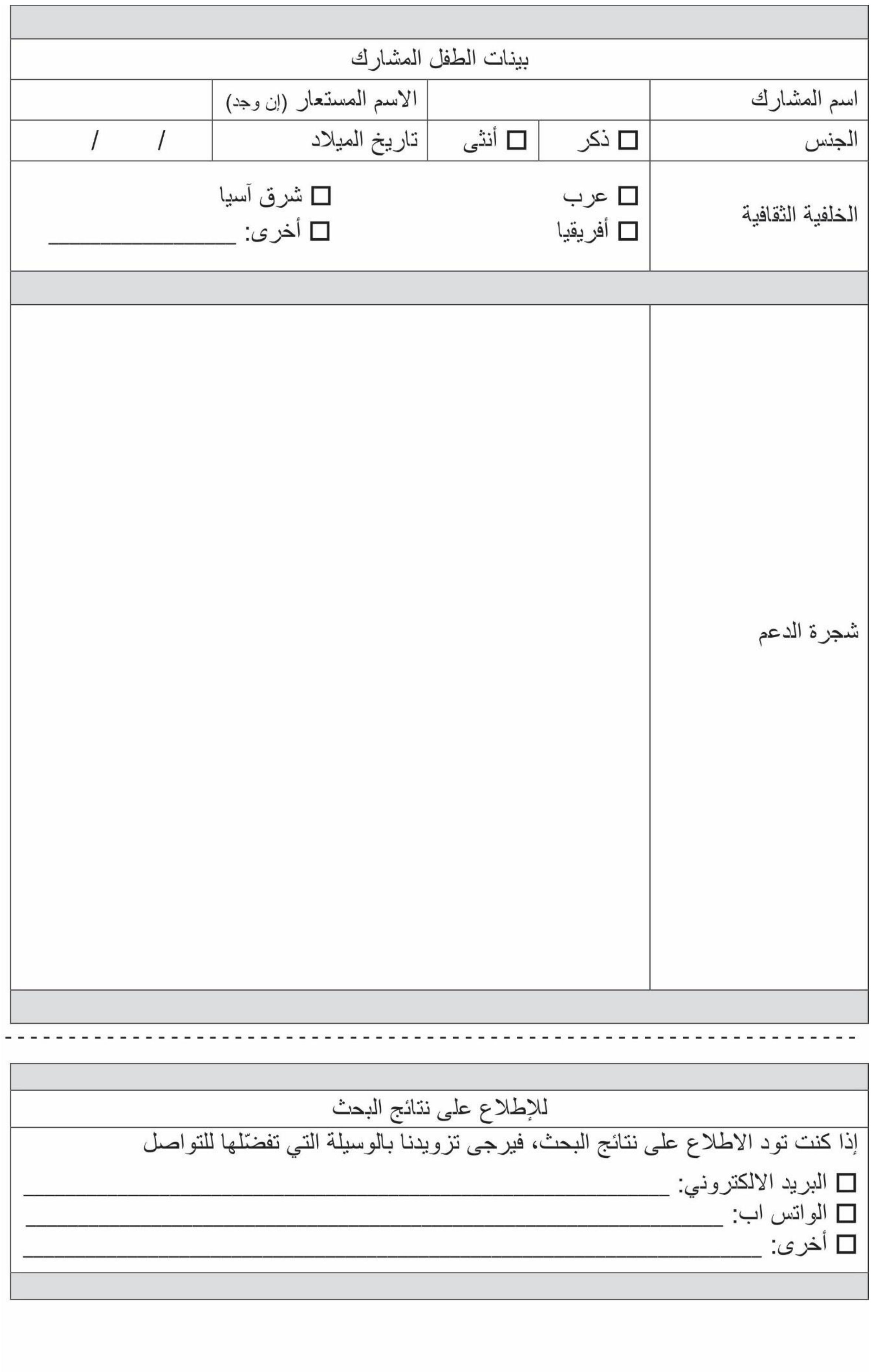
Study Title: Play environments for children living with serious and complex health problems

Case Report Form (Children)					
Participant ID		Date	/ /	Country	Kuwait
Setting	☐ hospice	☐hospital w.	Method	☐Q methodology	☐Observation
Participant eligibility review	5- 11 years old	Diagnosed with LTC/LLC	Admitted to inpatient health service	Speak Arabic or English as native language	
	☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No	
Child's condition					
Children's PC spectrum	☐ red	☐ amber	☐ yellow	☐ green	
When applicable	Caregiver ID:				

(The first page to be filled by the researcher with a senior nurse familiar with the child; the second page to be filled by the participant with the researcher)

[6/10/2017] [V 1.0] **[ERGO no: 27832]**

Appendix J



بينات الطفل المشارك				
اسم المشارك			الاسم المستعار (إن وجد)	
الجنس	☐ ذكر	☐ أنثى	تاريخ الميلاد	/ /
الخلفية الثقافية	☐ عرب ☐ أفريقيا	☐ شرق آسيا ☐ أخرى: ________		
شجرة الدعم				

- -

للإطلاع على نتائج البحث

إذا كنت تود الاطلاع على نتائج البحث، فيرجى تزويدنا بالوسيلة التي تفضّلها للتواصل

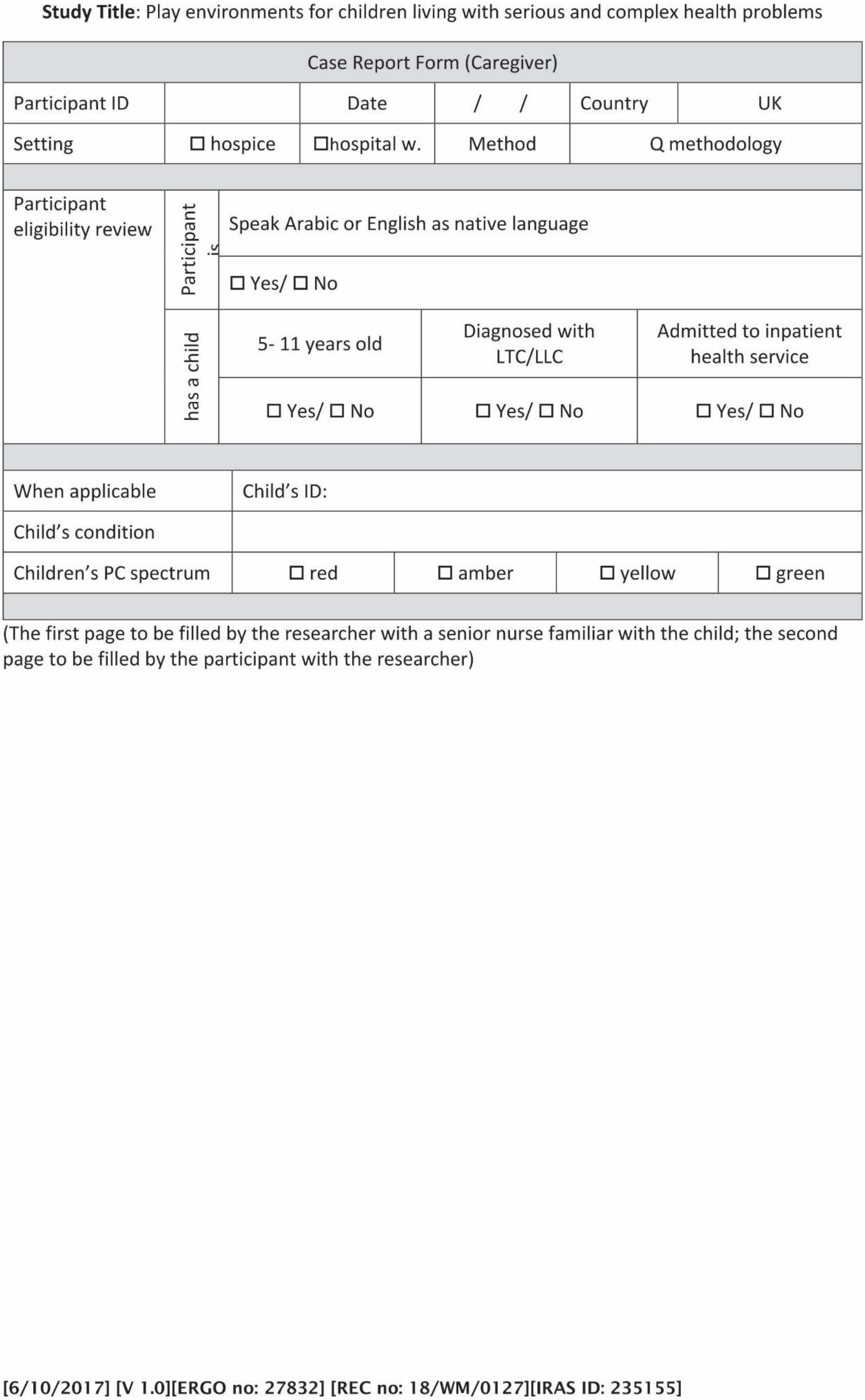
☐ البريد الالكتروني: ________________________________

☐ الواتس اب: ________________________________

☐ أخرى: ________________________________

[6/10/2017] [V 1.0] **[ERGO no: 27832]**

J.3 Caregivers' case report form (English version)



Study Title: Play environments for children living with serious and complex health problems

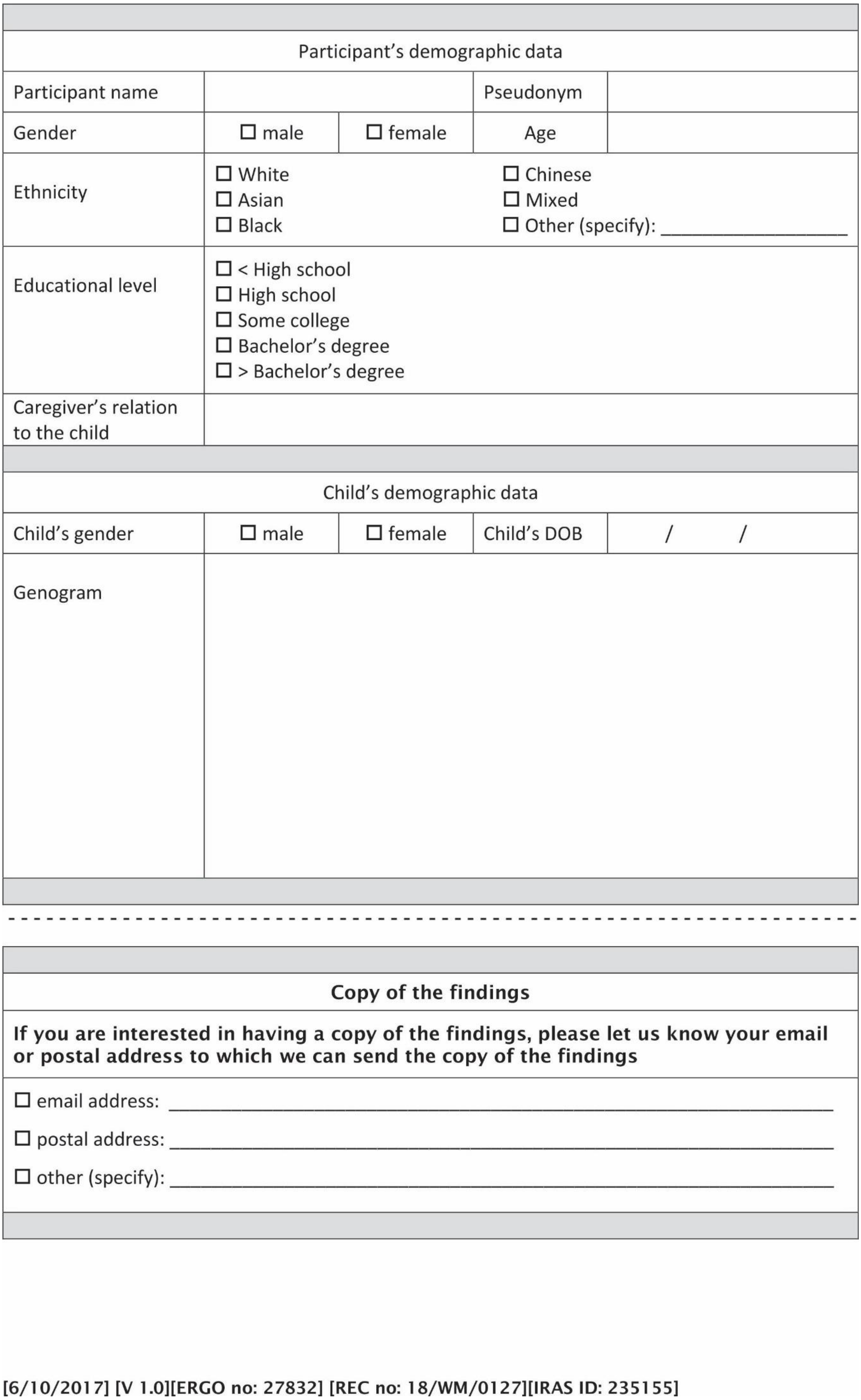
Case Report Form (Caregiver)					
Participant ID		Date	/ /	Country	UK
Setting	☐ hospice	☐hospital w.	Method	Q methodology	

Participant eligibility review	Participant is	Speak Arabic or English as native language		
		☐ Yes/ ☐ No		
	has a child	5- 11 years old	Diagnosed with LTC/LLC	Admitted to inpatient health service
		☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No

When applicable	Child's ID:			
Child's condition				
Children's PC spectrum	☐ red	☐ amber	☐ yellow	☐ green

(The first page to be filled by the researcher with a senior nurse familiar with the child; the second page to be filled by the participant with the researcher)

[6/10/2017] [V 1.0][ERGO no: 27832] [REC no: 18/WM/0127][IRAS ID: 235155]



Participant's demographic data

Participant name			Pseudonym	
Gender	☐ male	☐ female	Age	
Ethnicity	☐ White ☐ Asian ☐ Black		☐ Chinese ☐ Mixed ☐ Other (specify): ___________________	
Educational level	☐ < High school ☐ High school ☐ Some college ☐ Bachelor's degree ☐ > Bachelor's degree			
Caregiver's relation to the child				

Child's demographic data

Child's gender	☐ male	☐ female	Child's DOB	/ /
Genogram				

- -

Copy of the findings

If you are interested in having a copy of the findings, please let us know your email or postal address to which we can send the copy of the findings

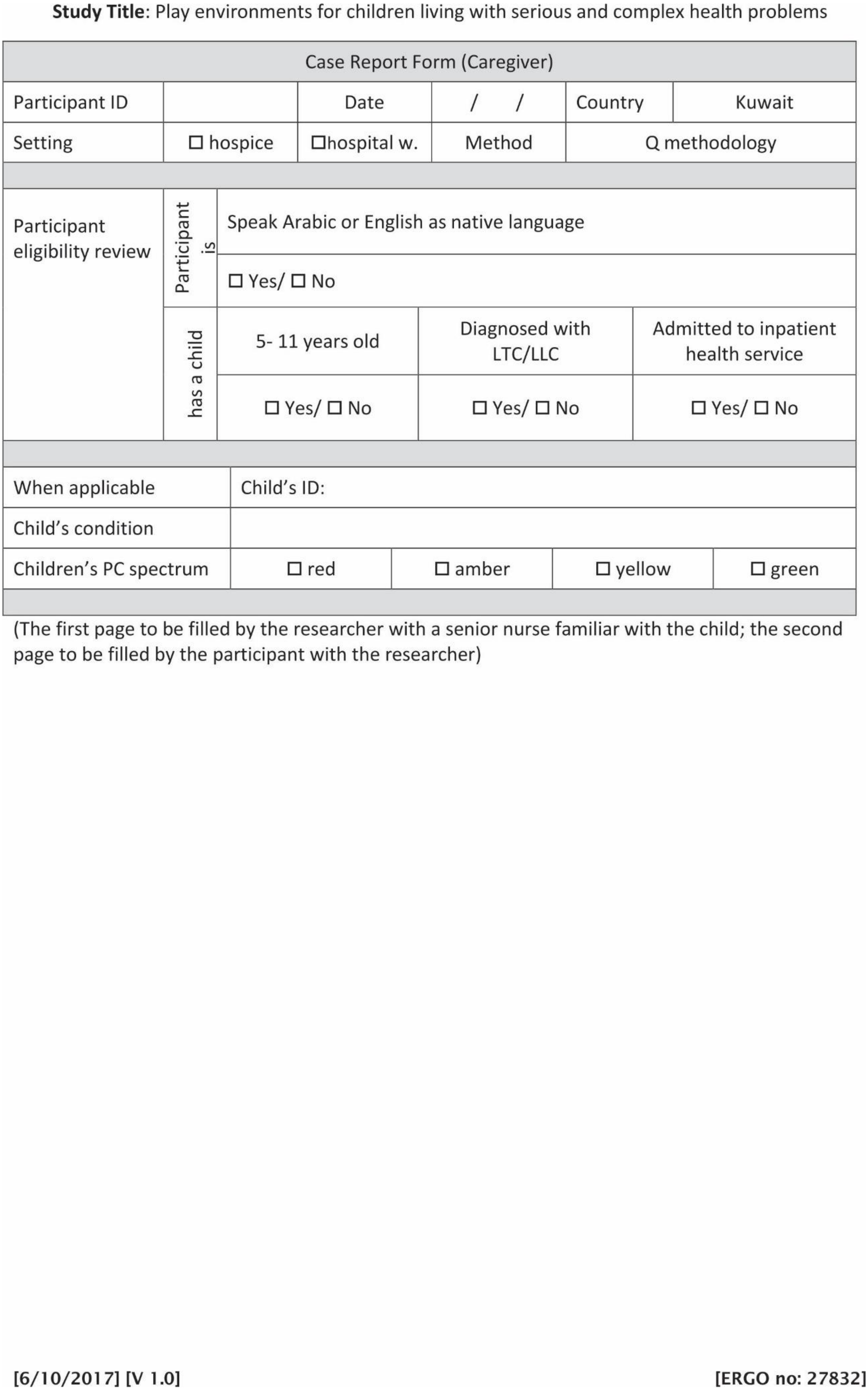
☐ email address: ____

☐ postal address: ____

☐ other (specify): ____

[6/10/2017] [V 1.0][ERGO no: 27832] [REC no: 18/WM/0127][IRAS ID: 235155]

J.4 Caregivers’ case report form (Arabic version)



Study Title: Play environments for children living with serious and complex health problems

Case Report Form (Caregiver)					
Participant ID		Date	/ /	Country	Kuwait
Setting	☐ hospice	☐hospital w.	Method	Q methodology	
Participant eligibility review	Participant is	Speak Arabic or English as native language			
		☐ Yes/ ☐ No			
	has a child	5- 11 years old	Diagnosed with LTC/LLC	Admitted to inpatient health service	
		☐ Yes/ ☐ No	☐ Yes/ ☐ No	☐ Yes/ ☐ No	
When applicable	Child’s ID:				
Child’s condition					
Children’s PC spectrum	☐ red	☐ amber	☐ yellow	☐ green	

(The first page to be filled by the researcher with a senior nurse familiar with the child; the second page to be filled by the participant with the researcher)

[6/10/2017] [V 1.0] **[ERGO no: 27832]**

بينات المشارك				
اسم المشارك			الاسم المستعار (إن وجد)	
الجنس	☐ ذكر	☐ أنثى	العمر	
الخلفية الثقافية	☐ عرب ☐ أفريقيا		☐ شرق آسيا ☐ أخرى: ________________	
المؤهل الدراسي	☐< الشهادة الثانوية ☐ الشهادة الثانوية ☐ دبلوم ☐ بكلريوس ☐ دراسات عليا			
علاقة الحاضن بالطفل				
بينات الطفل				
جنس الطفل	☐ ذكر	☐ أنثى	تاريخ ميلاد الطفل	/ /
شجرة الدعم				

للإطلاع على نتائج البحث

إذا كنت تود الاطلاع على نتائج البحث، فيرجى تزويدنا بالوسيلة التي تفضّلها للتواصل

☐ البريد الالكتروني: ____

☐ الواتس اب: ____

☐ أخرى: ____

[6/10/2017] [V 1.0] **[ERGO no: 27832]**

Appendix K Concourse items

1) Knee space for table and w/c user
2) Height of chair and table the child sit
3) Furnishings do not over crowd space
4) Furnishing for gross motor activities
5) Availability of noisy centres
6) Availability of cozy area (a place to relax, read, listen to music)
7) Pleasant spaces
8) Varied spaces both in and outdoor available daily
9) Separate space for younger children from older children
10) Convenient access to outdoor space
11) Soft surface suitable for different types of play (e.g.,Protecting cushions under climbing equipment)
12) Space for gross motor activities/ Enlarged rooms
13) Space for privacy
14) specific area that allows children privacy
15) Children are able to create their private space
16) Child able to bring self-selected materials into private spaces
17) Easy access to areas where reference materials are stored
18) provision for appropriate, independent use of materials
19) Spaces are easy to supervise
20) Accessible indoor area for gross motor play
21) Accessible outdoor area for gross motor play
22) Room arrangement
23) Good maintenance of space (e.g.,Floors cleaned, Trash cleared , Carpeting vacuumed)
24) Paints on wall and ceiling
25) Smooth pavement
26) Sufficient amount of space for number of children
27) Room arrangement that fosters child's autonomy
28) space that provide children with the opportunity to be engaged in a small group play (two children) without the interruption of others
29) Sufficient amount of space for number of children
30) Room arrangement that fosters child's autonomy
31) space that provide children with the opportunity to be engaged in a small group play (two children) without the interruption of others
32) full range of recreational activity furnishings use
33) distance of hospital to child's friends/relatives houses
34) Distance of park
35) Distance of beach
36) transportation service
37) lighting
38) ventilation
39) air quality
40) window open
41) adjustable blinds or curtains
42) temperature
43) climate conditions
44) fauna (pets, wild animals)
45) flora (plants, trees)
46) Adaptive device
47) Moving about in and around the hospital
48) Ramp
49) Stairs
50) Elevator
51) Doors
52) Suitable doorway
53) accessibility to materials
54) Accessible stuffed toys for the children to play with during the day
55) Division of areas into specific interest areas – allowing active play were blended with other areas; toys arranged in sort of order or packed on shelves
56) Playing with construction toys (building blocks, puzzle)
57) Playing games with rules
58) Playing computer games
59) Art and craft
60) Music
61) Block and construction

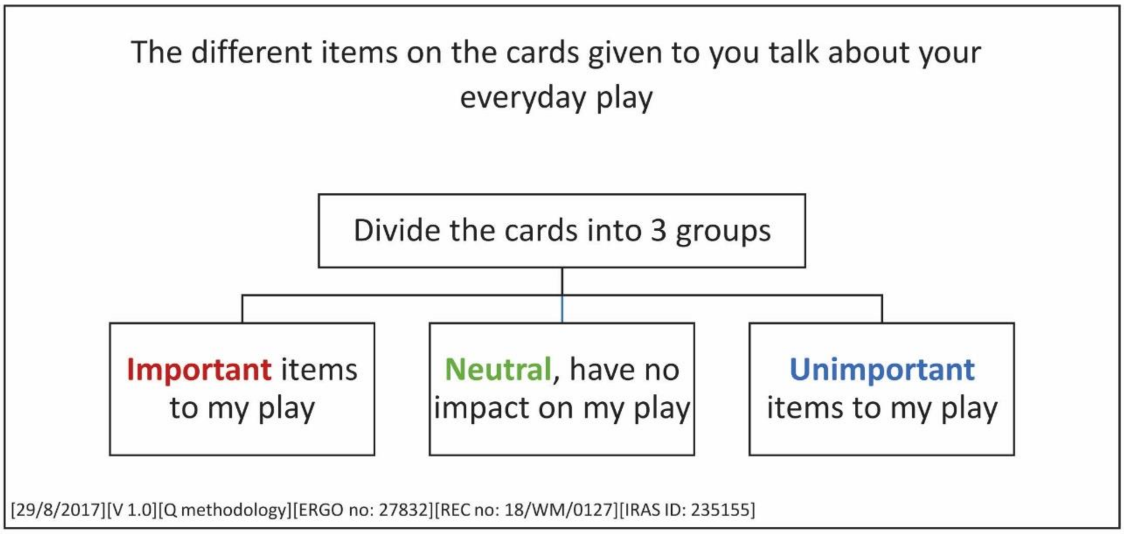
62) Taking part in pretend or make believe play
63) Listening to story
64) Watching TV
65) Doing art and craft
66) Location of toys and games
67) Accessibility to water play components
68) Stepper
69) Handrails
70) Clear space for a person with wheelchair to turn around
71) Ground level play components
72) Accessible to elevated play components
73) Safety
74) other people's attitudes toward child
75) Support and encouragement
76) prompting and praise
77) prejudice or discrimination
78) Needs someone's help
79) Delayed response in providing help
80) Free play
81) Child's independence
82) sufficient time for free play during the day
83) Availability of friends
84) playing with a friend
85) a friend visiting
86) knowledge of how to accommodate activity
87) inviting a friend
88) attending party
89) attending family events
90) sleeping over with friends
91) communicating with other children
92) communicating with other adults
93) attending events as team sport or fairs
94) play with friends outdoor
95) talking on the phone
96) enjoys joking with others
97) tells funny stories
98) adult-child communication
99) adults supervision
100) people positive attitudes towards child
101) emotional support from wider family/friends
102) encouragement from wider family and friends
103) listening to child's views
104) child receive physical help
105) people's attitude
106) assistance from people
107) support from family and close friends
108) attitudes of family and close friends towards the child
109) support from strangers
110) attitudes of strangers
111) the religious beliefs of people in the community (faith, spirituality)
112) number of people caring for the child
113) Computer and videogames
114) Indoor play games
115) Music
116) Hobbies
117) Watching videos and DVDs
118) Socialising using technology
119) Fields trips
120) Community events
121) the hospital events
122) Organised physical activities
123) Unstructured physical activities
124) Furnishings for recreations
125) Music and movement
126) Drama/ theatre
127) Staff-child interaction
128) Peer interactions
129) Free choices
130) clean, comfortable, and in good repair indoor space
131) outdoor and indoor space, to exercise large muscles
132) run in open spaces, and exercise gross motor skills
133) Space for privacy escape from the pressures of group situations
134) wide variety of age appropriate activities
135) Basic furniture, such as tables and chairs, should be sturdy and appropriate to the size of the children (should encourage a variety of learning and recreational activities.)
136) stationary and portable equipment to promote a wide variety of skills that exercise large muscles
137) child-initiated art activities
138) Books and language materials
139) stories in sufficient number
140) Free choice, manage play independently
141) Types of available games and toys
142) Location of the toys

143) Location of crafts
144) Location of paints and papers
145) Tables and chair to use
146) Tables and chair to sit
147) Tables and chair to draw
148) Attitudes of staff
149) Attitudes of new people
150) Physical accessibility to different areas
151) Noise
152) Social rules
153) Design and layout of the setting
154) Suitable leisure facilities
155) Runs, hops, skips, jumps
156) Enjoys joking with other children
157) Sing
158) Initiate and respond while play
159) Attending circle time
160) Playing at yard
161) Attending music
162) Dancing lesson
163) Sport lesson
164) Going/attending an event
165) Choosing a game
166) Playing games with rules (cards, board games)
167) Bike
168) Playing baseball
169) Playing basketball
170) Playing football/soccer
171) Play catch
172) kickball
173) Hide and seek
174) Jump rope
175) Roller-skate
176) Play at beach, lake, river
177) Go on picnic
178) Swim
179) Garden
180) Take care of pet
181) Do puzzle
182) Build things
183) Draw or paint
184) Cook or bake
185) gymnastics
186) play superheroes
187) play school
188) play house
189) play dress up or make up
190) play by myself
191) play with friends
192) play with a grown-up
193) Listening to story
194) Blocks, lego
195) Sand, clay
196) Figures (cars, trains, dolls)
197) Reading, writing, crossword, colouring books
198) sorting, and aligning objects
199) building models
200) making block towers
201) Fitting Lego blocks together
202) using modelling clay
203) pouring water from one container to another
204) Construction play
205) Playing PlayStation/ Xbox/ Nintendo
206) Constructing a castle
207) Flower arrangement
208) Wood working
209) Gardening
210) Playing the piano
211) Fantasy Activity
212) Imitation (Literal) Activity
213) Pretend play
214) Animal actions
215) Pretend play work, take care
216) Pretend Disney princess / superheroes
217) Play house: kitchen, dolls
218) Sensory Activity
219) Exploratory Activity
220) Cause-Effect Activity
221) Rough-and-tumble play
222) Play-fighting or play-chasing
223) Physical exercise
224) Risky or deep play: caving, kayaking, snowballing
225) Hopscotch, Piggyback
226) Roller skating, roller blading
227) Play checkers
228) Play Connect Four
229) Play Monopoly
230) Jazz, rock music
231) Play with noises, syllables, words, and phrases
232) Informal social play
233) Tickling

234) Imitating gestures or verbalizations
235) Solitary play
236) Parallel play
237) Cooperative play
238) Mind or subjective play
239) Put together train tracks to make a pattern
240) Alternating shapes and sizes of pieces to achieve the desired result

Appendix L Q instructions sheet

L.1 Children's Q instructions sheet (English version)



The different items on the cards given to you talk about your everyday play

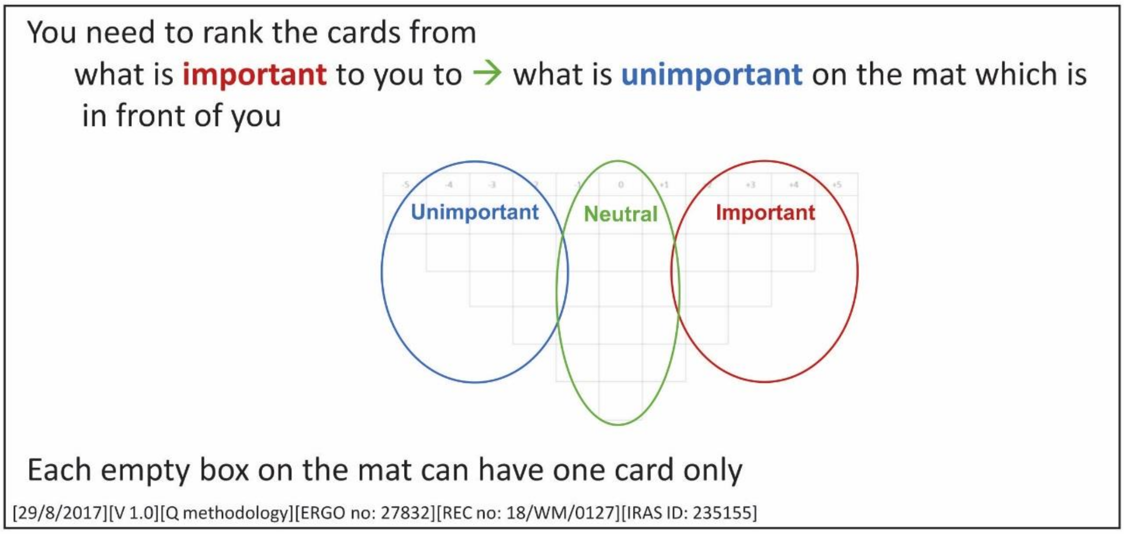
Divide the cards into 3 groups

Important items to my play

Neutral, have no impact on my play

Unimportant items to my play

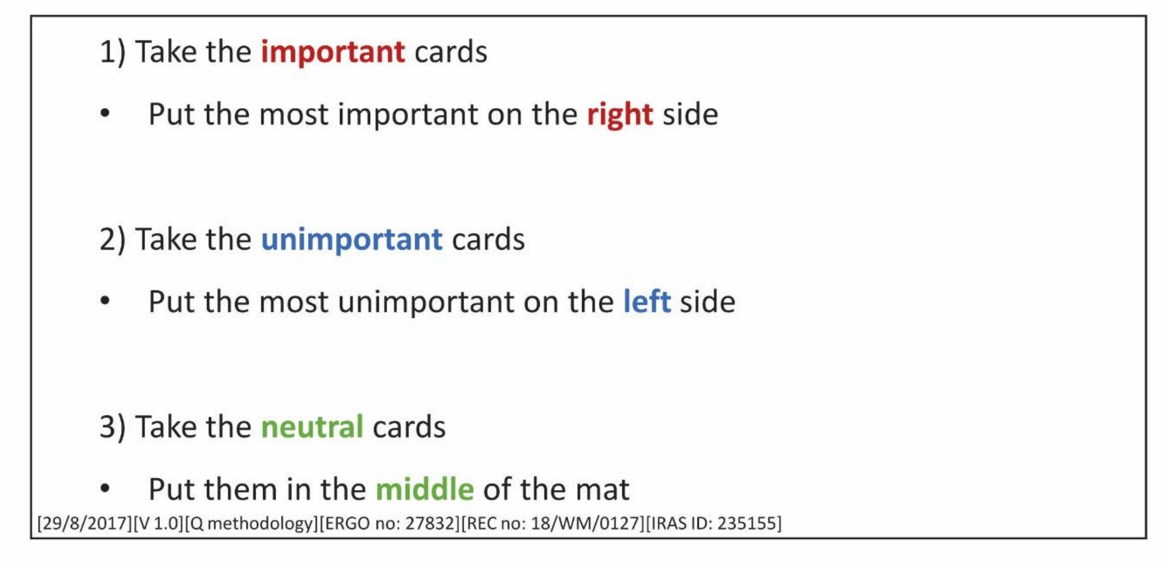
[29/8/2017][V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]



You need to rank the cards from what is **important** to you to → what is **unimportant** on the mat which is in front of you

Each empty box on the mat can have one card only

[29/8/2017][V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]



1) Take the **important** cards

- Put the most important on the **right** side

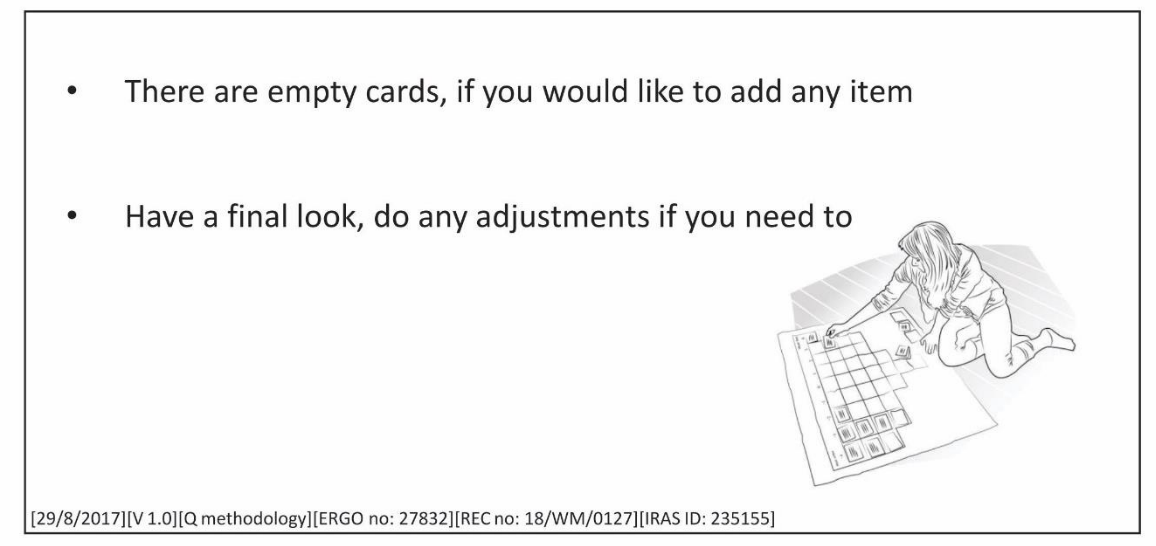
2) Take the **unimportant** cards

- Put the most unimportant on the **left** side

3) Take the **neutral** cards

- Put them in the **middle** of the mat

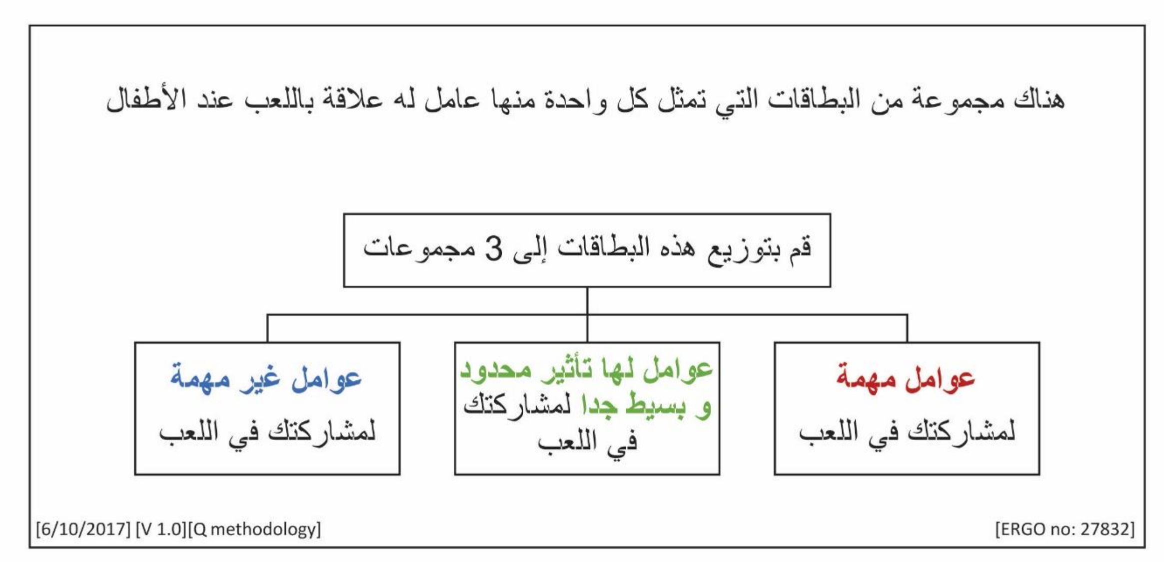
[29/8/2017][V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]



- There are empty cards, if you would like to add any item
- Have a final look, do any adjustments if you need to

[29/8/2017][V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

L.2 Children's Q instructions sheet (Arabic version)



هناك مجموعة من البطاقات التي تمثل كل واحدة منها عامل له علاقة باللعب عند الأطفال

قم بتوزيع هذه البطاقات إلى 3 مجموعات

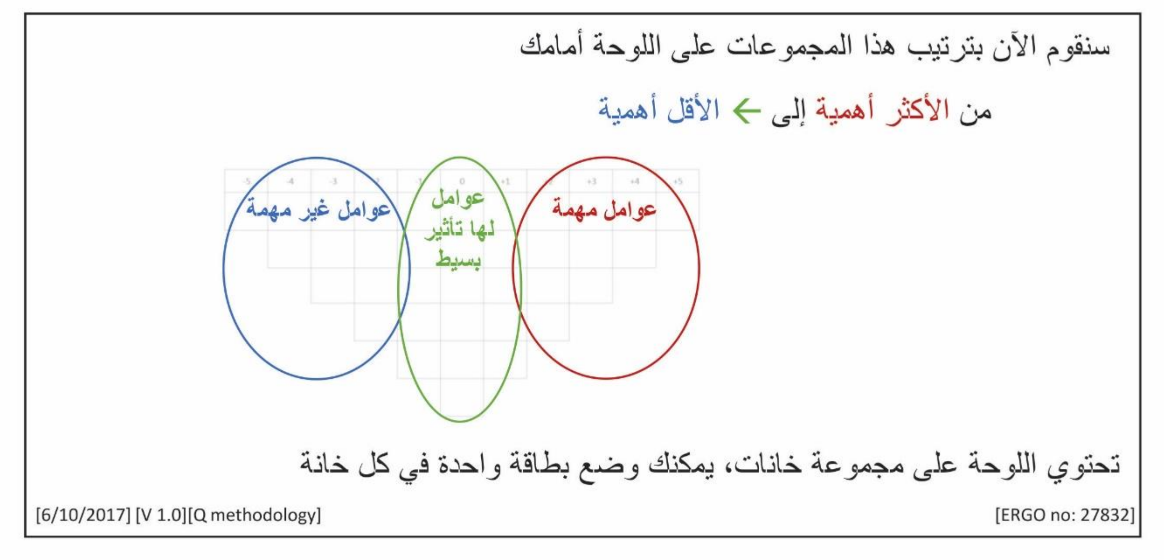
عوامل مهمة لمشاركتك في اللعب

عوامل لها تأثير محدود و بسيط جدا لمشاركتك في اللعب

عوامل غير مهمة لمشاركتك في اللعب

[6/10/2017] [V 1.0][Q methodology]

[ERGO no: 27832]



سنقوم الآن بترتيب هذا المجموعات على اللوحة أمامك

من الأكثر أهمية إلى ← الأقل أهمية

تحتوي اللوحة على مجموعة خانات، يمكنك وضع بطاقة واحدة في كل خانة

[6/10/2017] [V 1.0][Q methodology]

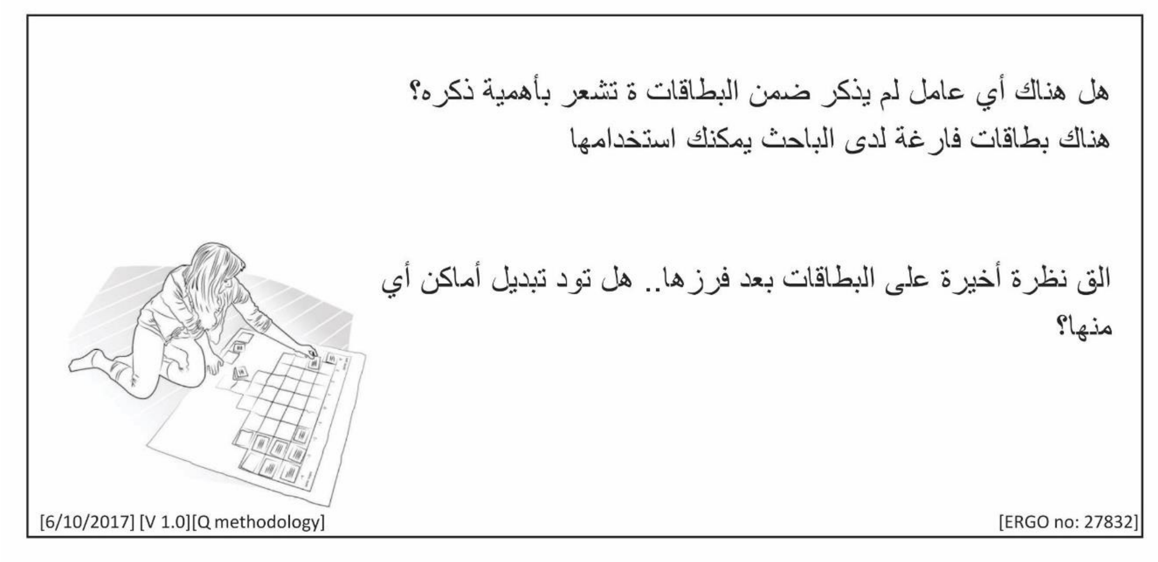
[ERGO no: 27832]

1)خذ المجموعة الأولى التي تحتوي على العوامل المهمة و قم بوضع هذه العوامل على اللوحة أمامك حسب أهميتها ابتداء من جهة اليمين

2)خذ المجموعة التالية و التي تحتوي على العوامل الغير مهمة و قم بترتيب هذه العوامل على اللوحة أمامك ابتداء من جهة اليسار

3)خذ المجموعة الأخيرة و التي تحتوي على العوامل ذات الأهمية المحدودة و قم بترتيب هذه العوامل على اللوحة أمامك لملئ المساحة في المنتصف

[6/10/2017] [V 1.0][Q methodology] [ERGO no: 27832]

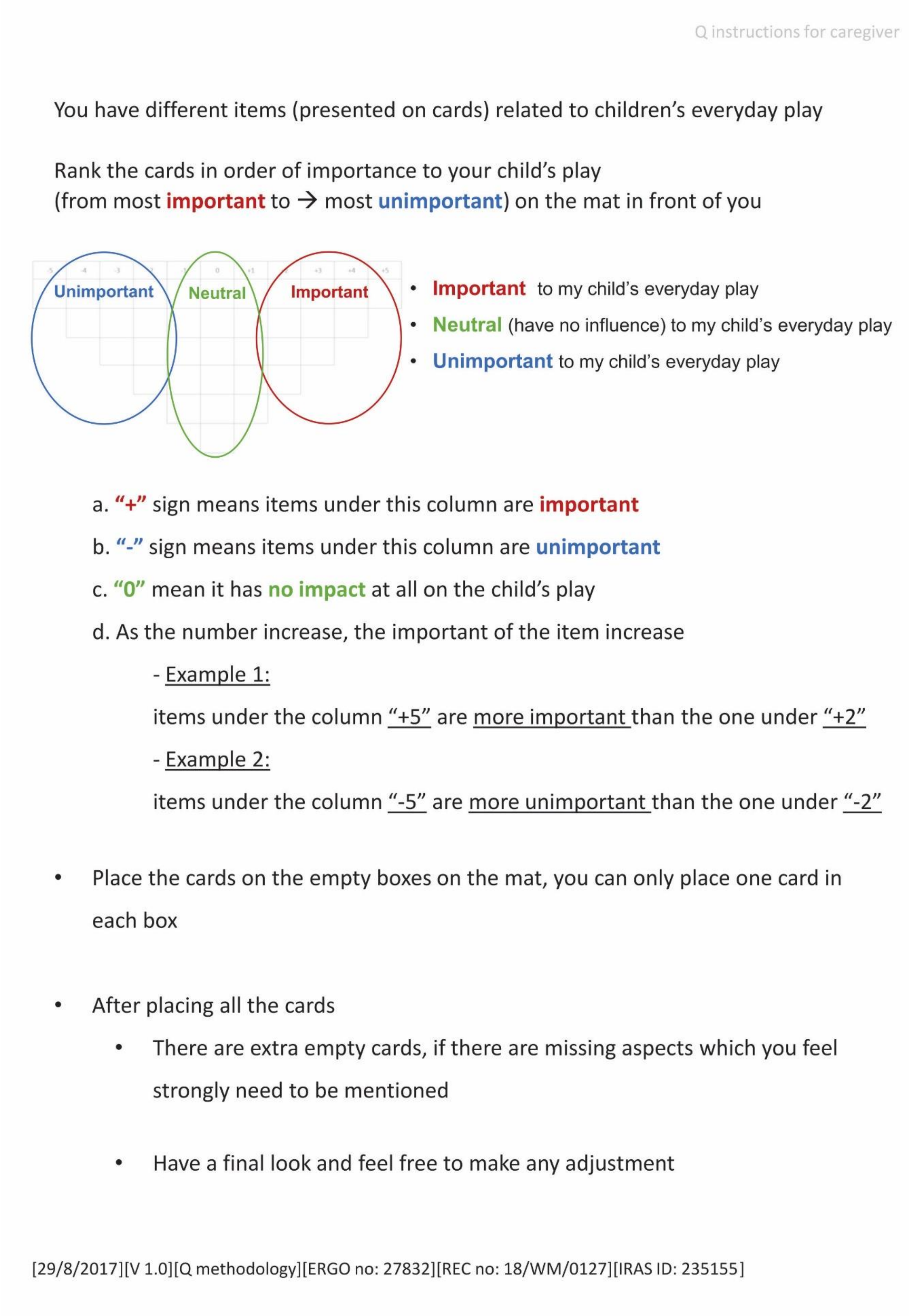


هل هناك أي عامل لم يذكر ضمن البطاقات ة تشعر بأهمية ذكره؟
هناك بطاقات فارغة لدى الباحث يمكنك استخدامها

الق نظرة أخيرة على البطاقات بعد فرزها.. هل تود تبديل أماكن أي منها؟

[6/10/2017] [V 1.0][Q methodology] [ERGO no: 27832]

L.3 Caregivers' Q instructions sheet (English version)



Q instructions for caregiver

You have different items (presented on cards) related to children's everyday play

Rank the cards in order of importance to your child's play
(from most **important** to → most **unimportant**) on the mat in front of you

- **Important** to my child's everyday play
- **Neutral** (have no influence) to my child's everyday play
- **Unimportant** to my child's everyday play

a. **"+"** sign means items under this column are **important**

b. **"-"** sign means items under this column are **unimportant**

c. **"0"** mean it has **no impact** at all on the child's play

d. As the number increase, the important of the item increase

- Example 1:

items under the column "+5" are more important than the one under "+2"

- Example 2:

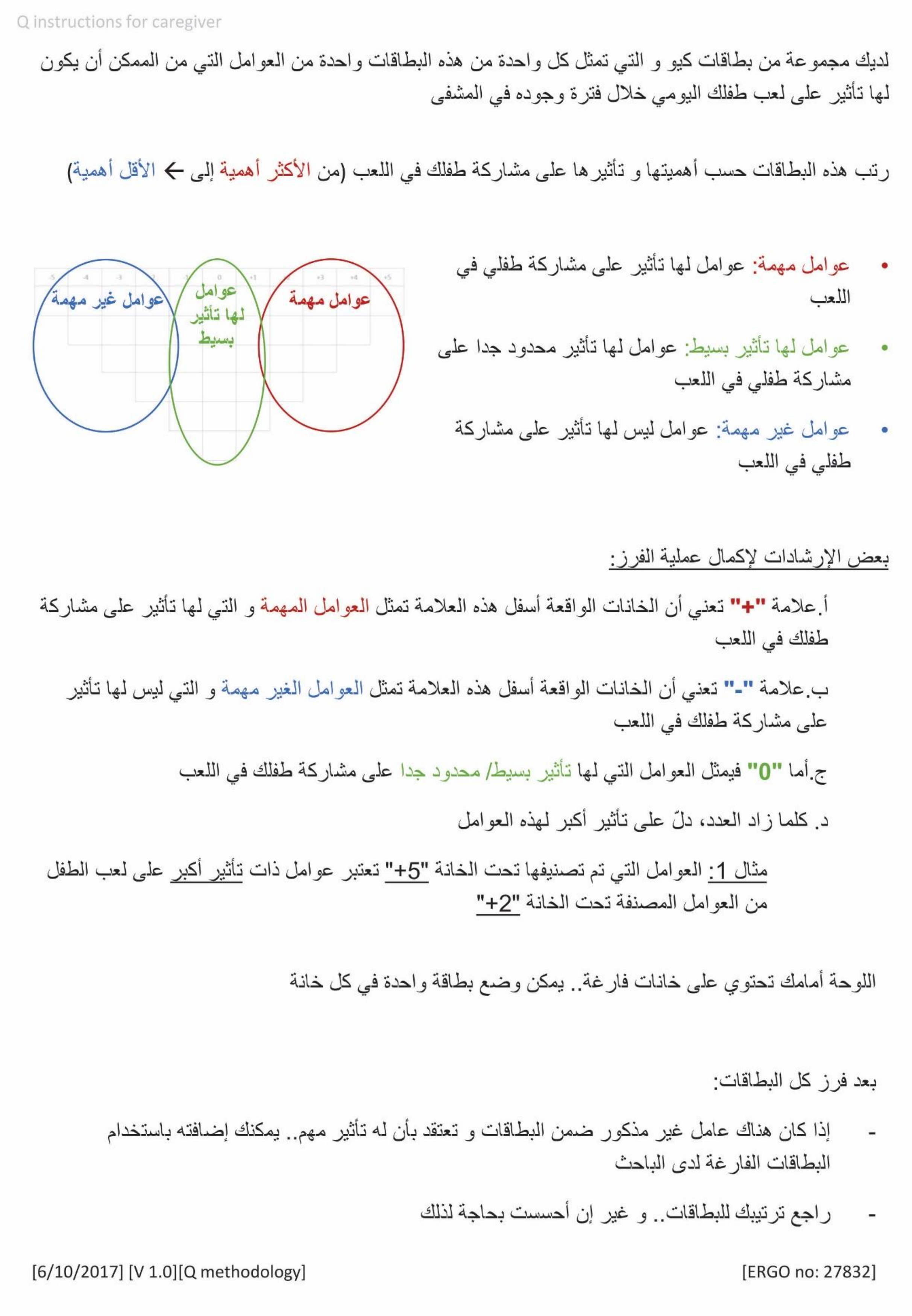
items under the column "-5" are more unimportant than the one under "-2"

- Place the cards on the empty boxes on the mat, you can only place one card in each box

- After placing all the cards
  - There are extra empty cards, if there are missing aspects which you feel strongly need to be mentioned
  - Have a final look and feel free to make any adjustment

[29/8/2017][V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

L.4 Caregivers’ Q instructions sheet (Arabic version)



Q instructions for caregiver

لديك مجموعة من بطاقات كيو و التي تمثل كل واحدة من هذه البطاقات واحدة من العوامل التي من الممكن أن يكون لها تأثير على لعب طفلك اليومي خلال فترة وجوده في المشفى

رتب هذه البطاقات حسب أهميتها و تأثيرها على مشاركة طفلك في اللعب (من الأكثر أهمية إلى ← الأقل أهمية)

- عوامل مهمة: عوامل لها تأثير على مشاركة طفلي في اللعب
- عوامل لها تأثير بسيط: عوامل لها تأثير محدود جدا على مشاركة طفلي في اللعب
- عوامل غير مهمة: عوامل ليس لها تأثير على مشاركة طفلي في اللعب

<u>بعض الإرشادات لإكمال عملية الفرز:</u>

أ.علامة **"+"** تعني أن الخانات الواقعة أسفل هذه العلامة تمثل العوامل المهمة و التي لها تأثير على مشاركة طفلك في اللعب

ب.علامة **"-"** تعني أن الخانات الواقعة أسفل هذه العلامة تمثل العوامل الغير مهمة و التي ليس لها تأثير على مشاركة طفلك في اللعب

ج.أما **"0"** فيمثل العوامل التي لها تأثير بسيط/ محدود جدا على مشاركة طفلك في اللعب

د. كلما زاد العدد، دلّ على تأثير أكبر لهذه العوامل

مثال 1: العوامل التي تم تصنيفها تحت الخانة "+5" تعتبر عوامل ذات تأثير أكبر على لعب الطفل من العوامل المصنفة تحت الخانة "+2"

اللوحة أمامك تحتوي على خانات فارغة.. يمكن وضع بطاقة واحدة في كل خانة

بعد فرز كل البطاقات:

- إذا كان هناك عامل غير مذكور ضمن البطاقات و تعتقد بأن له تأثير مهم.. يمكنك إضافته باستخدام البطاقات الفارغة لدى الباحث
- راجع ترتيبك للبطاقات.. و غير إن أحسست بحاجة لذلك

[6/10/2017] [V 1.0][Q methodology] [ERGO no: 27832]

Appendix M Q sorting categories

M.1 Sorting categories (English version)

neutral

unimportant

M.2 Sorting categories (Arabic version)

عوامل مهمة

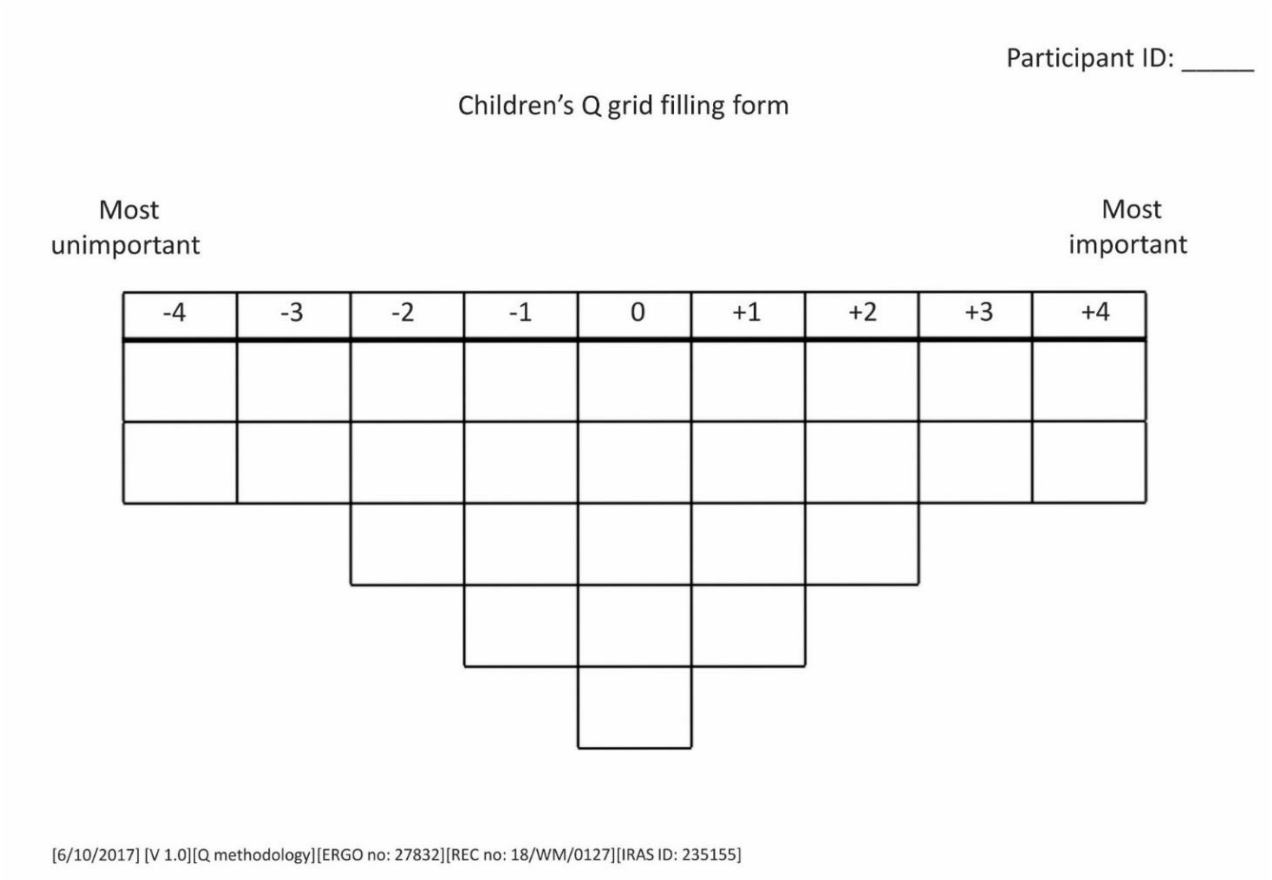
عوامل لها تأثير بسيط

Appendix M

عوامل غير مهمة

Appendix N Q filling form

N.1 Children's Q filling form (UK version)



Participant ID: _____

Children's Q grid filling form

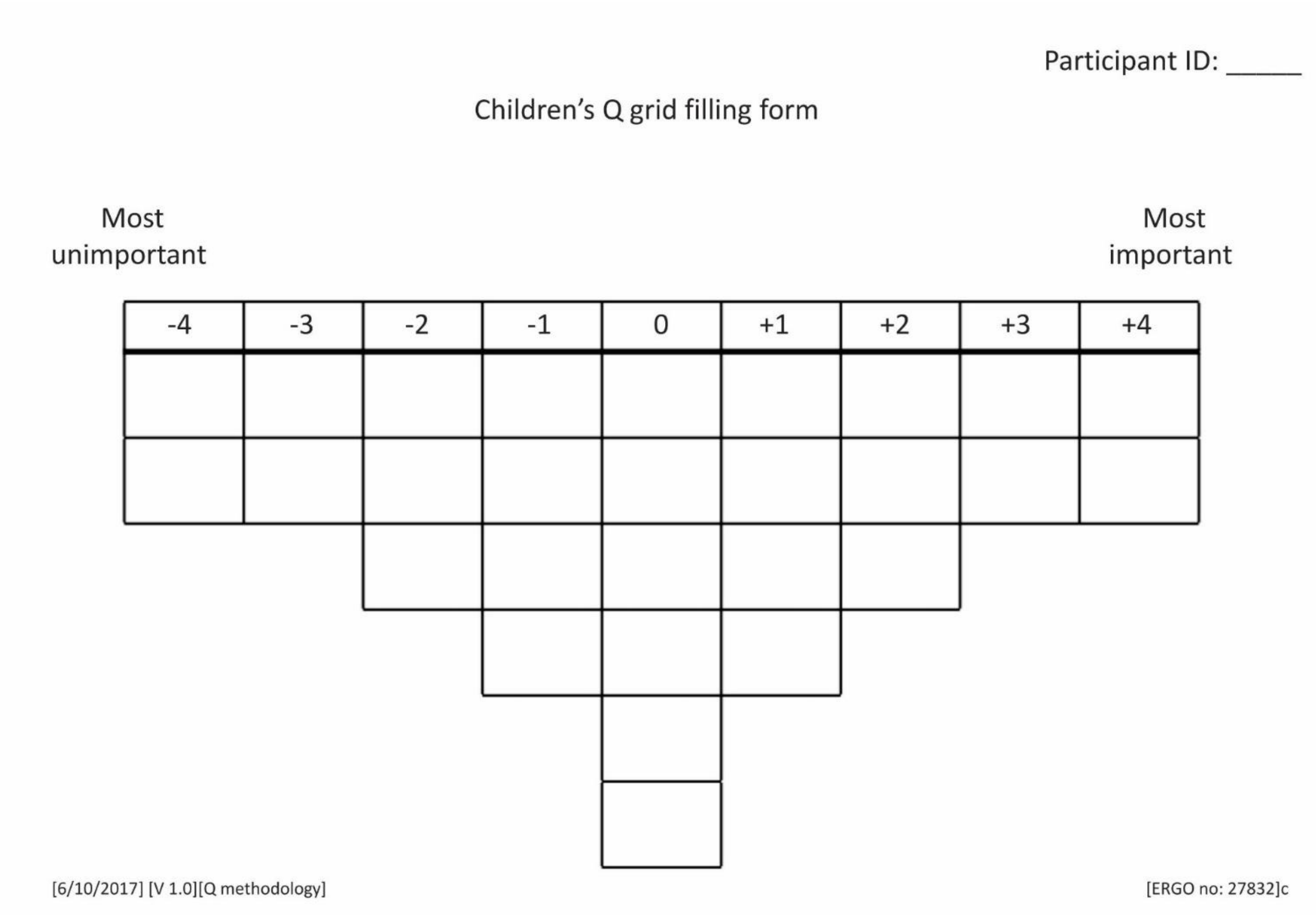
Most unimportant

Most important

-4	-3	-2	-1	0	+1	+2	+3	+4

[6/10/2017] [V 1.0][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

N.2 Children's Q filling form (Kuwait version)



Participant ID: _____

Children's Q grid filling form

Most unimportant

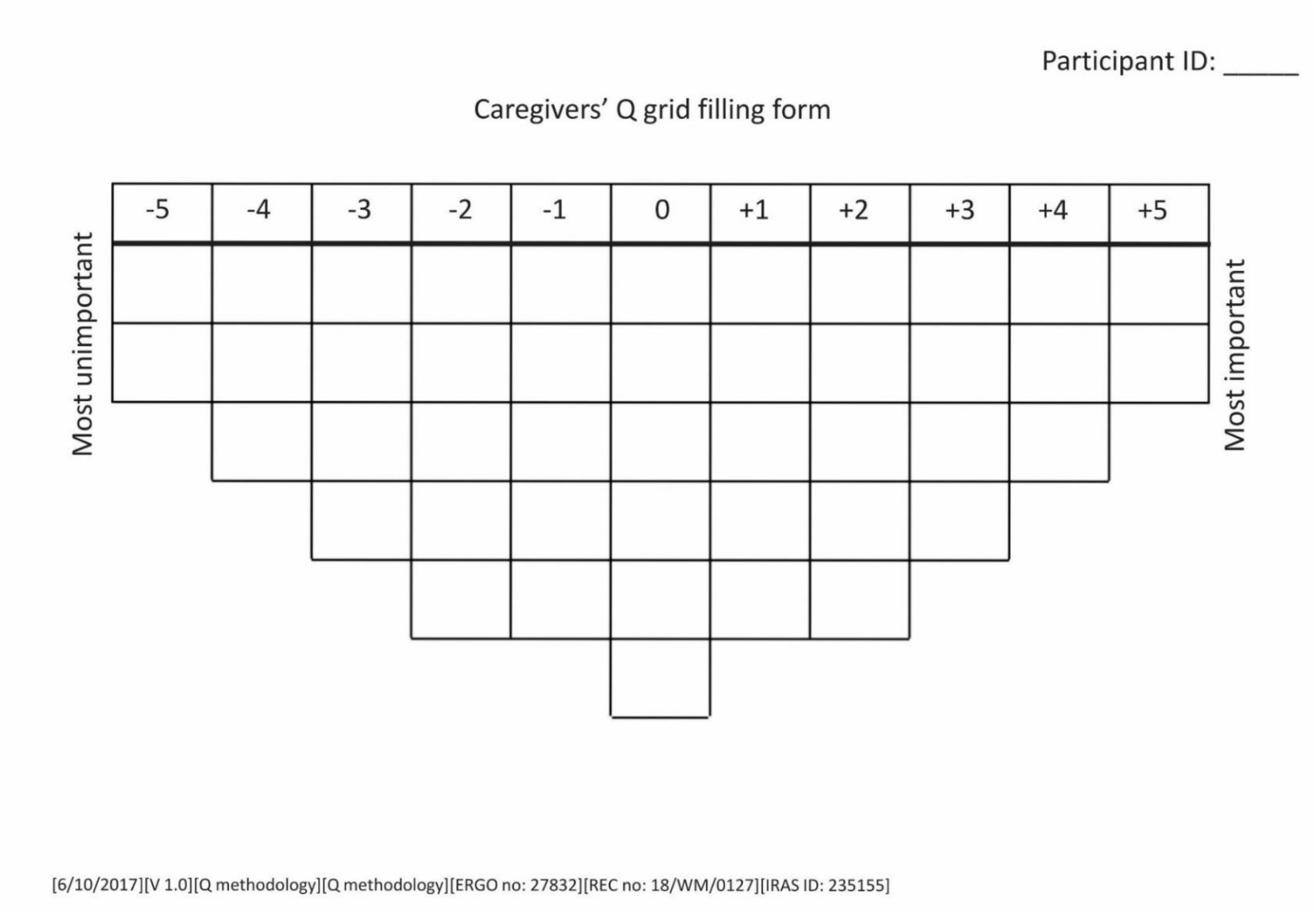
Most important

-4	-3	-2	-1	0	+1	+2	+3	+4

[6/10/2017] [V 1.0][Q methodology]

[ERGO no: 27832]c

N.3 Caregivers' Q filling form (UK version)

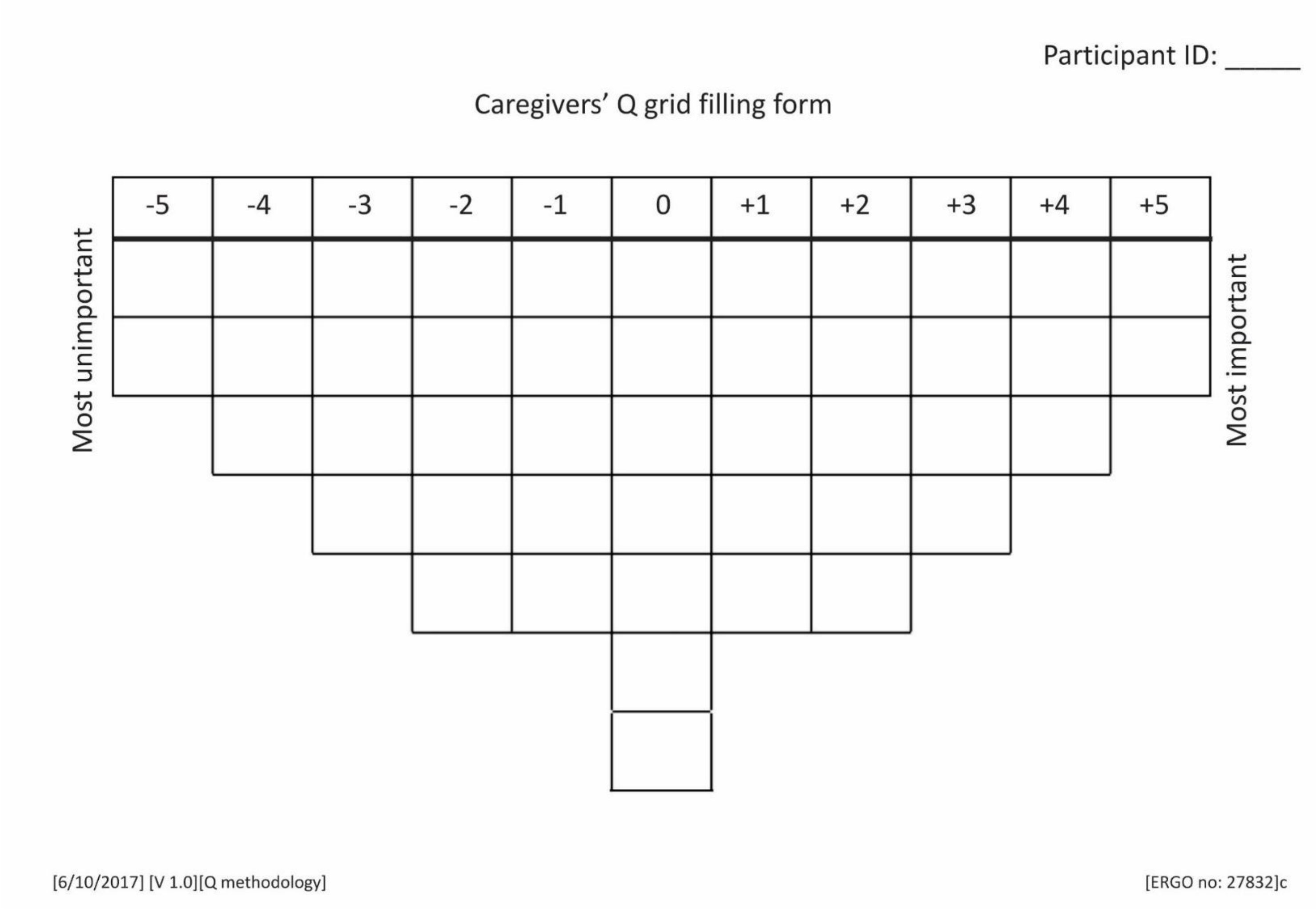


Participant ID: ______

Caregivers' Q grid filling form

[6/10/2017][V 1.0][Q methodology][Q methodology][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

N.4 Caregivers’ Q filling form (Kuwait version)



Participant ID: ______

Caregivers’ Q grid filling form

Most unimportant

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5

Most important

[6/10/2017] [V 1.0][Q methodology]

[ERGO no: 27832]c

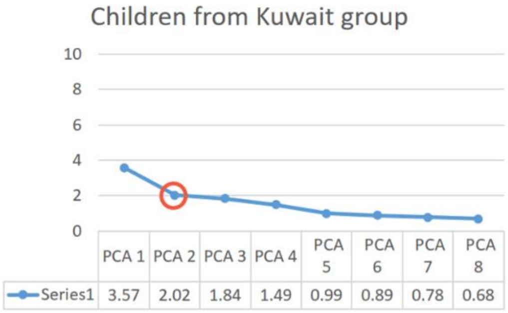
Appendix O Values used to select number of extracted factors

Participants' group	The standard error (SE)[1]		The significant loading value[2]		Variance covered by the extracted factors
	The calculated equation	SE=	The calculated equation	Significant loading value=	
Children from Kuwait	$1 \div \sqrt{28}$	0.188	$2.58 \times (1 \div \sqrt{28})$	0.487	37%
Children from the UK	$1 \div \sqrt{27}$	0.192	$2.58 \times (1 \div \sqrt{27})$	0.49	40%
Caregivers from Kuwait	$1 \div \sqrt{45}$	0.149	$2.58 \times (1 \div \sqrt{45})$	0.384	35%
Caregivers from the UK	$1 \div \sqrt{44}$	0.15	$2.58 \times (1 \div \sqrt{44})$	0.388	49%

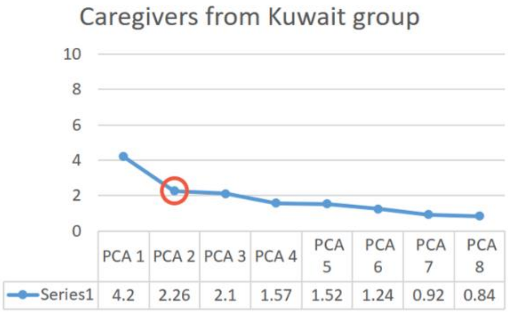
[1] SE= $1 \div \sqrt{\text{no. items in Q set}}$

[2] Significant loading value$_{\text{(at P-value < 0.01)}}$= $2.58 \times (1 \div \sqrt{\text{no. items in Q set}})$

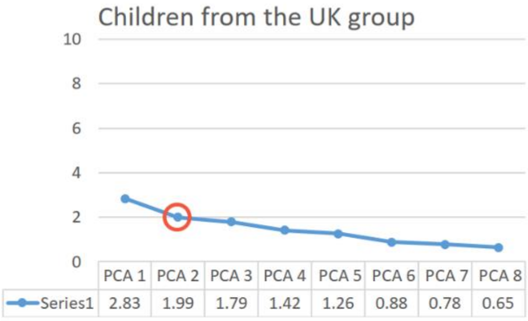
Appendix PScree plot



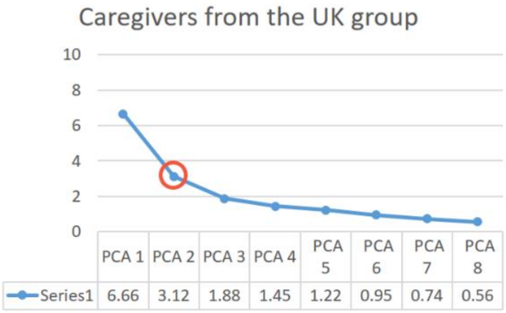
(a)



(c)



(b)

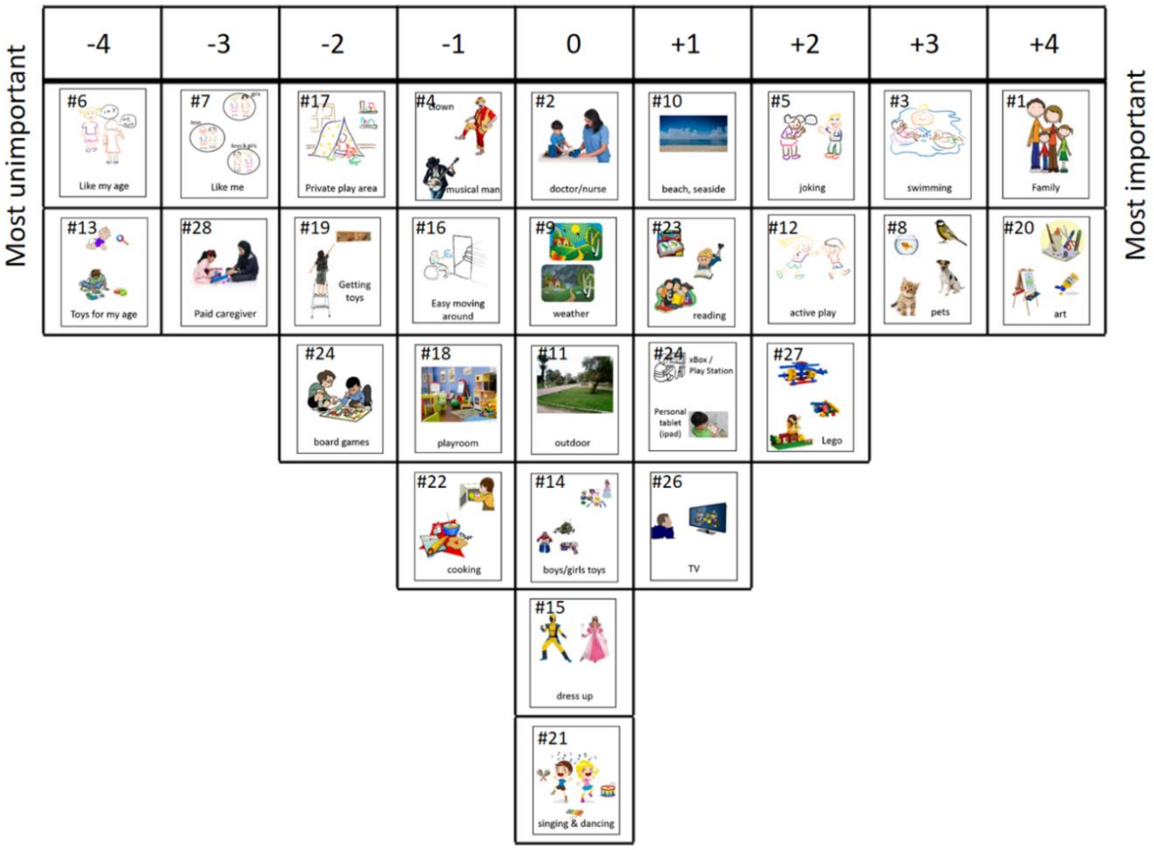


(d)

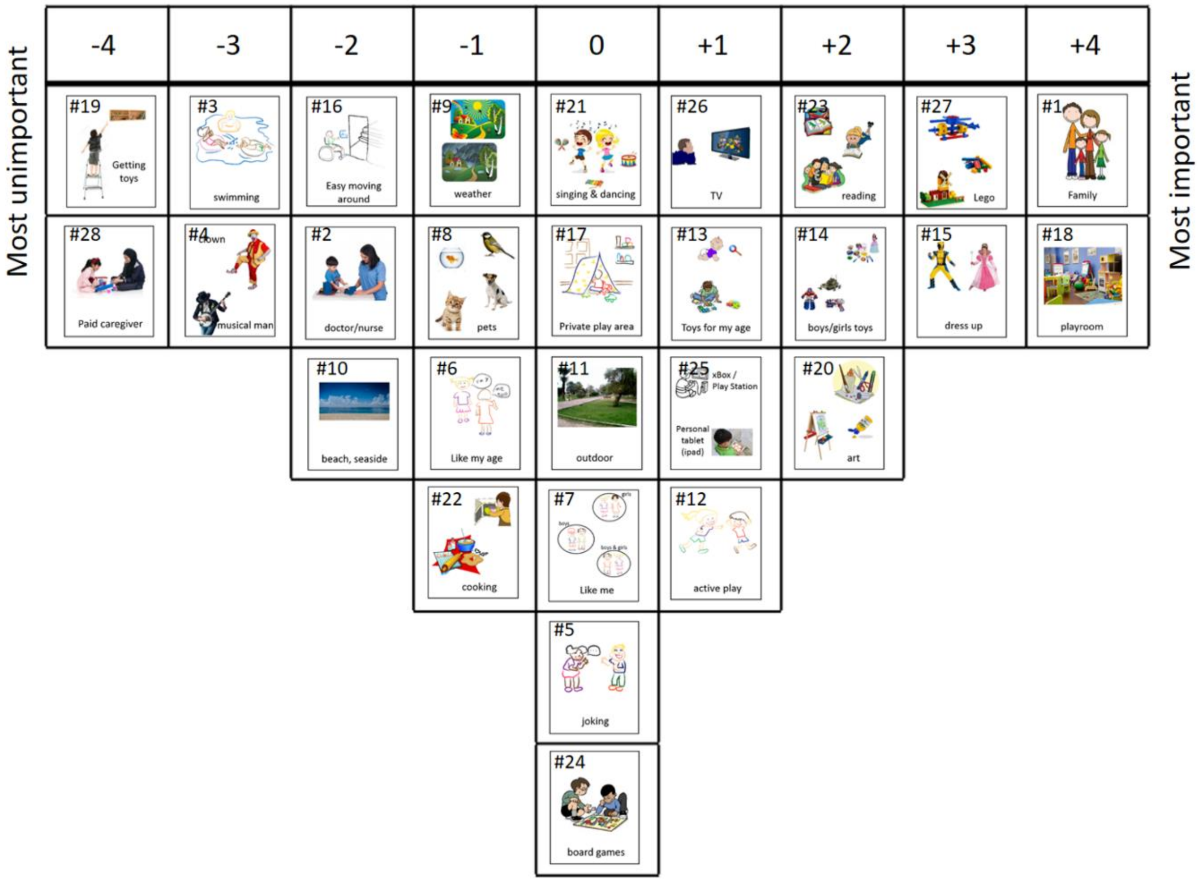
Appendix Q Factor array and crib sheet

Q.1 Factor array group 1: children from Kuwait

Q.1.1 Factor array for factor 1



Q.1.2 Factor array for factor 2



Most unimportant

-4	-3	-2	-1	0	+1	+2	+3	+4
#19 Getting toys	#3 swimming	#16 Easy moving around	#9 weather	#21 singing & dancing	#26 TV	#23 reading	#27 Lego	#1 Family
#28 Paid caregiver	#4 clown musical man	#2 doctor/nurse	#8 pets	#17 Private play area	#13 Toys for my age	#14 boys/girls toys	#15 dress up	#18 playroom
		#10 beach, seaside	#6 Like my age	#11 outdoor	#25 xBox / Play Station Personal tablet (ipad)	#20 art		
			#22 cooking	#7 Like me	#12 active play			
				#5 joking				
				#24 board games				

Most important

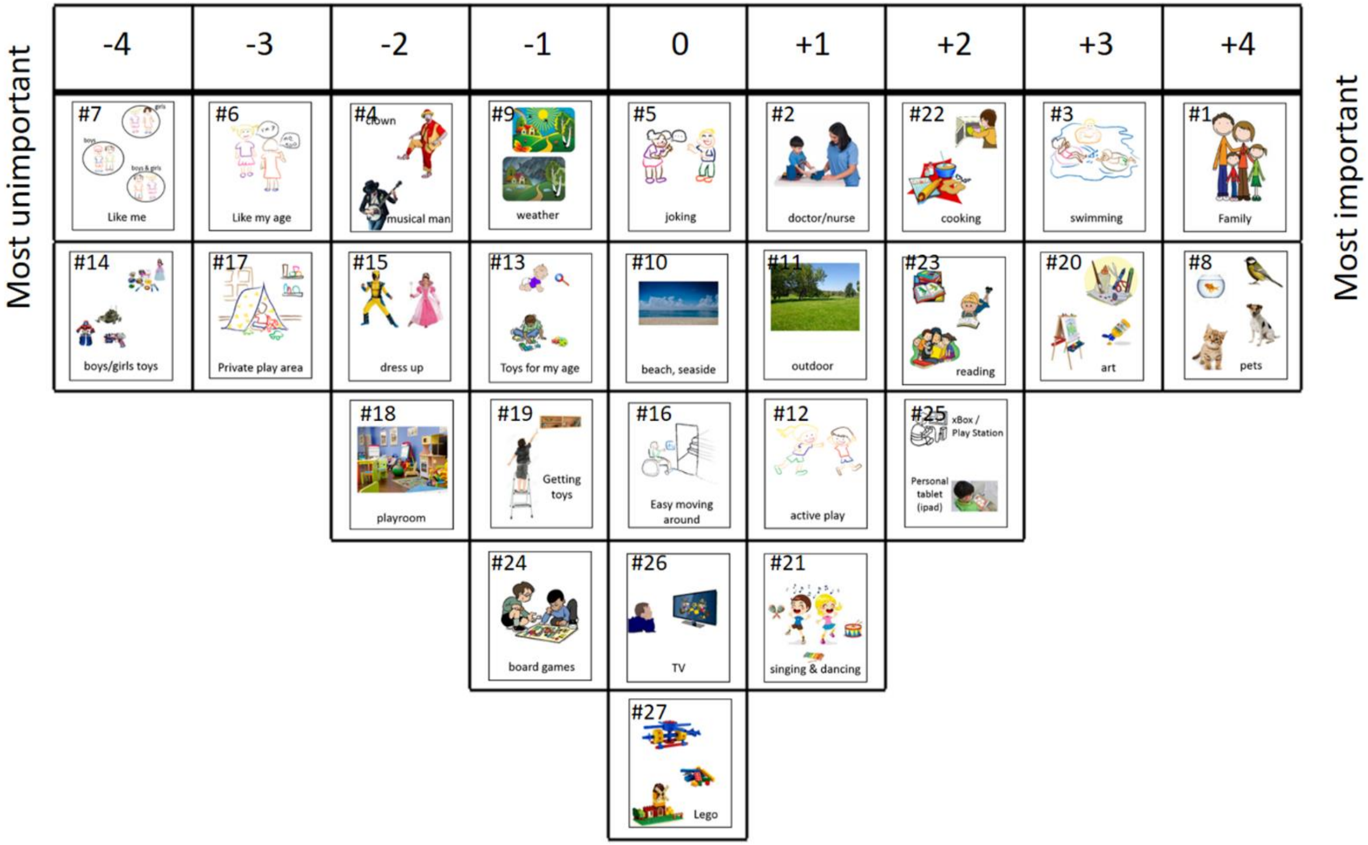
Q.1.3 Crib sheet

	factor 1	
	items ranked at **+4**	
1	family	+4
20	art	+4
	items ranked **higher in factor 2** array than in any other factor arrays	
3	swimming	+3
8	pets	+3
	items ranked **lower in factor 2** array than in any other factor arrays	
6	like my age	-4
7	like me	-3
13	toys for my age	-4
	items ranked at **-4**	
6	like my age	-4
13	toys for my age	-4

	factor 2	
	items ranked at **+4**	
1	family	+4
18	playroom	+4
	items ranked **higher in factor 1** array than in any other factor arrays	
15	dress up	+3
18	playroom	+4
	items ranked **lower in factor 1** array than in any other factor arrays	
3	swimming	-3
4	clown/musical man	-3
8	pets	-1
	items ranked at **-4**	
19	getting toys	-4
28	paid caregiver	-4

Q.2 Factor array group 2: children from the UK

Q.2.1 Factor array for factor 1



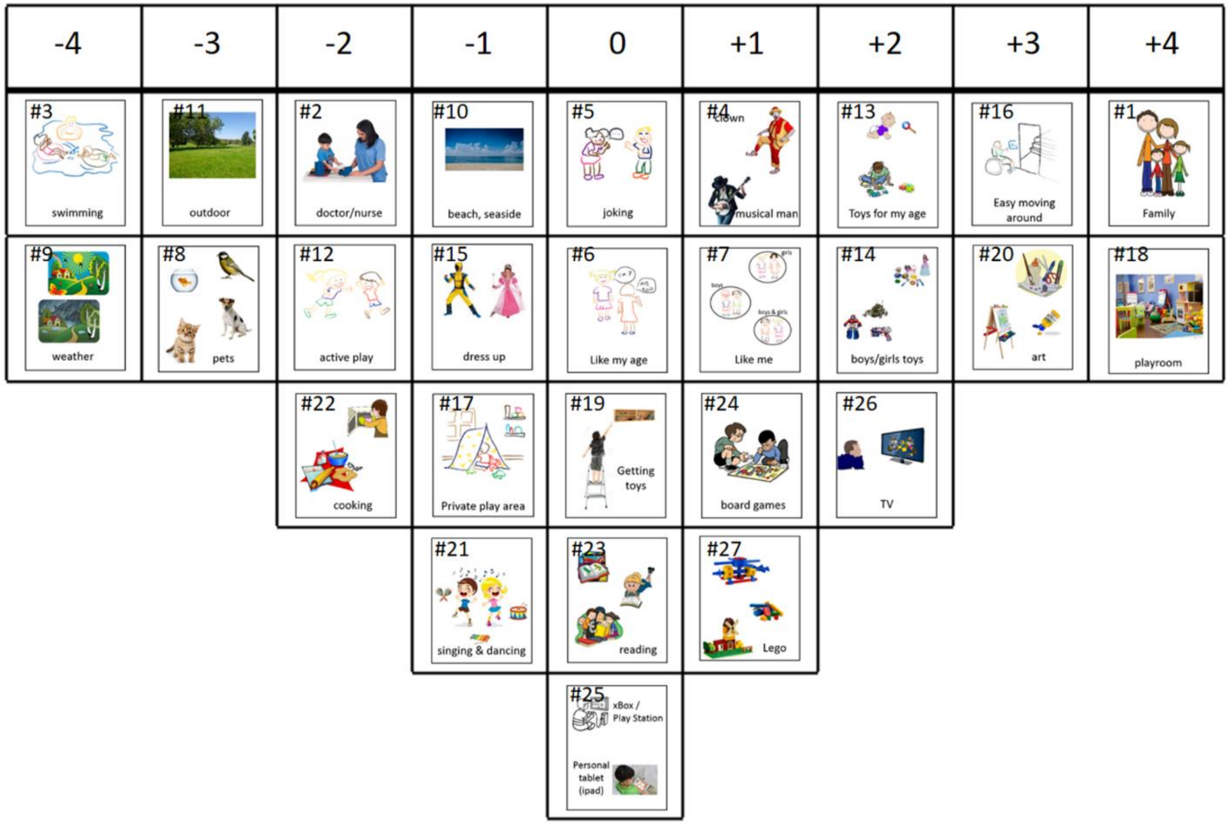
Most unimportant

-4	-3	-2	-1	0	+1	+2	+3	+4
#7 Like me	#6 Like my age	#4 clown musical man	#9 weather	#5 joking	#2 doctor/nurse	#22 cooking	#3 swimming	#1 Family
#14 boys/girls toys	#17 Private play area	#15 dress up	#13 Toys for my age	#10 beach, seaside	#11 outdoor	#23 reading	#20 art	#8 pets
		#18 playroom	#19 Getting toys	#16 Easy moving around	#12 active play	#25 xBox / Play Station Personal tablet (ipad)		
			#24 board games	#26 TV	#21 singing & dancing			
				#27 Lego				

Most important

Q.2.2 Factor array for factor 2

Most unimportant



-4	-3	-2	-1	0	+1	+2	+3	+4
#3 swimming	#11 outdoor	#2 doctor/nurse	#10 beach, seaside	#5 joking	#4 clown musical man	#13 Toys for my age	#16 Easy moving around	#1 Family
#9 weather	#8 pets	#12 active play	#15 dress up	#6 Like my age	#7 Like me	#14 boys/girls toys	#20 art	#18 playroom
		#22 cooking	#17 Private play area	#19 Getting toys	#24 board games	#26 TV		
			#21 singing & dancing	#23 reading	#27 Lego			
				#25 xBox / Play Station Personal tablet (ipad)				

Most important

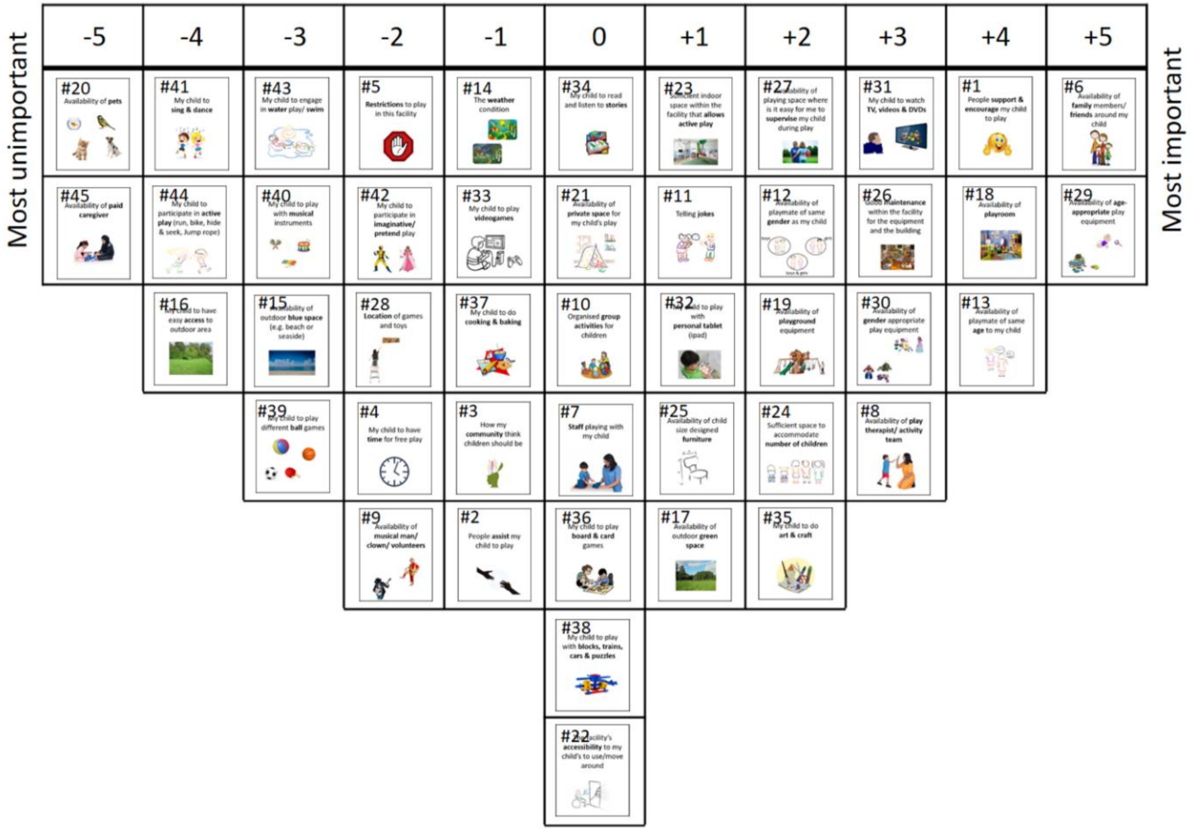
Q.2.3 Crib sheet

factor 1		
items ranked at **+4**		
1	family	+4
8	pets	+4
items ranked **higher in factor 1** array than in any other factor arrays		
3	swimming	+3
8	pets	+4
items ranked **lower in factor 1** array than in any other factor arrays		
14	boys/ girls toys	-4
6	like my age	-3
7	like me	-4
items ranked at **-4**		
7	like me	-4
14	boys/ girls toys	-4

factor 2		
items ranked at **+4**		
1	family	+4
18	playroom	+4
items ranked **higher in factor 2** array than in any other factor arrays		
16	easy moving around	+3
18	playroom	+4
items ranked **lower in factor 2** array than in any other factor arrays		
8	pets	-3
9	wether	-4
11	outdoor	-3
items ranked at **-4**		
3	swimming	-4
9	weather	-4

Q.3 Factor array group 3: caregivers from Kuwait

Q.3.1 Factor array for factor 1



Most unimportant

Most important

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
#20 Availability of **pets**	#41 My child to **sing & dance**	#43 My child to engage in **water** play/ **swim**	#5 **Restrictions** to play in this facility	#14 The **weather** condition	#34 My child to read and listen to **stories**	#23 Sufficient indoor space within the facility that **allows active play**	#27 Availability of playing space where is it easy for me to **supervise** my child during play	#31 My child to watch **TV, videos & DVDs**	#1 People **support & encourage** my child to play	#6 Availability of **family** members/ **friends** around my child
#45 Availability of **paid caregiver**	#44 My child to participate in **active play** (run, bike, hide & seek, Jump rope)	#40 My child to play with **musical** instruments	#42 My child to participate in **imaginative/ pretend** play	#33 My child to play **videogames**	#21 Availability of **private space** for my child's play	#11 Telling **jokes**	#12 Availability of playmate of same **gender** as my child	#26 Good **maintenance** within the facility for the equipment and the building	#18 Availability of **playroom**	#29 Availability of **age-appropriate** play equipment
	#16 My child to have easy **access** to outdoor area	#15 Availability of outdoor **blue space** (e.g. beach or seaside)	#28 **Location** of games and toys	#37 My child to do **cooking & baking**	#10 Organised **group activities** for children	#32 My child to play with **personal tablet** (ipad)	#19 Availability of **playground** equipment	#30 Availability of **gender** appropriate play equipment	#13 Availability of playmate of same **age** to my child	
		#39 My child to play different **ball** games	#4 My child to have **time** for free play	#3 How my **community** think children should be	#7 **Staff** playing with my child	#25 Availability of child size designed **furniture**	#24 Sufficient space to accommodate **number of children**	#8 Availability of **play therapist/ activity team**		
			#9 Availability of **musical man/ clown/ volunteers**	#2 People **assist** my child to play	#36 My child to play **board & card** games	#17 Availability of outdoor **green space**	#35 My child to do **art & craft**			
					#38 My child to play with **blocks, trains, cars & puzzles**					
					#22 The facility's **accessibility** to my child's to use/move around					

Q.3.2 Factor array for factor 2

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
#37 My child to do **cooking & baking**	#43 My child to engage in **water** play/ **swim**	#9 Availability of **musical man/ clown/ volunteers**	#44 My child to participate in **active play** (run, bike, hide & seek, Jump rope)	#20 Availability of **pets**	#5 **Restrictions** to play in this facility	#28 **Location** of games and toys	#31 My child to watch **TV, videos & DVDs**	#8 Availability of **play therapist/ activity team**	#40 My child to play with **musical** instruments	#45 Availability of **paid caregiver**
#3 How my **community** think children should be	#14 The **weather** condition	#15 Availability of outdoor **blue space** (e.g. beach or seaside)	#12 Availability of playmate of same **gender** as my child	#41 My child to **sing & dance**	#42 My child to participate in **imaginative/ pretend** play	#19 Availability of **playground** equipment	#18 Availability of **playroom**	#24 Sufficient space to accommodate **number of children**	#26 Good **maintenance** within the facility for the equipment and the building	#6 Availability of **family** members/ **friends** around my child
	#36 My child to play **board & card** games	#35 My child to do **art & craft**	#32 My child to play with **personal tablet** (ipad)	#27 Availability of playing space where is it easy for me to **supervise** my child during play	#4 My child to have **time** for free play	#13 Availability of playmate of same **age** to my child	#21 Availability of **private space** for my child's play	#2 People **assist** my child to play	#1 People **support & encourage** my child to play	
		#30 Availability of **gender** appropriate play equipment	#29 Availability of **age-appropriate** play equipment	#16 My child to have easy **access** to outdoor area	#39 My child to play different **ball** games	#10 Organised **group activities** for children	#44 Sufficient indoor space within the facility that **allows active play**	#7 **Staff** playing with my child		
			#33 My child to play **videogames**	#17 Availability of outdoor **green space**	#22 facility's **accessibility** to my child's to use/move around	#11 Telling **jokes**	#25 Availability of child size designed **furniture**			
					#34 My child to read and listen to **stories**					
					#38 My child to play with **blocks, trains, cars & puzzles**					

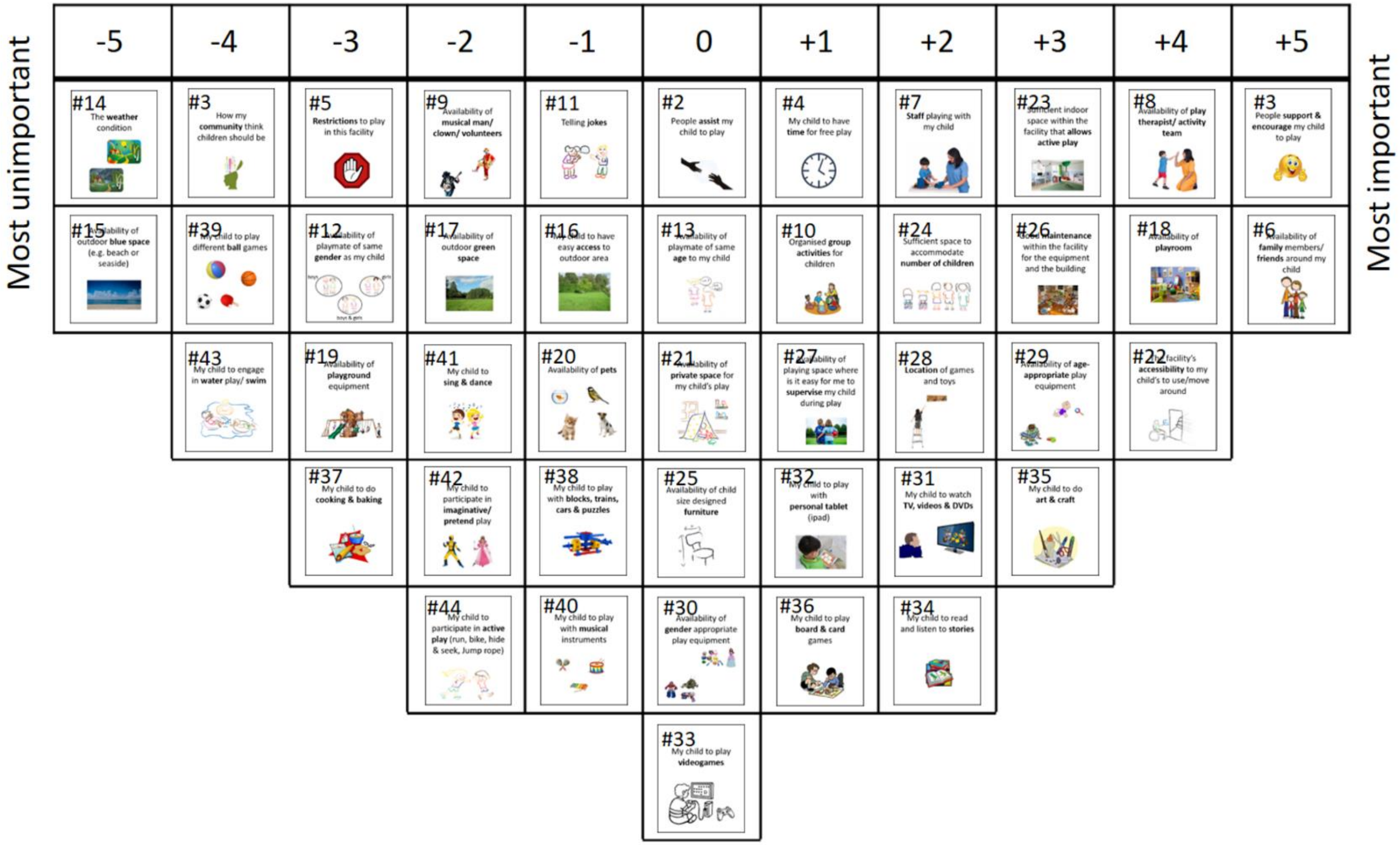
Q.3.3 Crib sheet

	factor 1	
	items ranked at **+5**	
6	family & friends	+5
29	age appropriate play equip	+5
	items ranked **higher in factor 1** array than in any other factor arrays	
13	playmate age	+4
29	age appropriate play equipment	+5
30	gender appropriate play equipment	+3
	items ranked **lower in factor 1** array than in any other factor arrays	
16	easy access to outdoor	-4
20	pets	-5
39	ball games	-3
40	musical instruments	-3
41	sing & dance	-4
	items ranked at **-5**	
20	pets	-5
45	paid caregiver	-5

	factor 2	
	items ranked at **+5**	
6	family & friends	+5
45	paid caregiver	+5
	items ranked **higher in factor 2** array than in any other factor arrays	
2	assistant	+3
40	musical instruments	+4
45	paid caregiver	+5
	items ranked **lower in factor 2** array than in any other factor arrays	
3	community think	-5
12	playmate gender	-2
14	weather	-4
35	art & crafts	-3
36	board & card games	-4
37	cooking & baking	-5
	items ranked at **-5**	
3	community think	-5
37	cooking & baking	-5

Q.4 Factor array group 4: caregivers from the UK

Q.4.1 Factor array for factor 1



Most unimportant

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
#14 The **weather** condition	#3 How my **community** think children should be	#5 **Restrictions** to play in this facility	#9 Availability of **musical man/ clown/ volunteers**	#11 Telling **jokes**	#2 People **assist** my child to play	#4 My child to have **time** for free play	#7 **Staff** playing with my child	#23 Sufficient indoor space within the facility that **allows active play**	#8 Availability of **play therapist/ activity team**	#3 People **support & encourage** my child to play
#15 Availability of outdoor **blue space** (e.g. beach or seaside)	#39 My child to play different **ball** games	#12 Availability of playmate of same **gender** as my child	#17 Availability of outdoor **green space**	#16 My child to have easy **access** to outdoor area	#13 Availability of playmate of same **age** to my child	#10 Organised **group activities** for children	#24 Sufficient space to accommodate **number of children**	#26 **Good maintenance** within the facility for the equipment and the building	#18 Availability of **playroom**	#6 Availability of **family** members/ **friends** around my child
	#43 My child to engage in **water** play/ **swim**	#19 Availability of **playground** equipment	#41 My child to **sing & dance**	#20 Availability of **pets**	#21 Availability of **private space** for my child's play	#27 Availability of playing space where is it easy for me to **supervise** my child during play	#28 **Location** of games and toys	#29 Availability of **age-appropriate** play equipment	#22 The facility's **accessibility** to my child's to use/move around	
		#37 My child to do **cooking & baking**	#42 My child to participate in **imaginative/ pretend** play	#38 My child to play with **blocks, trains, cars & puzzles**	#25 Availability of child size designed **furniture**	#32 My child to play with **personal tablet** (ipad)	#31 My child to watch **TV, videos & DVDs**	#35 My child to do **art & craft**		
			#44 My child to participate in **active play** (run, bike, hide & seek, Jump rope)	#40 My child to play with **musical** instruments	#30 Availability of **gender** appropriate play equipment	#36 My child to play **board & card** games	#34 My child to read and listen to **stories**			
					#33 My child to play **videogames**					

Most important

Q.4.2 Factor array for factor 2

Most unimportant

Most important

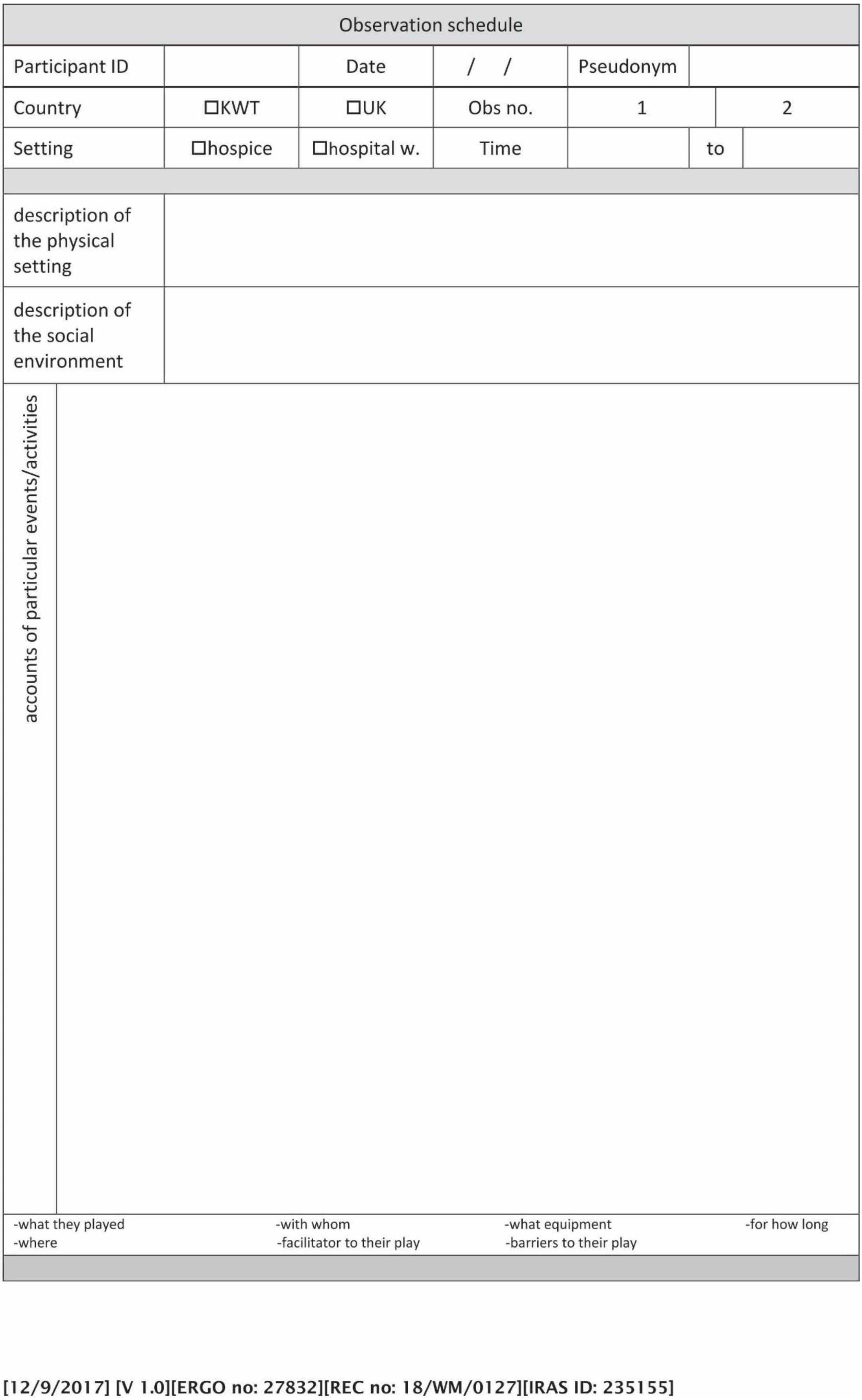
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
#33 My child to play **videogames**	#3 How my **community** think children should be	#11 Telling **jokes**	#5 **Restrictions** to play in this facility	#10 Organised **group activities** for children	#4 My child to have **time** for free play	#8 Availability of **play therapist/ activity team**	#15 Availability of outdoor **blue space** (e.g. beach or seaside)	#7 **Staff** playing with my child	#1 People **support & encourage** my child to play	#6 Availability of **family** members/ **friends** around my child
#36 My child to play **board & card** games	#12 Availability of playmate of same **gender** as my child	#13 Availability of playmate of same **age** to my child	#25 Availability of child size designed **furniture**	#14 The **weather** condition	#18 Availability of **playroom**	#9 Availability of **musical man/ clown/ volunteers**	#17 Availability of outdoor **green space**	#16 My child to have easy **access** to outdoor area	#2 People **assist** my child to play	#43 My child to engage in **water play/ swim**
	#30 Availability of **gender** appropriate play equipment	#39 My child to play different **ball** games	#35 My child to do **art & craft**	#19 Availability of **playground** equipment	#24 Sufficient space to accommodate **number of children**	#26 Good **maintenance** within the facility for the equipment and the building	#21 Availability of **private space** for my child's play	#34 My child to read and listen to **stories**	#32 My child to play with **personal tablet** (ipad)	
		#42 My child to participate in **imaginative/ pretend** play	#38 My child to play with **blocks, trains, cars & puzzles**	#37 My child to do **cooking & baking**	#28 **Location** of games and toys	#25 Availability of playing space where is it easy for me to **supervise** my child during play	#22 The facility's **accessibility** to my child's to use/move around	#40 My child to play with **musical** instruments		
			#44 My child to participate in **active play** (run, bike, hide & seek, Jump rope)	#29 Availability of **age-appropriate** play equipment	#41 My child to **sing & dance**	#31 My child to watch **TV, videos & DVDs**	#23 Sufficient indoor space within the facility that **allows active play**			
					#20 Availability of **pets**					

Q.4.3 Crib sheet

	factor 1	
	items ranked at **+5**	
1	support & encouragement	+5
6	family & friends	+5
	items ranked **higher in factor 1** array than in any other factor arrays	
8	play therapist	+4
18	playroom	+4
35	art & crafts	+3
	items ranked **lower in factor 1** array than in any other factor arrays	
43	water play/ swimming	-4
14	weather	-5
15	blue space	-5
	items ranked at **-5**	
14	weather	-5
15	blue space	-5

	factor 2	
	items ranked at **+5**	
1	family & friends	+5
43	water play/ swimming	+5
	items ranked **higher in factor 2** array than in any other factor arrays	
2	assistant	+3
32	personal tablets	+4
43	water play/ swimming	+5
	items ranked **lower in factor 2** array than in any other factor arrays	
30	gender appropriate play equipment	-4
33	videogames	-5
36	board & card games	-5
	items ranked at **-5**	
33	videogames	-5
36	board & card games	-5

Appendix R Observational schedule



Observation schedule						
Participant ID		Date	/ /	Pseudonym		
Country	☐KWT	☐UK	Obs no.	1	2	
Setting	☐hospice	☐hospital w.	Time		to	
description of the physical setting						
description of the social environment						
accounts of particular events/activities						
-what they played -where	-with whom -facilitator to their play	-what equipment -barriers to their play	-for how long			

[12/9/2017] [V 1.0][ERGO no: 27832][REC no: 18/WM/0127][IRAS ID: 235155]

Appendix S Classifications used for analysing children's play

Play type		definition
a) Nature of play type		
1.	Active/motor play	Gross bodily movements, play with motion, physical play. E.g., running, jumping, playing sports and rough-and-tumble.
2.	Explorative and manipulative play	Exploration of object/environment and simple manipulation of objects. E.g., listening to the sound of the ringing bells and exploring glass peddles coloured stones.
3.	Constructive play	Creation, making and building. E.g., arts and crafts, building blocks and puzzle.
4.	Pretend play	Use of objects and/or actions for imitation, role play, imaginative and make a believe play E.g., play house, fantasy figures and playing with cars.
5.	Games with rules	Games with pre-set rules, require some level of understanding. E.g., connect four and monopoly.
6.	Communication/ language play	Play using words and gestures. E.g., jokes, singing and storytelling.
7.	Play with electronic devices	Playing with electronic devices. E.g., watching TV and playing videogames.
b) Social participation during play		
1.	Solitary play	Child plays alone by themselves.
2.	Parallel play	Child plays alongside other playmate nearby but with no interaction.
3.	Co-operative play	Child plays and interact with others

Appendix TPlay classification sample sheet for analysing every child’s observation

Classifications of types of play		Social participation during play		
		a. Solitary play	b. Parallel play	c. Co-operative play
Nature of observed behaviours	1. Active Play			
	2. Explorative/ Manipulative Play			
	3. Constructive Play			
	4. Pretend Play			
	5. Games with rules			
	6. Communication/ language play			
	7. Play with electronic devices			

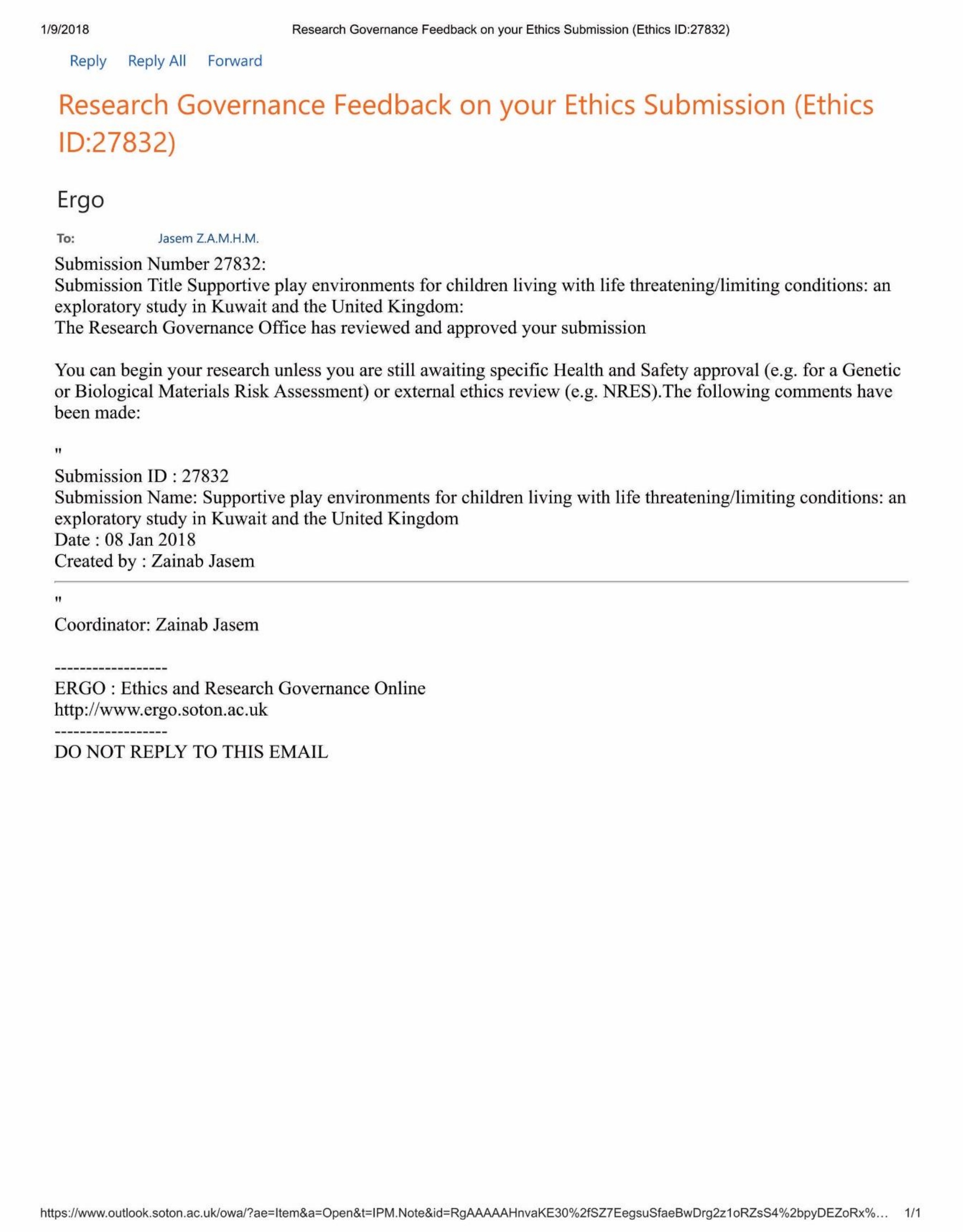
Appendix U Sample of coding the observational data

Theme	Sub-theme	Field note	Interpretation
Children’s play characteristics	Observed play behaviours and areas of play	P77 was lying on her bed and watching YouTube using her tablet, she was watching Mr. Tumble	Children’s behaviours were recorded to identify types of play they engaged in and the areas/spaces they spent in to play
	Children’s social interaction during play	P15 entered the playroom with his mother. The play specialist welcomed him, but he did not respond. There was another child playing on a table. He moved to the middle of the room, turned back to the first table next to the door (the that no one was using it) and sat there.	No-to-very limited interaction was observed between the children. They used to use table that no other child is using.
Social environmental factors	Assistance and facilitation of the children’s play	P52 pressed too hard on the glue to get the required amount. She said “mommy this is hard”, the mom moved nearer to P52, and she started pressing on the glue bottle. P52 asked the mom to stop when she reached the line.	Most of the children needed assistance during their play
	Child’s autonomy	P17 was watching TV. The TV was an adults’ TV show. I asked P17 about her favourite channel, it was MBC 3 (kids channel). The mother was talking to her other children over phone. Later on, she was looking at her mobile phone. I asked the mother if there was a children's channel on this TV. The mother nodded her head yes and said in low voice “I don't like these channels very noisy”	Despite the mother was not watching TV, she did not want it to be on children’s channel because of the noise.

Physical environmental factors	Availability and accessibility of resources	P66 entered the playroom by herself. Nobody was there. She sat on a table for a while. On the table, there was a cup filled with pens. P66 went and brought some papers. And started drawing.	Children found to play with whatever they found in front of their eyes.
	Used equipment qualities and properties	While P11 was in a playroom, she asked me that she want to play with dolls (pointing at the doll house). This is because she needs help when moving as someone to move the infusion.	Although the child is independent in mobility, she found it difficult to move and propel the infusion.

Appendix V Ethics approval

V.1 ERGO ethics approval



Research Governance Feedback on your Ethics Submission (Ethics ID:27832)

Ergo

To: Jasem Z.A.M.H.M.

Submission Number 27832:
Submission Title Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom:
The Research Governance Office has reviewed and approved your submission

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external ethics review (e.g. NRES).The following comments have been made:

"
Submission ID : 27832
Submission Name: Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom
Date : 08 Jan 2018
Created by : Zainab Jasem

"
Coordinator: Zainab Jasem

ERGO : Ethics and Research Governance Online
http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

Appendix V

University of
Southampton

Zainab Jasem
University of Southampton
Centre for Innovation and Leadership in Health Sciences

Date: 8th January 2018

Dear Zainab,

Professional Indemnity and Clinical Trials Insurance

Project Title: Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom

ERGO Ref: 27832

Participant Type	**Number of participants**	**Participant age group**
Healthy volunteers	Adult	45
Patients	Minors	75

Thank you for submitting the completed questionnaire and attached papers.

Having taken note of the information provided, I can confirm that this project will be covered under the terms and conditions of the above policy, subject to informed consent being obtained from the participating volunteers.

If there are any changes to the above details, please advise us, as failure to do so may invalidate the insurance.

Jenny King.

Mrs Jenny King
Senior Insurance Services Assistant

Tel: 023 8059 2417
email: jsk1n08@soton.ac.uk
Finance Department, University of Southampton, Highfield Campus, Southampton SO17 1BJ U.K.
Tel: +44(0)23 8059 5000 Fax: +44(0)23 8059 2195 www.southampton.ac.uk

V.2 Children’s hospital ward, Ministry of Health (Kuwait) ethics approval

State Of Kuwait
Ministry Of Health
Asst. Undersecretary for Planning & Quality

دولة الكويت
وزارة الصحة
وكيل الوزارة المساعد لشئون التخطيط والجودة

صادر
مكتب الوكيل المساعد
لشئون الخدمات الطبية المساندة
لجنة الأبحاث
رقم : ١٤١٠
التاريخ ٢٥/ ١ / 20١٨م

التاريخ: ٢٥/ ١ / ٢٠١٨م
الرقم : ١٤٠٩

السيد الفاضل / د. وكيل الوزارة المحترم

تحية طيبة وبعد،،،،

<u>الموضوع / تسهيل مهمة الباحثة / زينب عبد العزيز جاسم وآخرون – طالبة دكتوراه في جامعة ساوثهامبتون – المملكة المتحدة (رقم البحث 2017/718) لأجراء البحث تحت عنوان:</u>

<u>Supportive play environments for children living with life threatening / limiting conditions: an exploratory study in Kuwait and the UK</u>

يرجي التفضل بالإحاطة بأن اللجنة الدائمة لتنسيق البحوث الطبية والصحية المشكلة بموجب القرار الوزاري رقم 207 لسنة 2012 قد أوصت باجتماعها الواحد والاربعون (10 / 2017) المنعقد يوم الثلاثاء الموافق 26 / 12 /2017 بالموافقة على إجراء البحث رقم (718 / 2017) المقدم من **الباحثة / زينب عبد العزيز جاسم وآخرون –طالبة دكتوراه في جامعة ساوثهامبتون – المملكة المتحدة -** بتاريخ 2017/12/25 تحت عنوان:

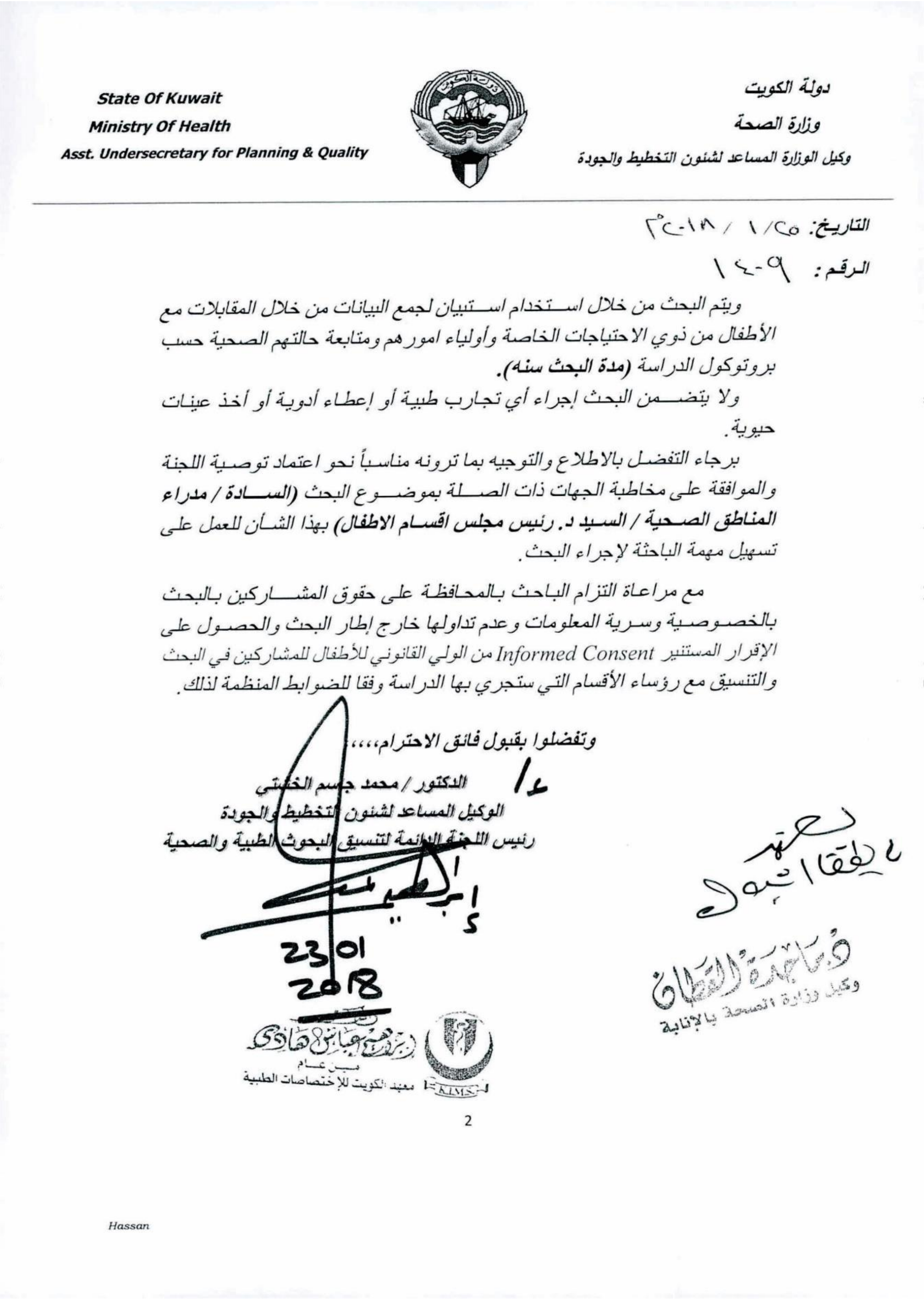
<u>Supportive play environments for children living with life threatening / limiting conditions: an exploratory study in Kuwait and the UK</u>

وذلك بعد أن قامت اللجنة استنادا للقرار الوزاري رقم 207 لسنة 2012 والتعميم الصادر من السيد / وكيل الوزارة برقم 156 لسنة 2012 باستطلاع آراء الجهات ذات العلاقة بموضوع البحث حيث وافق السيد / الوكيل المساعد للشئون القانونية بالكتاب الوارد برقم 379 بتاريخ 21 / 1 / 2018 ووافق السيد / د. رئيس مجلس اقسام الأطفال بالكتاب رقم 372 بتاريخ 17 / 1 / 2018.

السيد د. مدير منطقة الصباح الصحية لتنفيذه المحترم

1

Hassan



State Of Kuwait
Ministry Of Health
Asst. Undersecretary for Planning & Quality

دولة الكويت
وزارة الصحة
وكيل الوزارة المساعد لشئون التخطيط والجودة

التاريخ: ٢٥/١ / ٢٠١٨م
الرقم: ١٤-٩

ويتم البحث من خلال استخدام استبيان لجمع البيانات من خلال المقابلات مع الأطفال من ذوي الاحتياجات الخاصة وأولياء امورهم ومتابعة حالتهم الصحية حسب بروتوكول الدراسة **(مدة البحث سنه).**

ولا يتضمن البحث إجراء أي تجارب طبية أو إعطاء أدوية أو أخذ عينات حيوية.

برجاء التفضل بالاطلاع والتوجيه بما ترونه مناسباً نحو اعتماد توصية اللجنة والموافقة على مخاطبة الجهات ذات الصلة بموضوع البحث **(السادة / مدراء المناطق الصحية / السيد د. رئيس مجلس اقسام الاطفال)** بهذا الشأن للعمل على تسهيل مهمة الباحثة لإجراء البحث.

مع مراعاة التزام الباحث بالمحافظة على حقوق المشاركين بالبحث بالخصوصية وسرية المعلومات وعدم تداولها خارج إطار البحث والحصول على الإقرار المستنير Informed Consent من الولي القانوني للأطفال للمشاركين في البحث والتنسيق مع رؤساء الأقسام التي ستجري بها الدراسة وفقا للضوابط المنظمة لذلك.

وتفضلوا بقبول فائق الاحترام،،،،

د/

الدكتور / محمد جاسم الخشتي
الوكيل المساعد لشئون التخطيط والجودة
رئيس اللجنة الدائمة لتنسيق البحوث الطبية والصحية

23 01
2018

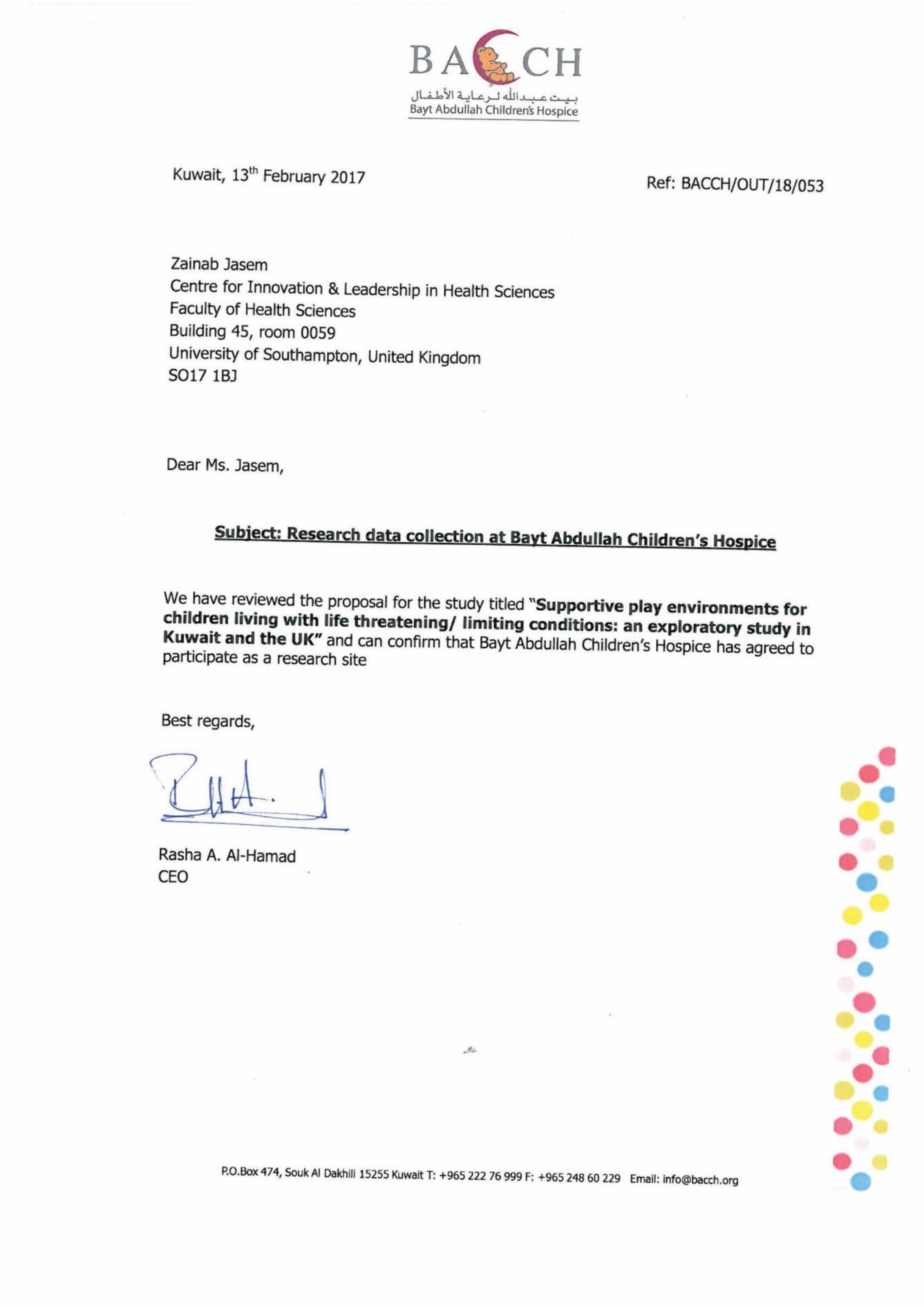
د. إبراهيم عباس هادي
مدير عام
معهد الكويت للإختصاصات الطبية
KIMS

د. ماجدة القطان
وكيل وزارة الصحة بالإنابة

2

Hassan

V.3 Children's Hospice (Kuwait) ethics approval



BACCH
بيت عبدالله لرعاية الأطفال
Bayt Abdullah Children's Hospice

Kuwait, 13th February 2017

Ref: BACCH/OUT/18/053

Zainab Jasem
Centre for Innovation & Leadership in Health Sciences
Faculty of Health Sciences
Building 45, room 0059
University of Southampton, United Kingdom
SO17 1BJ

Dear Ms. Jasem,

Subject: Research data collection at Bayt Abdullah Children's Hospice

We have reviewed the proposal for the study titled **"Supportive play environments for children living with life threatening/ limiting conditions: an exploratory study in Kuwait and the UK"** and can confirm that Bayt Abdullah Children's Hospice has agreed to participate as a research site

Best regards,

Rasha A. Al-Hamad
CEO

P.O.Box 474, Souk Al Dakhili 15255 Kuwait T: +965 222 76 999 F: +965 248 60 229 Email: info@bacch.org

V.4 Research Ethics Committee (REC) ethics approval

NHS
Health Research
Authority

West Midlands - Black Country Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

06 June 2018

Miss Zainab Jasem
Faculty of Health Sciences
University of Southampton
Southampton
SO17 1BJ

Dear Miss Jasem,

Study title:	**Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom**
REC reference:	**18/WM/0127**
Protocol number:	**27832**
IRAS project ID:	**235155**

Thank you for your letter of 04 June 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

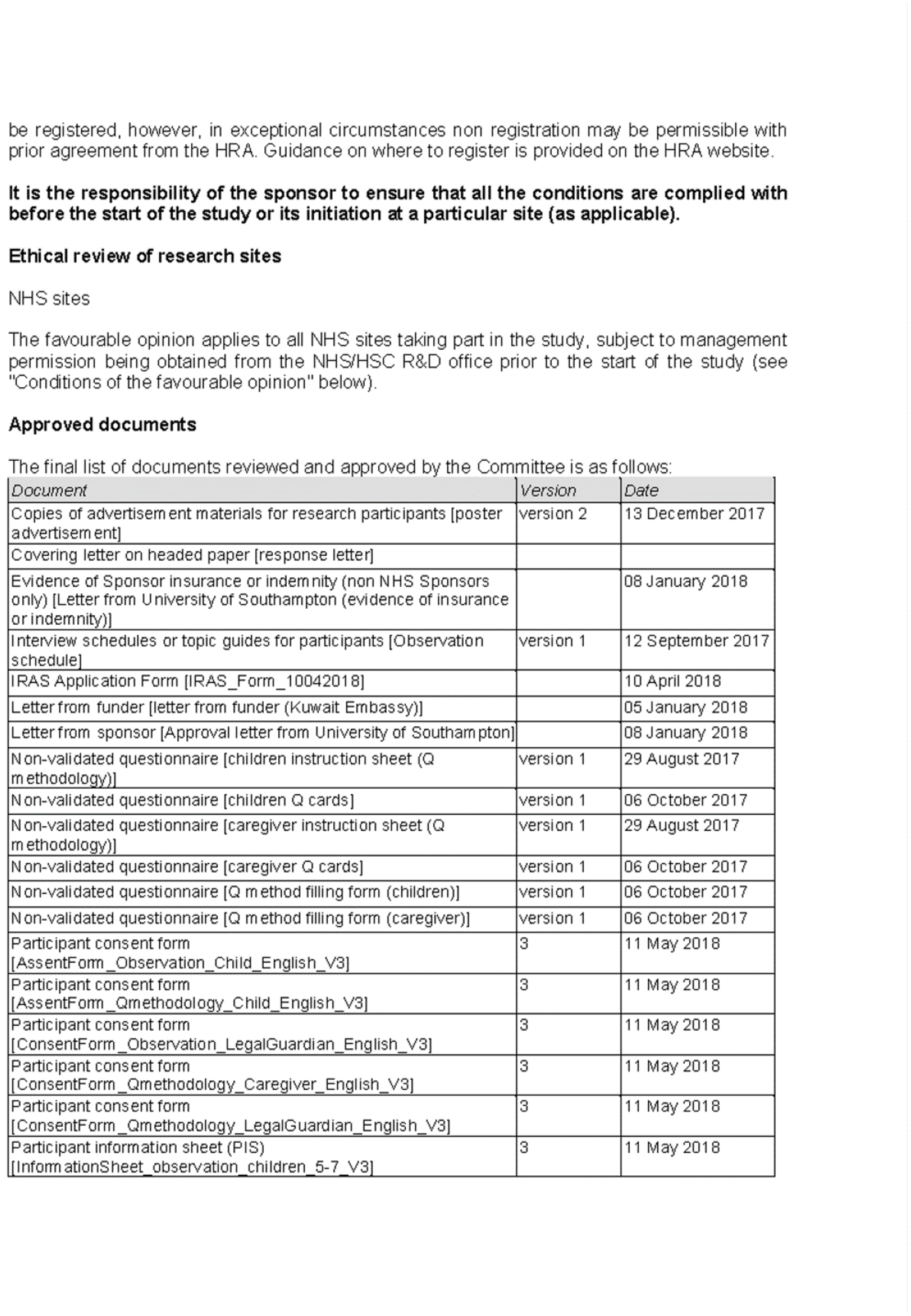
Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will



be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [poster advertisement]	version 2	13 December 2017
Covering letter on headed paper [response letter]		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from University of Southampton (evidence of insurance or indemnity)]		08 January 2018
Interview schedules or topic guides for participants [Observation schedule]	version 1	12 September 2017
IRAS Application Form [IRAS_Form_10042018]		10 April 2018
Letter from funder [letter from funder (Kuwait Embassy)]		05 January 2018
Letter from sponsor [Approval letter from University of Southampton]		08 January 2018
Non-validated questionnaire [children instruction sheet (Q methodology)]	version 1	29 August 2017
Non-validated questionnaire [children Q cards]	version 1	06 October 2017
Non-validated questionnaire [caregiver instruction sheet (Q methodology)]	version 1	29 August 2017
Non-validated questionnaire [caregiver Q cards]	version 1	06 October 2017
Non-validated questionnaire [Q method filling form (children)]	version 1	06 October 2017
Non-validated questionnaire [Q method filling form (caregiver)]	version 1	06 October 2017
Participant consent form [AssentForm_Observation_Child_English_V3]	3	11 May 2018
Participant consent form [AssentForm_Qmethodology_Child_English_V3]	3	11 May 2018
Participant consent form [ConsentForm_Observation_LegalGuardian_English_V3]	3	11 May 2018
Participant consent form [ConsentForm_Qmethodology_Caregiver_English_V3]	3	11 May 2018
Participant consent form [ConsentForm_Qmethodology_LegalGuardian_English_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_observation_children_5-7_V3]	3	11 May 2018

Participant information sheet (PIS) [InformationSheet_observation_children_8-11_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_Observation_LegalGuardian_UK_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_Qmethodology_Caregiver_UK_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_Qmethodology_children_5-7_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_Qmethodology_children_8-11_V3]	3	11 May 2018
Participant information sheet (PIS) [InformationSheet_Qmethodology_LegalGuardian_UK_V3]	3	11 May 2018
Referee's report or other scientific critique report [The research project has been reviewed by independent external examiner Dr Bernadette Waters]		30 October 2017
Research protocol or project proposal [research protocol]	version 3	13 December 2017
Sample diary card/patient card [children case report form]	version 1	06 October 2017
Sample diary card/patient card [caregiver case report form]	version 1	06 October 2017
Summary CV for Chief Investigator (CI) [chief investigator]		11 October 2017
Summary CV for student [Zainab Jasem (student) CV]		11 October 2017
Summary CV for student [Good Clinical Practice (Primary Care) course certificate]		06 June 2017
Summary CV for student [Good Clinical Practice (Secondary Care) course certificate]		06 June 2017
Summary CV for student [Informed Consent in Paediatric Research course certificate]		06 June 2017
Summary CV for supervisor (student research) [Dr Duncan Randall (academic supervisor) CV]		24 October 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

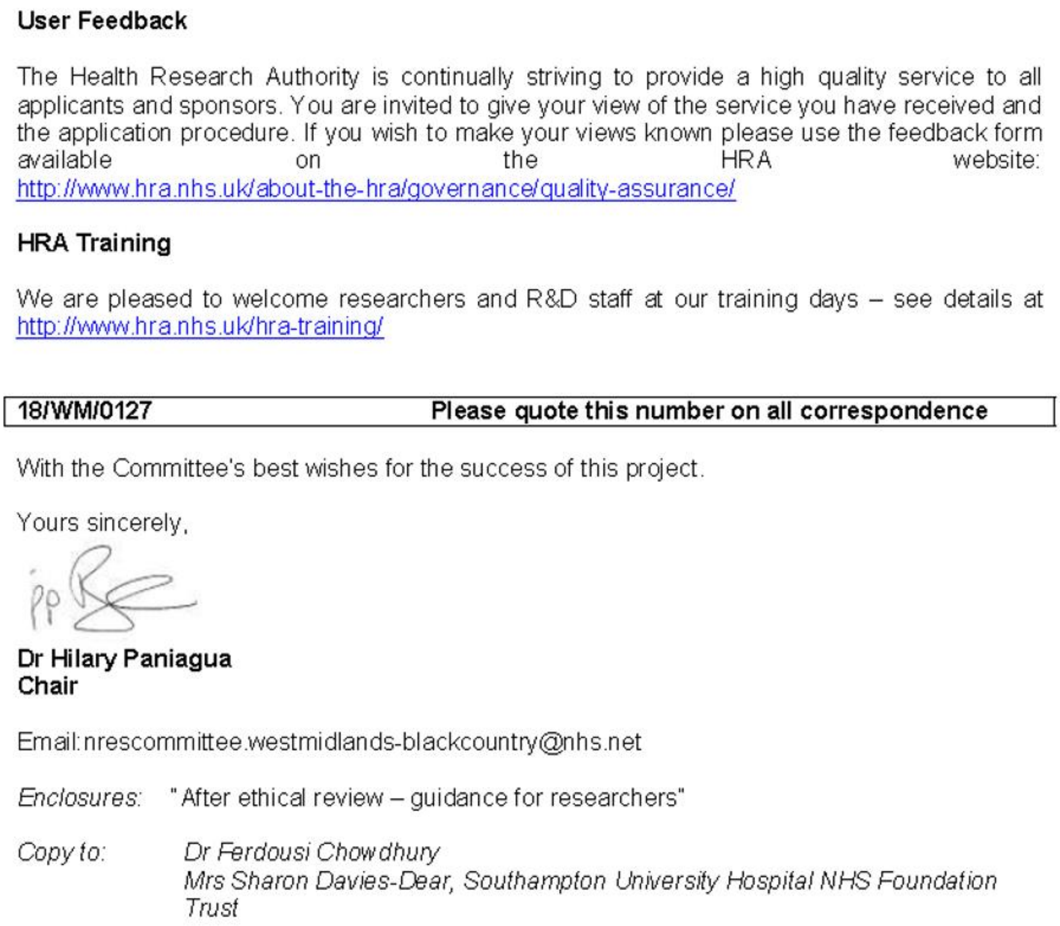
After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.



User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/WM/0127 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp

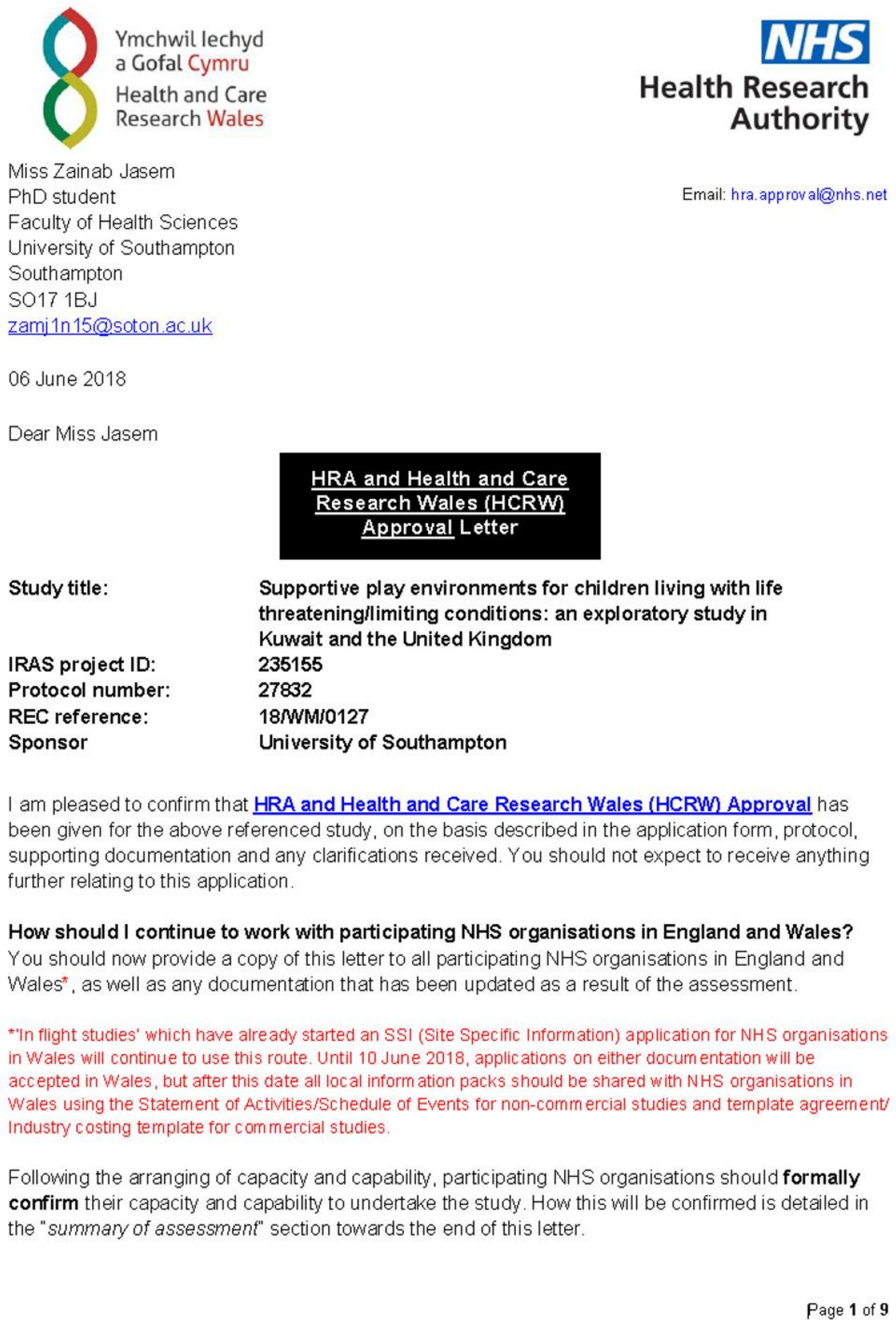
Dr Hilary Paniagua
Chair

Email: nrescommittee.westmidlands-blackcountry@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Ferdousi Chowdhury*
Mrs Sharon Davies-Dear, Southampton University Hospital NHS Foundation Trust

V.5 Health Research Authority (HRA) ethics approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Zainab Jasem
PhD student
Faculty of Health Sciences
University of Southampton
Southampton
SO17 1BJ
zamj1n15@soton.ac.uk

Email: hra.approval@nhs.net

06 June 2018

Dear Miss Jasem

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom**
IRAS project ID:	**235155**
Protocol number:	**27832**
REC reference:	**18/WM/0127**
Sponsor	**University of Southampton**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

Page **1** of **9**

IRAS project ID	235155

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA/HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA/HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Dr Ferdousi Chowdhury
Tel: 023 8059 5058
Email: rgoinfo@soton.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **235155**. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Ferdousi Chowdhury, University of Southampton [Sponsor Contact]*
rgoinfo@soton.ac.uk
Mrs Sharon Davies-Dear, Southampton University Hospital NHS Foundation Trust [Lead NHS R&D Contact]
Sharon.Davies-Dear@uhs.nhs.uk

V.6 Letter of access from the Research & Development Department

University Hospital Southampton NHS
NHS Foundation Trust

Clinical Governance
R&D Department
SCBR Level E, Laboratory & Pathology Block
Mailpoint 138
Southampton General Hospital
Southampton
SO16 6YD

Tel: 023 8120 4245
Katie.Benjamin@uhs.nhs.uk

Zainab Jasem
University of Southampton
University Road,
Highfield,
Southampton
SO17 1BJ

10 August 2018

Dear Zainab,

Letter of access for research
(RHM CHI0945: Supportive play environments for children living with life threatening/limiting conditions: an exploratory study in Kuwait and the United Kingdom)

This letter confirms your right of access to conduct research through **University Hospital Southampton NHS Foundation Trust (UHS)** for the purpose and on the terms and conditions set out below. This right of access commences on **10/08/2018** and ends on **30/09/2020** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at **UHS** has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to **UHS** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **UHS**, you will remain accountable to your employer **(University of Southampton)** but you are required to follow the reasonable instructions of **Ms Claire Pickett** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **UHS** policies and procedures, which are available to you upon request, and the Research Governance Framework.

LoA non-NHS – V1, Dec 2008
www.uhs.nhs.uk

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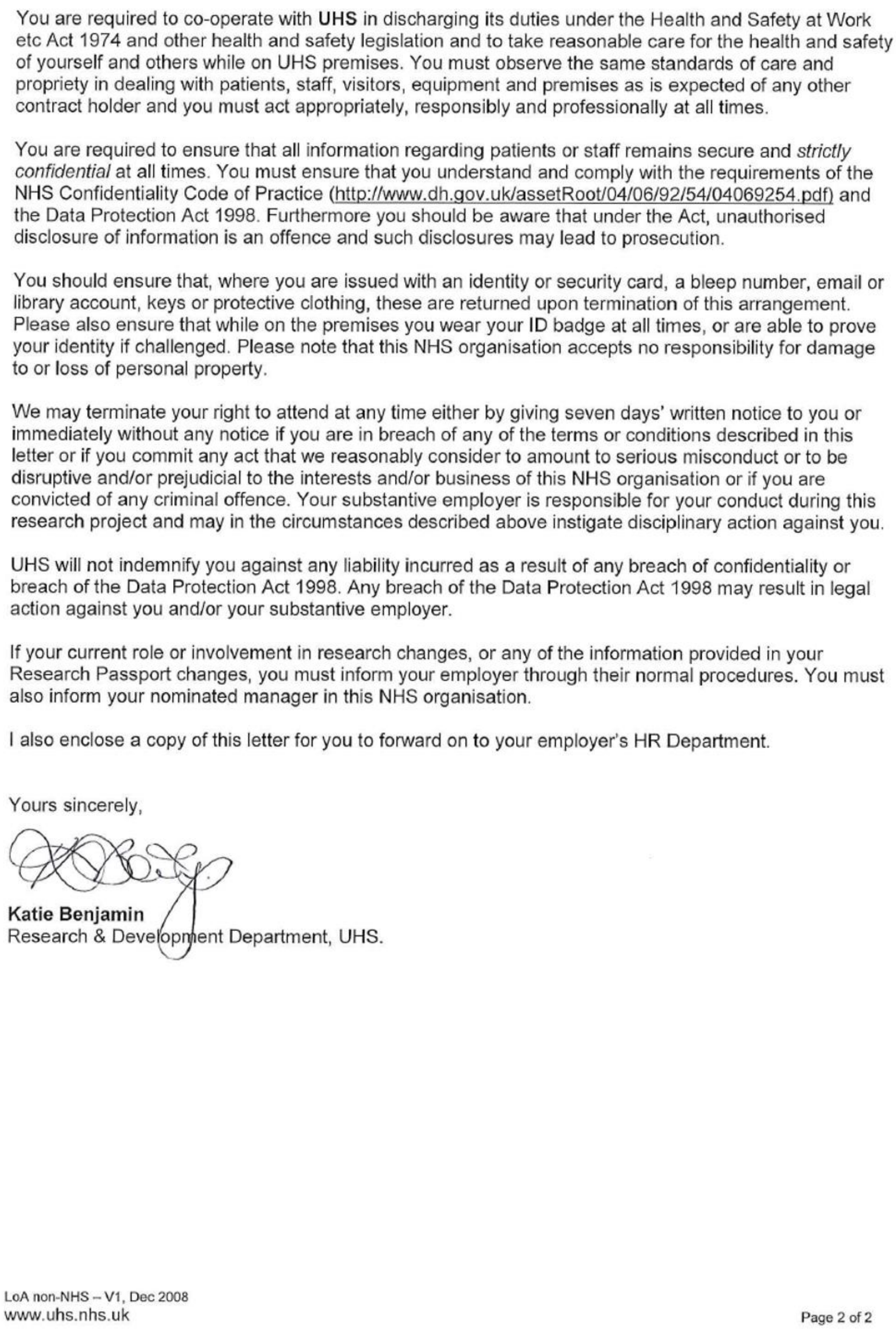

You are required to co-operate with **UHS** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on UHS premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your **ID** badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

UHS will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

I also enclose a copy of this letter for you to forward on to your employer's HR Department.

Yours sincerely,

Katie Benjamin
Research & Development Department, UHS.

V.7 Children's Hospice (UK) ethics approval

Julia's House
Dorset & Wiltshire Children's Hospices

For the attention of the University of Southampton.

To whom it may concern

We at Julia's House are happy to support Zainab Jasem, PhD student at University of Southampton, to do her research data collection regarding the play of children with palliative care needs.

Whilst Zainab visits and works alongside us at Julia's House her main point of contact will be with the Playmaker Sue Keenan for whom Zainab has the contact number and email address.

We are happy to share our enthusiasm for Play and its benefits for all our children and will do everything possible to introduce Zainab to the families that will meet the criteria for her research.

Yours sincerely,

Sue Keenan.

Playmaker Julia's House Children's Hospice.

Care for the child, there for the family

Julia's House, 135 Springdale Road, Corfe Mullen, Dorset BH18 9BP
Telephone 01202 389837 Email info@juliashouse.org www.juliashouse.org

Company registered in England and Wales. Registered Office: Julia's House Ltd, Barclays House, 1 Wimborne Road, Poole, Dorset BH15 2BB
Company Registration No. 3465868. Registered Charity No. 1067125

Appendix W Data management plan

Data Management Plan

A crucial part of making data user-friendly, shareable and with long-lasting usability to ensure they can be understood and interpreted by any user. This requires clear data description, annotation, contextual information and documentation. This data management plan will represent how the data will be created, stores and shared. The primary researcher, who is a PhD student at University of Southampton (UoS), will be responsible for each data management activity.

1. Data creation

1.1. Format of the data

The data will be collected by the primary researcher in two types: print-based data and digital/electronic research data (table-1). The formats of the digital/electronic research data are illustrated in table-2 as these are the recommended formats since they will enable long-term access to the data and can be easily shared due to the software used.

Table 1: types of data will be used	
print-based data	Signed consent forms Field notes Written of Q sorts Information sheet
digital/electronic research data	Photos Audio-recordings Interviews transcriptions Recorded field notes transcriptions Written field notes

Table 2: format used for digital/electronic research data	
docx	for textual data
xlsx	for spreadsheet data
PDF/A	for Portable Document Format (PDF)
FLAC	for audio
TIFF	For photos

1.2. Metadata

Metadata, describing the data, will be assigned through the use of meaningful filenames and the use of the document properties and tag option (in Word and Excel programs) when creating the files. Sensible filenames will be originated to each file explaining the geographical location, setting, participant's group, method used, file type, time reference and version. Table-3 is an example of file naming.

These files will be saved within a folder structure in a hierarchical tree structure. This is in order to facilitate locating, finding, and using the necessarily file on any future occasion and enable others to replicate and enhance the data in their own research.

Since the filled consent forms will have sensitive information, they will be kept in a separate password controlled folder with access restricted to retain anonymity.

The structure of folders and file naming of the data set will be kept recorded in a spreadsheet where a track of how the field notes, transcriptions, audio and photos are kept.

Table 3: file naming

Geographic location	KWT	data collected in Kuwait
	UK	data collected in United Kingdom
Setting	HS	data collected in hospice
	HW	data collected in hospital ward
Population / participant's group	CH	Child
	CG	Caregiver
	LG	Legal guardian
Method type	OBS	Data collection from observation
	Q	Data collection from Q methodology
File type	FN	Field notes
	PH	Photos
	Aud	Audio-recording
	Wrt	Written
	Int	Interview
	CF	Consent form
	PIS	Participant Information sheet
	CRF	Case report form
Participant no.	Pn	P1, P2, P3
time references	Yr_M_D	Year_month_day (17_06_13)
Version	n.	1.0, 2.0, 3.0, … (for minor changes the decimal point will be used e.g. n1.1, n1.2, and for major changes the nominal to be used e.g. 1.0, 2.0)
Example: KWT_HS_P1_LG_Aud_17_06_17		

2. Data storage

2.1. Preserving data

All the print-based data documents will be labelled and securely stored in a locked cabinet in a private storage locations at UoS until being scanned and transferred to a digitalised format.

The previous mentioned points will ensure that the digital/electronic research data will be saved in a computer-readable form. They will be stored using the UoS iSolutions network which ensures sufficient storage and provides a secure research data storage service to the research community where data are regularly backed up off-sited. It is managed under the governance of the UoS Research Data Management Policy which will ensure control access that is password protected.

Due to the nature of the study, the data, unfortunately, cannot be anonymised. But all data will be treated as sensitive and confidential, numbers will be used instead of their actual names to protect participant's confidentiality.

Those data that cannot be anonymised will be stored securely with restricted access in a password-protected computer or as paper records in locked filing cabinets in secure offices (the researcher's office at Kuwait University in Kuwait and in the PGR research office at the University of Southampton in the UK) with keys kept only by the primary researcher.

In addition, personal data relating to the participants (compoleted consent forms and case-report forms) will have sensitive information, they will be kept separately from anonymised data in a locked cabinet and the keys kept with the researcher in a different cabinet, separate from the anonymised data (in the researcher's office at Kuwait University in Kuwait and in the PGR research office at the University of Southampton in the UK) in accordance with university regulations. Thus, folders will have restricted access to retain anonymity.

UoS and the researcher hold a copyright of the data. Before the primary researcher graduation and prior to leaving the university, she will deposit all the non-identifiable research data with Pure. The data will be stored for at least 10 years from last use then it will be securely destroyed. However, the identifiable data will be stored till the end of the PhD programme in 2020 and then it will be destroyed.

2.2. Destroying data

To enable the secure disposal of print-based data, they will be treated as confidential waste, which means sensitive research data that requires destruction to ensure that the contents remain private. This will be done by putting these data in white woven sacks for collection as "confidential waste". DBAN will be used for the destruction of the digital/electronic research data, thus is a free disk wiping utility.

3. Sharing data

Consent will be obtained from the participants to allow data to be shared and reused with the primary researcher's supervisors and for publication and teaching purposes and this is subject to their consent. At all times, the confidentiality of the participants will be maintained and their privacy protected by the controlled access to the data and using pseudonyms in publications. The participants will be given the option in the consent form to choose how they agree for their data to be used. In case photographs are used, subject to their consent and the level of confidentiality they impose, photos will not be linked to any personal information or data.

For sharing large files containing sensitive identifiable data among the research team, DropOff Service offered by the University of Southampton will be used for sharing data so that files may be transferred across the network securely, encrypted internally and externally, to the University with access to data being very tightly and strictly controlled. Shared data will be subject to the University's Data Protection Regulations and uploaded

data will only be held temporarily on Dropoff service, for a maximum of 32 days, after which they will be automatically deleted.

Appendix X Demographic characteristics of participants according to the setting

X.1 Children who participated in Q methodology

		Kuwait's hospital participants	Kuwait's hospice participants	UK's hospital participants	UK's hospice participants
Characteristics		n (%)	n (%)	n (%)	n (%)
Sample size		12 (44.4%)[1]	2 (7.4%)[1]	12 (44.4%)[1]	1 (3.7%)[1]
Gender	Male	5 (41.7%)	1 (50%)	6 (50%)	
	Female	7 (58.3%)	1 (50%)	6 (50%)	1 (100%)
Age[2], mean(SD)		7.7 (1.8)	7.5 (3.5)	8.6 (2.1)	8
Ethnicity		10 (83.3%) Arab 1 (8.3%) African 1 (8.3%) South-Asian	2 (100%) Arab 0 African 0 South-Asian	11 (91.7%) While 0 Asian 1 (8.3%) Black 0 Chinese	1 (100%) While 0 Asian 0 Black 0 Chinese
LTC/LLC	Neurology	1 (8.3%)	0	1 (8.3%)	0
	Oncology	3 (25%)	1 (50%)	4 (33.3%)	1 (100%)
	Haematology	5 (41.7%)	0	1 (8.3%)	0
	Congenital	3 (25%)	0	0	0
	Genitourinary	0	1 (50%)	3 (25%)	0
	Cardiology	0	0	1 (8.3%)	0
	Metabolic	0	0	2 (16.7%)	0
Severity of the condition[3]	Yellow	10 (83.3%)	1 (50%)	10 (83.3%)	0
	Amber	2 (16.7%)	1 (50%)	2 (16.7%)	1 (100%)
Response rate		92.3%	100%	66.6%	50%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

X.2 Children who participated in observation

Characteristics		Kuwait's hospital participants n (%)	Kuwait's hospice participants n (%)	UK's hospital participants n (%)	UK's hospice participants n (%)
Sample size		10 (32.2%)[1]	3 (9.6%)[1]	10 (32.2%)[1]	8 (25.8%)[1]
Gender	Male	3 (30%)	1 (33.3%)	3 (30%)	4 (50%)
	Female	7 (70%)	2 (66.7%)	7 (70%)	4 (50%)
Age[2], mean(SD)		6.9 (2.07)	6.6 (2.8)	7.9 (1.9)	8.7 (2.05)
Ethnicity		8 (80%) Arab	3 (100%) Arab	9 (90%) While	6 (75%) While
		1 (10%) African	0 African	0 Asian	1 (12.5%) Asian
		1 (10%) South-Asian	0 South-Asian	0 Black	1 (12.5%) Black
				1 (10%) Chinese	0 Chinese
LTC/LLC	Neurology	1 (10%)	1 (33.3%)	1 (10%)	5 (62.5%)
	Oncology	3 (30%)	1 (33.3%)	2 (20%)	1 (12.5%)
	Haematology	4 (40%)	0	2 (20%)	0
	Congenital	2 (20%)	0	0	2 (25%)
	Genitourinary	0	1 (33.3%)	1 (10%)	0
	Cardiology	0	0	2 (20%)	0
	Metabolic	0	0	2 (20%)	0
Severity of the condition	Yellow	8 (80%)	2 (66.7%)	8 (80%)	6 (75%)
	Amber	2 (20%)	1 (33.3%)	2 (20%)	2 (25%)
Total hours of observation[3]		20 hours	5 hours	20 hours	16 hours
Response rate		90.9%	75%	90.9%	100%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

X.3 Caregivers who participated in Q methodology

		Kuwait's hospital participants	Kuwait's hospice participants	UK's hospital participants	UK's hospice participants
Characteristics		n (%)	n (%)	n (%)	n (%)
Sample size		12 (30.7%)^1	7 (17.9%)^1	12 (30.7%)^1	8 (20.5%)^1
Caregivers' age^2, mean(SD)		31.1 (6.02)	35.2 (7.1)	40.2 (6.7)	45.88 (16.08)
Caregiver's gender	Male	0	2 (28.6%)	4 (33.3%)	2 (25%)
	Female	12 (100%)	5 (71.4%)	8 (66.7%)	6 (75%)
Educational level	Primary	4 (33.3%)	0	1 (8.3%)	0
	Secondary	1 (8.3%)	2 (28.6%)	1 (8.3%)	2 (25%)
	Higher education	7 (58.3%)	5 (71.5%)	10 (83.4%)	6 (75%)
Relationship to the child	Father	0	2 (28.6%)	4 (33.3%)	2 (25%)
	Mother	8 (66.7%)	5 (71.4%)	8 (66.7%)	4 (50%)
	Grandparent	0	0	0	1 (12.5%)
	Paid caregiver	4 (33.3%)	0	0	1 (12.5%)
Ethnicity		8 (66.7%) Arab	7 (100%) Arab	11 (91.7%) While	7 (87.5%) While
		2 (16.7%) African	0 African	0 Asian	0 Asian
		2 (16.7%) South Asian	0 South Asian	0 Black	0 Black
				1 (8.3%) Chinese	0 Chinese
				0 Mixed	1 (12.5%) Mixed
Children's gender	Male	7 (58.3%)	3 (42.9%)	8 (66.7%)	4 (50%)
	Female	5 (41.7%)	4 (57.1%)	4 (33.3%)	4 (50%)
Children's age^2, mean(SD)		6.6 (1.3)	6.2 (1.8)	7.9 (2.06)	7.1 (2.1)
Children's LTC/LLC	Neurology	2 (16.7%)	1 (14.3%)	1 (8.3%)	4 (50%)
	Oncology	2 (16.7%)	4 (57.1%)	4 (33.3%)	1 (12.5%)
	Haematology	6 (50%)	0	3 (25%)	0
	Congenital	2 (16.7%)	1 (14.3%)	0	2 (25%)
	Genitourinary	0	1 (14.3%)	1 (8.3%)	0
	Cardiology	0	0	2 (16.7%)	0
	Metabolic	0	0	1 (8.3%)	1 (12.5%)

Characteristics		Kuwait's hospital participants n (%)	Kuwait's hospice participants n (%)	UK's hospital participants n (%)	UK's hospice participants n (%)
Severity of the children's condition[3]	Yellow	8 (66.7%)	3 (42.9%)	10 (83.3%)	4 (50%)
	Amber	4 (33.3%)	4 (57.1%)	2 (16.7%)	4 (50%)
Response rate		75%	87.5%	91.3%	100%

[1] The percentage is calculated for the total sample size

[2] Mean and standard deviation are used to present the descriptive data

[3] According to the Spectrum of Children's Palliative Care Needs (Shaw et al. 2015)

Appendix YFactor matrix

Y.1 Factor matrix for group 1: children from Kuwait

Participant code		Factor loadings on Factor 1	Factor loadings on Factor 2
1.	P01	0.1043	0.6123*
2.	P03	0.6397*	0.0965
3.	P05	-0.3286	0.0435
4.	P07	0.3145	0.7733*
5.	P08	0.2224	0.7542*
6.	P12	-0.1635	0.4997*
7.	P18	0.2555	0.6509*
8.	P20	0.3136	0.3495
9.	P23	0.6875*	-0.0325
10.	P33	0.5318*	0.2357
11.	P37	0.5634*	0.0763
12.	P38	0.5838*	-0.3787
13.	P40	0.0773	0.4424
14.	P44	0.7420*	0.1348

*indicates a defining sort

Y.2 Factor matrix for group 2: children from the UK

Participant code		Factor loadings on Factor 1	Factor loadings on Factor 2
1.	P54	0.5017*	-0.2450
2.	P58	0.6822*	-0.0101
3.	P63	-0.1552	0.7696*
4.	P67	-0.0315	-0.0440
5.	P68	0.4502	0.3468
6.	P71	-0.0837	0.8113*
7.	P73	0.3941	0.6064*
8.	P80	0.4995*	0.2824
9.	P82	-0.1088	-0.0551
10.	P87	0.5213*	-0.1081
11.	P89	0.6701*	-0.0199
12.	P91	0.8621*	-0.2252
13.	P92	-0.0014	0.2228

*indicates a defining sort

Y.3 Factor matrix for group 3: caregivers from Kuwait

Participant code		Factor loadings on Factor 1	Factor loadings on Factor 2
1.	P04	0.1510	0.4467*
2.	P09	0.5809*	0.2536
3.	P13	0.6115*	-0.1189
4.	P14	0.4926*	0.1150
5.	P19	0.7032*	0.3159
6.	P21	0.5727*	-0.1959
7.	P24	0.0736	-0.0232
8.	P25	0.0637	0.1570
9.	P27	-0.0086	0.2832
10.	P28	0.2193	0.7624*
11.	P29	0.3149	0.6227*
12.	P30	-0.2325	0.5172*
13.	P31	0.0307	0.4956*
14.	P32	0.0480	0.4603*
15.	P34	0.5554*	0.3525
16.	P36	0.5253	0.5021
17.	P39	0.7144*	0.1218
18.	P43	0.5017*	-0.2490
19.	P45	0.5820*	-0.2883

*indicates a defining sort

Y.4 Factor matrix for group 4: caregivers from the UK

Participant code		Factor loadings on Factor 1	Factor loadings on Factor 2
1.	P47	-0.0182	0.7342*
2.	P53	0.3645	-0.1831
3.	P56	0.2192	0.6183*
4.	P59	0.5944*	0.2249
5.	P64	0.5602*	0.0052
6.	P65	0.7883*	-0.2147
7.	P69	0.7179*	-0.2756
8.	P72	0.6640*	0.1275
9.	P75	0.6177*	0.3913
10.	P76	0.7359*	0.0464
11.	P78	0.7988*	-0.1213
12.	P81	0.8083*	0.0526
13.	P84	-0.1261	0.5114*
14.	P85	0.4096	0.6657*
15.	P86	0.5703	0.4507
16.	P93	0.1999	0.7197*
17.	P94	0.3190	0.6914*
18.	P95	0.2347	0.6754*
19.	P96	0.6130*	0.2478
20.	P97	0.4732*	0.3170

*indicates a defining sort

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