

**Children's and Parents' Experiences and Expectations of their
Roles in Hospital During the COVID-19 Pandemic – A
Constructivist Grounded Theory study**

Volume 2

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Doctor of Philosophy**

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By

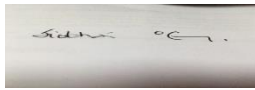
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Declaration

I declare that this thesis is entirely my own work. It has not been submitted in any form as an exercise for a degree or award at any other university.

Information derived from the published or unpublished work within this thesis has been acknowledged in the text and a list of references is given.

Signature:



Siobhán O'Connor

Date:

06/09/2023

Abstract

Background

Family-centred care (FCC) is the preferred model of care for hospitalised children and their families, both in Ireland (Coyne, 2013) and internationally (Feeg *et al*, 2016). There is no internationally agreed definition for FCC for hospitalised children. This lack of definition has been cited as contributing to an inconsistent application of FCC in practice (Coyne *et al*, 2011; Feeg *et al*, 2016; Coats *et al*, 2018).

A concept analysis identified that increased day-case activity, early discharge and increased patient throughput results in reduced time spent in hospital and increased patient acuity. An extensive literature review revealed that parents wish to participate in the care of their child in hospital, but the degree to which they wish to do so varies and must be negotiated between the nurse and the individual child and parent (Coyne, 2013; Watts *et al*, 2014; Feeg *et al*, 2016). There is also evidence that children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. The evidence indicates that children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. There is no hard evidence to inform healthcare professionals if the application of a family-centred approach to care makes a difference to the families' healthcare experience. Furthermore the voice of the child is noticeably absent from existing research on the topic.

Aim

To explore children's and parents' experiences and expectations of their roles while in hospital and develop a theory to explain the involvement of the child and parent in care in hospital.

Methodology

This research study used a constructivist grounded theory approach (Charmaz, 2006; 2014). Ethical approval was obtained. Data were collected during the Coronavirus 2019 (COVID-19) pandemic, through semi-structured, face-to-face interviews with hospitalised children (n=9) aged 9-12 years and with adolescents (n=14) aged 13-16 years. Parents (n=24) of hospitalised children were also interviewed. Initially purposeful sampling was used. Data collection and analysis occurred simultaneously. Following analysis of the data from initial interviews, theoretical sampling was employed until data saturation was achieved.

Findings

The three main concerns of children and adolescents were: a) my parent keeping me company and providing emotional support, b) my parent helping me/advocating for me and c) doing my own personal care. The parents' key concerns were a) keeping my child company, b) advocating for my child, c) parental roles evolving with limited guidance from nurses, d) parents helping nurses and e) parents "making do with" inadequate facilities. The emergent grounded theory that explains the parents' roles and responsibilities while being with their sick child in hospital during the COVID-19 pandemic is: "An advocating companion with parental roles evolving in an *ad hoc* manner".

Conclusion

Ongoing education for registered nurses must include child- and family-centred care and advocacy. Parents helping nurses in the context of the nurses being constantly busy was a recurring concern of parents. Parents clearly need better support, and clear negotiation of care. The development of the role of the Healthcare Assistant may be another way of supporting nurses in the delivery of safe and effective child- and family-centred care.

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Appendix 1 Vision, mission and values from around the world

Institute	Vision	Mission	Values
Children's Health Ireland (CHI) at Crumlin, Dublin, Ireland.	Healthier children and young people throughout Ireland	To promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence, in partnership with each other, with children, young people and their families through a network of children's services in Ireland.	In living our values we will be: child-centred, compassionate, progressive and we will react with respect, excellence and integrity.
Great Ormond Street Hospital (GOSH), London, UK.	To provide world-class clinical care and training, pioneering new research and treatments, in partnership with others, for the benefit of children in the UK and worldwide. To help the sickest children with complex health needs to fulfil their potential.	To put the child first and always	Always welcoming, helpful, expert and one team. We will: <ul style="list-style-type: none"> • Provide the safest, most effective and efficient care. • Attract and retain the right people through creating a culture that enables us to learn and thrive. • Research and innovation. • Harness technology.
Children's Hospital of Philadelphia (CHOP) - Department of Nursing and Clinical Care Services, Philadelphia, USA	Our vision is to be a global leader of innovative care consistent with CHOP's mission.	This care is provided by highly engaged and inspired CHOP nurses, respiratory therapists, neuro-diagnostic and other health professionals. We lead at all levels. We are early adopters of science and technology that enhances patient care outcomes. We value care provided with integrity, teamwork, compassion, accountability and professionalism.	CHOP is committed to highly reliable, safe patient care and to achieve excellent value-based outcomes for patients and families. The care we provide is family-centered, our partnerships with patients and their families are paramount to our practice.

Institute	Vision	Mission	Values
Starship Hospital, Auckland, New Zealand	Our <i>vision</i> Healthy communities - World-class healthcare - Achieved together		We see you and welcome you as a person We respect, nurture and care for each other Together we are a high performing team We aspire to excellence and safest care
Royal Children's Hospital (RCH), Melbourne, Australia	The Royal Children's Hospital, a great children's hospital, leading the way.	The RCH improves the health and wellbeing of children and adolescents through leadership in healthcare, research and education.	Unity: we work as a team and in partnership with our communities. Respect: we respect the rights of all and treat people the way we would like them to treat us. Integrity: We believe that how we work is as important as the work we do. Excellence: We are committed to achieving our goals and improving outcomes.
Boston Children's Hospital, Massachusetts, USA	For over 150 years, Boston Children's Hospital has maintained the same vision: to advance pediatric care worldwide.	Our mission is to: <ul style="list-style-type: none"> • provide highest quality of health care • lead the way in research and discovery • educate the next generation of leaders in health care • enhance the health and well-being of the children and families in our local community 	
SickKids, Toronto, Canada.	Healthier Children: A Better World	As leaders in child health, we partner locally and globally to improve the health of children through the integration of care, research and education	Our Values <ol style="list-style-type: none"> 1. Compassion 2. Integrity 3. Collaboration 4. Inclusion 5. Innovation 6. Excellence

Appendix 2 Key search words/terms for systematic literature search for Concept Analysis

How is family-centred care understood by children's nurses, hospitalised children and their parents?

Concept 1: Family-centred care

Keywords: "Family-centred-care" OR "Family centred care" OR "Family-centered-care" OR "Family centered care" OR "FCC" OR "Collaboration in care" OR "Collaboration-in-care" OR "Partnership in care" OR "Partnership-in-care" OR "Parent* involvement in care" OR "Parent* and child involvement in care" OR "Parent* and family centred care" OR "Parent* and family centered care" OR "Child and family centred care" OR "Child and family centered care" OR "Parent and family engag* care" OR "Family engag* care" OR "Engag* Care" OR "Partner*-in-care"

Concept 2: Children's Nurses

Keywords: "Children's nurs*" OR "Paediatric nurs*" OR "Pediatric nurs" OR "Child nurs*" OR "sick child* nurs*" OR "Child care nurs*" OR "Nursery nurs*"

Concept 3: Parents

Keywords: "Parent*" OR "Guardian*" OR "Mother*" OR "Father*"

Concept 4: Children

Keywords: "child*" OR "adolescent*" OR "minor*" OR "schoolchild*" OR "boy*" OR "girl*" OR "prepubescen*" OR "preadolescen*" OR "teen*" OR "student*" OR "pupil*" OR "youth*" OR "young person*" OR "young people" OR "Newborn*" OR "Infant*" OR "Newborn Infant*" OR "Neonat*" OR "Preschool*" OR "Paediatric*" OR "Pediatric*"

Concept 5: Understanding

Keywords: "understanding*" OR "experience*" OR "view*" OR "observation*" OR "expectation*" OR "feeling*" OR "comprehension*" OR "grasp*" OR "perception" OR "appreciation*" OR "interpretation" OR "attitude*" OR "cognizance" OR "knowledge" OR "awareness"

Databases:

- **CINAHL Complete** is the definitive research tool for nursing and allied health professionals. Users get fast and easy full-text access to top journals, including 50 nursing specialties, speech and language pathology, nutrition, general health and medicine and more. Full text for more than 1,300 journals indexed in *CINAHL Database*.

- **MEDLINE®** contains journal citations and abstracts for biomedical literature from around the world.
- **PsycInfo** is an expansive abstracting and indexing database with more than 3 million records devoted to peer-reviewed literature for the 1800s to the present day.
- Embase is a highly versatile multipurpose and up-to-date biomedical database. It covers the most important international biomedical literature from 1947 to the present day.

Then **manually check the references** cited in the papers included in the study to ensure any relevant ones are included i.e. pearl-growing. See additional references document saved.

Appendix 3 Inclusion / Exclusion Criteria for Concept Analysis

Inclusion / Exclusion Criteria

An objective list of inclusion and exclusion criteria was established at an early stage based on my knowledge of the topic and in collaboration with my supervisors. Clearly outlining the inclusion and exclusion criteria will ensure the quality and similarity of the studies included in the concept analysis, and define the boundaries of the analysis (Siddaway, 2014). Establishing clear inclusion and exclusion criteria and applying them consistently to the resultant studies from searches is important in order to avoid bias and maintain the integrity of the analysis.

The acronym **P**opulation, **E**xposure, **O**utcomes and **S**tudy type (PEOS) was used as a guiding framework to identify inclusion and exclusion criteria, see Table 1 below.

Participants

The research question in this concept analysis included children's nurses, parents and children / young people who have not yet reached their 16th birthday. Studies involving any or all of these populations were included in the analysis. Studies involving adults were excluded. Furthermore studies involving new-born infants in the neonatal/maternity setting were also excluded as the focus of this concept analysis focuses on the child/young person admitted to a children's hospital or unit in the acute hospital setting. Nurses working with children in the acute in-patient setting are also participants in this study. Studies exploring their perspectives/understanding and experiences of family-centred care were also included in the analysis.

Exposure

In the context of this concept analysis, exposure refers to the participants' perspectives/ understanding and experiences of family-centred care, either as in-patients and parents receiving nursing care or as nurses delivering care to children and their families in the acute hospital setting. Articles were included which were peer-reviewed and relevant to family-centred care as it was applied to the care of children as in-patients in the acute hospital setting and their families.

Outcome

This concept analysis focuses on children's nurses', parents' and children's perspectives/ understanding and experiences of the concept of family-centred care. All peer reviewed studies which addressed the populations' understanding, experiences, perceptions, expectations and views of FCC were included.

Study type

The analysis explored peer-reviewed studies which reported the participants' experiences and expectations of FCC during the period 2007-2018. Due to the unavailability of translation services, only studies which were published in English were included. Only journal articles based on original research were included. Non-primary research publications such as commentaries, editorials, opinion articles and guidelines were not included.

Table 1 – Inclusion and Exclusion Criteria.

PEOS term	Inclusion Criteria	Exclusion Criteria
Population / Participants		
Children	Children aged from new-born to 16 years of age, including infants, toddlers, school children, adolescents and young persons up to 16 years of age who have been admitted as in-patients to a children's unit in the acute hospital setting.	Young people over 16 years of age. Newborn infants in the neonatal / maternity setting.
Parents/ Guardians	Parents, including legal guardians acting in <i>loco parentis</i> of the above cohort.	Parents/guardians whose infants are in patients in the neonatal / maternity setting.
Children's Nurses	Children's nurses, including all those nurses working with children in the acute in-patient hospital setting.	Nurses not working with children. Nurses working with children but in the day-care, non-acute in-patient/ residential or home settings.
Exposure		
Family-Centred Care (FCC)	All peer reviewed articles relevant to children, their families and children's nurses' perspectives/understanding and/ or experiences of family-centred care as it is applied to children and their families as in-patients in the acute hospital setting.	Articles which were not peer reviewed. Articles relating to medical or surgical day-care settings, care at home, care in the community, care in school, care in residential care facilities or care in the neonatal unit in the maternity setting.
Outcomes		
Understanding, perception or experiences of FCC by the above population.	All peer reviewed studies which addressed the populations' experiences, perceptions, understanding and expectations of family-centred care.	Studies which did not address this populations' experiences were not included.
Study Type		
Primary studies published within the 10 years prior to this analysis.	Peer-reviewed studies, Descriptive studies, Systematic Reviews, Reports of Concept Analysis and Narrative reviews. Full text in English.	Not peer reviewed. Published prior to 2007, unless considered seminal work. Not published in English.

The initial systematic and comprehensive searching of the relevant electronic databases using the search strings developed yielded 21 articles in total, following removal of duplicates. The title and abstracts of all 21 articles were reviewed, using the above inclusion and exclusion criteria as a guide, and resulted in 12 articles being excluded as

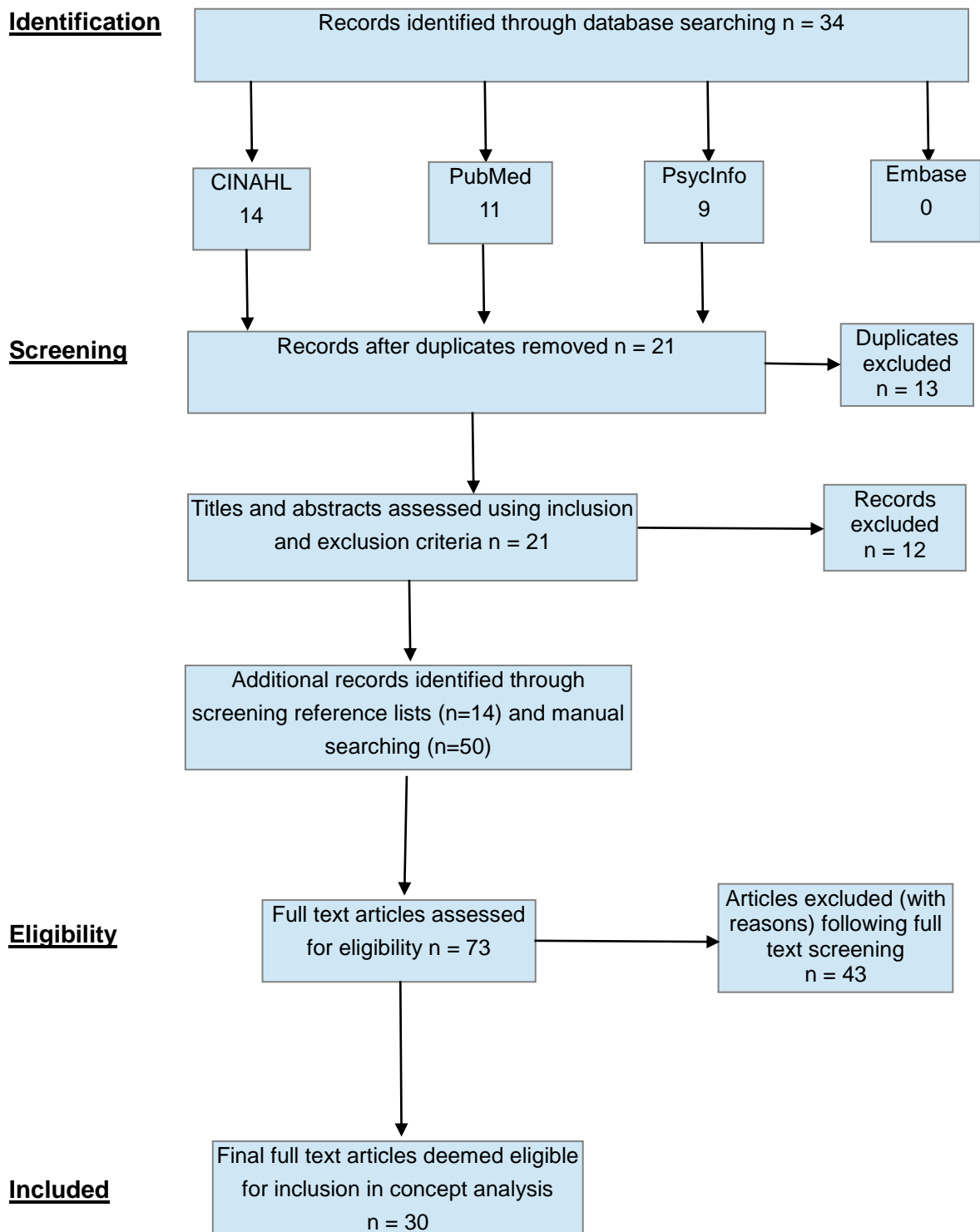
they did not meet the inclusion criteria. Additional records were identified through review of the reference lists of the above articles and manual searching, these sources yielded a further 64 articles, see Prisma Flow Diagram for further details.

Once the databases and additional data searches were complete and the relevant studies identified, full text reading of all resultant studies was carried out (n=73). During this stage a data extraction record and quality assessment tool for each article were completed. The above agreed inclusion and exclusion criteria were applied consistently throughout this process in order to arrive at an unbiased and objective final list of studies for inclusion in this exploration. This stage of the process was conducted in close collaboration with my supervisors. Discussion and shared decision-making between my supervisors and I was a feature throughout this process.

Reference

Siddaway, A. (2014) What is a Systematic Literature Review and How Do I Do One?
Available at:
<https://pdfs.semanticscholar.org/2214/2c9cb17b4baab118767e497c93806d741461.pdf>
Last accessed on 13th November 2017.

Appendix 4 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA (2009) flow diagram for concept analysis



Source: Moher, D., Liberati, A., Tetzlaff, J. Altman, D.G. The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement*. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097. For more information, visit www.prisma-statement.org.

Appendix 5 Summary of the characteristics of theoretical articles for inclusion in Concept Analysis

No.	Author/year	Setting/Country of origin	Design	Aim of study	Key conclusions
1	Banerjee, J., Alousius, A., Platonos, K. and Deierl, A. (2018)	Neonatal setting, United Kingdom (UK)	Discussion paper	This paper discusses the historical perspective, the basic principles and recent evidence around family-integrated care (FIC) and compared this with family-centred care (FCC). It also compares the various existing professional and parent focused neonatal care programmes and the advantages of FIC over those traditional models of care.	FCC has become an integral part of high quality neonatal care in the developed countries. The Bliss Baby Charter provides the core principles of FCC and advocates FCC as one of the best practices for neonatal care in units across the UK. FIC or family delivered care (FDC) involves providing parents and carers with competency based training and tools so that they are able to become confident and independent primary carers of their infants under the team's supervision. FIC is a step further to FCC as here the parents become integrated as equal partners in the neonatal team, giving them confidence, knowledge and independence to take care of their infants, who may have complex medical needs, while in the neonatal unit and post discharge.
2	Bedells, E. and Bevan, A. (2016)	UK	Literature review	A review of the literature on nurses' & parents' self-perceived roles when caring for hospitalised children, focusing on research since 2003. Potential barriers to negotiation, including poor communication and failure to provide information are explored.	Three main themes emerge: nurses' perceptions, parents' perceptions, and negotiation. Clarification of what nurses and parents consider to be their respective roles when caring for hospitalised children is a prerequisite for negotiation of those roles. The family's background, life experiences and circumstances influence the effectiveness of negotiation between nurses and parents.
3	Casey and Mobbs (1988)	Acute children's nursing setting in the UK	Descriptive paper	Describes how nurses and parents form a primary nursing team	The partnership model of paediatric nursing evolved as a description of nursing practice. It is serving as a guide for developing the nursing process in a form more suited to paediatric care. It has generated a wealth of research questions which when explored, should contribute to the development of paediatric nursing knowledge.
4	Chenery, K. (2004)	Paediatric wards in New Zealand	Discussion paper	Drawing on findings from a recent historical research study this paper argues that current practice paradoxes are historically ingrained.	The concept of FCC is broadly accepted in New Zealand child health sector. Commitment to the ethos of FCC is reflected in the philosophies of care delivery in paediatric wards and is a stated principle in the Ministry of Health's (1998) Child Health Strategy. Despite this, its application remains problematic.

No	Author/year	Setting/Country of origin	Design	Aim of paper	Key conclusions
5	Coyne, I. (1996)	UK	Concept analysis	The purpose of this paper is to explore the meaning of parent participation, to clarify the concept to benefit children and their families, and to increase understanding among practitioners.	Parent participation has become a central tenet of paediatric nursing in the UK. A review of British literature and research studies indicated that parent participation is a complex and multi-dimensional concept. In the evolution of parent participation, the terminology changed from 'parental involvement' to 'partnership in care', to 'care-by-parent' and finally to 'family-centred care' but the underlying theme remaining parent participation. To adopt a family-centred care approach, a radical paradigm shift is required.
6	Coyne, I. (2008)	Ireland	Commentary	Commentary on Lee (2007) What does partnership in care mean for children's nurses?	Lee (2007) points out that families may enter hospital with different expectations because of lack of information or preparation prior to admission. Preparing children and families for hospitalisation and ward routines, etc is an area that nurses could focus on. The ways partnership contributes (or otherwise) to improved outcomes, or improved experience of care remains poorly understood. This is another issue worth researching as it is assumed that parent participation leads to improved outcomes for all parties concerned. One could assume that parents' constant caring presence would greatly enhance the emotional welfare of the child. But, does it have significant benefits for all parents, nurses and allied health professionals?
7	Coyne, I., Hallstrom, I. and Soderback, M. (2016)	Europe	Discussion paper	In this article, the authors argue for a conceptual move from FCC to a child-centred care (CCC) approach and the implications for clinical nursing practice.	In the delivery of FCC, the child's perspective is not prominent nor the focus, rather there is a parent and professional dominance. The approach of FCC needs to be redirected towards a CCC approach, incorporating the rights of the child to participate in all aspects of healthcare delivery in conjunction with the needs of their family. To plan and implement a CCC approach requires a commitment from health professionals, involves education and discussions that require both commitment and managerial support from leaders in children's healthcare. Otherwise, there is a risk that CCC like FCC becomes something to which health professionals say they use but are not fully aware of it.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
8	Curtis, K., Foster, K., Mitchell, R. and Van, C. (2016)	Australia	Integrative Review of International Literature	The aim of this paper is to examine the impact of models of care that have been implemented for families of critically ill children, to extend understandings of, and inform future care delivery for, this group. The review sought to describe: 1. Models of care for families of critically ill children. 2. The outcomes of models of care that have been implemented for families of critically ill children.	Models of care applying family-centred care principles targeting critically ill children and their families can create positive changes in care delivery for the family. However a model which provides continuity across the span of care is required and there is need to describe how best to design, implement and sustain such models. There is a need to design and evaluate models of care that aim to implement FCC to support more positive outcomes for critically ill children and their families.
9	Dennis, C., Baxter, P., Ploeg, J. And Blatz, S. (2016)	Acute paediatric setting, Canada	A discussion paper	A discussion of partnership in the context of FCC in the acute paediatric setting, through a critical analysis of partnership models.	One partnership model had both high overall maturity and best fit with family-centred care principles. All models originate from Western and developed countries, indicating that future partnership models should be more geographically, culturally and economically diverse.
10	Dunst, & Trivette (2009)	United States of America (USA)	Meta-analytic structural equation modelling	FCC is based on the contention that the physical and psychological health of a child is influenced by the parents' psychological health where FCC enhances parent well-being which in turn influences child well-being. This paper assesses whether these relationships are supported by available evidence.	FCC is now practiced throughout the world by physicians, nurses and allied health care professionals. . FCC had direct effects on self-efficacy beliefs and indirect effects on parent psychological health mediated by belief appraisals. Self-efficacy beliefs had direct effects on parent and child psychological health and indirect effects on child health mediated by parent health. The results provide support for the contention that FCC influences parent psychological health which in turn influences child psychological health (Shields <i>et al</i> , 2006).

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
11	Foster, M., Whitehead, L. and Maybee, P. (2010).	New Zealand	Literature review.	The aim of this review was to explore the attitudes towards and experiences of FCC by healthcare professionals and parents during the hospitalization of a child.	Four themes emerged: communication, roles and relationships, caring for parents and available resources. A broad spectrum of variability exists in the perceptions of healthcare professionals and parents on parental needs and FCC within a hospital context. A lack of knowledge or resources were common themes reported by healthcare professionals that facilitated an 'ad hoc' operationalized FCC practice.
12	Foster, M., Whitehead, L. and Maybee, P. (2016)	New Zealand, Australia and USA	Synthesis of Quantitative Research	The aim of this review was to explore the parents', hospitalized child's, and health care providers' perception of FCC from primary quantitative studies conducted within a pediatric critical care setting.	FCC purports that unlimited presence and involvement of the family in the care of the hospitalized child will optimize the best outcome for the child, family, and institution. This review highlights that communication tailored to meet the parents' and child's needs is the key to facilitating FCC and positive health outcomes. Health care providers need to be available to provide clinical expertise and support throughout the health care journey.
13	Franck, L. S. & Callery, P. (2004).	UK	A critical literature review and theoretical discussion	This paper explores common concepts and issues forming the basis for a research agenda further strengthening the evidence base for FCC. A systematic identification of constructs, concepts and empirical indicators is developed and applied to exemplars in pain and asthma that span the continuum of children's healthcare in acute community settings.	Authors from different professional and policy perspectives have used different definitions and literatures when arguing the evidence for FCC and FCS. The extent to which the concepts are supported by research and applied in practice remains unclear. We propose that re-thinking FCC is required in order to develop a more coherent programme of research into the application of FCC in children's healthcare.
14	Harrison, T. (2010)	USA	A literature review	To summarize the development of family-centered pediatric care, review the current state of nursing research in this area and make recommendations.	Results revealed that evidence of consistent provision of family-centered pediatric care is lacking. Many areas of research remain undeveloped, but there is a solid foundation for moving forward in conducting research focused on assisting nurses in implementing this basic philosophy of practice in all settings in which children receive health care.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
15	Hutchfield, K. (1999)	UK	A concept analysis	The purposes of this article were to examine the current state of pediatric nursing research related to FCC and to propose directions for future study. This paper uses a combination of Rodgers' evolutionary model of concept analysis and Schwartz-Barcott & Kim's hybrid model of concept development to analysing the concept.	The process resulted in the identification of the antecedents and attributes of FCC, and the identification of a lack of clarity related to the consequences of FCC. Two alternative models of FCC emerged, both of which demonstrate strong associations with the concepts of partnership with parents, parental participation and care by parents. The paper concludes with an exploration of its usefulness in practice and considers how the concept might be operationalized. The tentative proposals for a hierarchy of FCC will require exploration, testing and evaluation by practitioners in the real world of children's nursing.
16	Kuo, D., Houtrow, A., Arango, P., Kuhlthau, K., Simmons, J. and Neff, J. (2012)	USA	Descriptive theoretical review	In this paper the authors enumerate the core principles of FCC in pediatric health care, describe recent advances applying FCC principles to clinical practice, and propose an agenda for practitioners, hospitals, and health care groups to translate FCC into improved health outcomes, health care delivery, and health care system transformation.	FCC is a partnership approach to health care decision-making between the family and health care provider. The authors conclude with 7 recommendations: <ul style="list-style-type: none"> • FCC should be acknowledged and actively incorporated within all clinical care delivery and practice guidelines. • FCC principles are best learned through exposure to daily practice. • FCC practices should be implemented and evaluated as part of quality improvement projects. • Measurement and evaluation tools for FCC should be developed and validated, and should be linked to positive health outcomes and parent satisfaction. • Institutions should be familiar with all FCC principles and integrate families in high-level planning and design. • Increases in external resources for care reform and system changes, specifically targeting FCC, should be offered. • Payment and reimbursement policies should recognize the time necessary to engage in FCC.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
17	Landis, M. (2007)	USA	Account of a parent's experience	A parent whose premature twins were cared for at Children's Hospitals and Clinics of Minnesota describes giving back to the hospital as a member of the Hospital's Family Advisory Council.	Family Advisory Council members assist the administration in developing, implementing and evaluating the services and the facilities of the hospital system and have input into hospital policies and initiatives. Members also educate hospital leadership, staff, managers, students and new employees through orientations and in-service training addressing the needs of families and how care can be improved. Family Advisory Council members interact with other patients and families by fielding concerns and suggestions.
18	Mikkelsen, G. and Frederiksen, K. (2011)	Denmark	A concept analysis.	This paper reports a theoretical concept analysis which was used to examine the structure and scientific maturity of the concept of family-centred nursing care of hospitalized children.	There is good agreement on the defining attributes of the concept, but they are described by sub concepts in need of clarification. The relationship between family and professionals is characterized by a mutual dependency and shared responsibility for the child's care, which may have both positive and negative consequences and holds potential areas of conflict not fully explained by the attribute of partnership. Few attempts have been made to operationalize FCC which is a partially mature and highly abstract concept. An increasing amount of scientific papers apply the concept with seemingly little consistency in use.
19	Pickler, R. & Tubbs-Cooley, H. (2014)	USA	Descriptive paper on healthcare research	To describe patient-centered outcomes research (PCOR) as it has evolved over time, since the establishment of PCOR Institute. It briefly addresses the potential of PCOR to revolutionize research & review some of the barriers that may thwart its potential. It concludes with a challenge to advanced practice nurses & specifically pediatric nurse practitioners to become involved in PCOR for the betterment of health care for patients & families.	Although pediatric nurses have been advocates for FCC for decades, our health care systems are not family centered, or even patient centered, from the perspective of the family, nor is the research we do particularly patient centered. The lack of partnerships between health care researchers, including nurses, patients, and their families, means that involvement of parents in decision making about their child's care remains limited and the role of children in care decisions is almost non-existent because they have had little input into what is studied and how it is studied. A likely first step will be to study how parents and families want to be involved in their child's care. Similar research on how children wish to be involved in their own care is also needed.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
20	Power, N. & Franck, L. (2008)	UK	Systematic review.	This paper is a report of a systematic literature review of research on parent participation in the care of hospitalized children.	Research prior to 1994 found that parents want to participate in basic child care activities normally performed at home. Nurses expected parents to participate in these activities but were reluctant for parents to take on technical roles. Further research has been conducted, but has not been systematically reviewed. Recent research has confirmed parents' desire & expectations to participate in their child's care & shown how the nature of their participation has evolved. The attitudes & activities of healthcare professionals are both barriers & facilitators to parent participation. Further research should examine how parents' expectations differ between specialties, and between acute & chronic care.
21	Shields, L., Pratt, J. and Hunter, J. (2006)	Australia and UK	Review of qualitative studies.	This paper aims to review systematically qualitative studies, which were found during a literature search for a Cochrane systematic review of the use of family centred care in children's hospitals.	Negotiation between staff & families, perceptions held by both parents & staff influenced the delivery of FCC. A sub-theme of cost of FCC to families & staff was discovered, including both financial & emotional costs. Further research is needed to generate evidence about FCC arising from modern models of care in which FCC is thought to be an inherent, but which leave families caring for sick children with little or no support. FCC has become a cornerstone of paediatric practice, however, its effectiveness is not known. No single definition exists, rather a list of elements that constitute FCC. However, it is recognized to involve the parents in care planning for a child in health services. A new definition is presented here.
22	Shields L., Pratt, J., Davis, L.M. and Hunter, J. (2007)	UK and Australia	Systematic Review	FCC is a widely used model & is felt to be the best way to care for hospitalised children. However, its effectiveness has not been measured. This review assesses the effects of family-centred models of care when compared to standard or professionally-centred models, on child, family & service outcomes.	No studies met inclusion criteria, and hence no analysis could be undertaken. This review has highlighted the dearth of high quality quantitative research about FCC. A much more stringent examination of the use of FCC as a model for care delivery to children and families in health services is needed.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
23	Shields, L. (2010).	Australia	Discussion paper	This article poses topics for discussion around FCC as a model of care delivery to children and families in health services. FCC developed over three decades following awareness that excluding parents during a child's hospital admission was detrimental to the child's mental health. Using resources from both past and current literature and existing research, the author argues that it is time for a revision of practices and policies that espouse FCC as the optimum model of care in paediatrics.	Current research shows a dearth of evidence about FCC, its use, implementation and applicability across cultures and nations. Five questions are discussed: is FCC relevant now? is it relevant only in Western countries?, what does it mean to implement FCC?, is FCC implemented effectively?, does it make a difference? Exemplars of good FCC practice are provided. It is difficult to know whether using FCC makes a difference to a child's & family's health outcomes, as there is no rigorous evidence to answer the question 'does it work?' Nurses must undertake studies so we can either support the successful implementation of FCC, or abandon it in the best interests of children, families & health services. Practitioners must be aware that FCC is a wonderful ideal that is almost impossible to implement & so new ways of delivering care to children may be needed.
24	Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J. and Pascoe, E. (2012)	Australia and UK	Systematic Review	An update of the Cochrane systematic review of FCC (Shields <i>et al</i> , 2007). The review aims to assess the effects of family-centred models of care for hospitalised children aged from birth (unlike the previous version of the review, this update excludes premature neonates) to 12 years, when compared to standard models of care, on child, family & health service outcomes.	This update of a review has found limited, moderate-quality evidence that suggests some benefit of a FCC intervention for children's clinical care, parental satisfaction, and costs, but this is based on a small dataset and needs confirmation in larger RCTs. There is no evidence of harms. Overall, there continues to be little high-quality quantitative research available about the effects of FCC. Further rigorous research on the use of FCC as a model for care delivery to children & families in hospitals is needed.

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
25	Shields, L. (2017).	Australia	Commentary	The article discusses the author's views regarding FCC in Great Britain claiming that FCC is in trouble. For 30 years, hospitals and health services around the world have been trying to implement it.	Topics covered include the studies relating to the development of a model for FCC, the challenges & problems encountered in providing FCC, & the development of new models for CCC. The asymmetric relationship created by involved professionals or family members towards the child which possibly compromises the fundamental rights of the child to protection, participation in care & promotion of their own well-being is also discussed. FCC is notoriously under-tested. There is no evidence that it works or makes a difference. It would be unethical to universally apply CCC to all children's healthcare situations unless we know it works. An international collaboration has been set up to develop Carter et al's (2014) definition further, to ensure everyone knows what CCC is about, & to work out how to test it in ways that were never applied to FCC, eg RTCs, quasi-experimental studies & qualitative studies, exploring the meaning of the new model for children, families & health professionals. Such studies are the only way we can avoid the mistakes that have dogged FCC in the past.
26	Smith, J., Swallow, V. and Coyne, I. (2014)	UK and Ireland	Theoretical concept synthesis	Fostering effective engagement, collaboration and empowerment are central to supporting parents caring for children with long-term conditions. A concept synthesis was undertaken to identify the shared antecedents and attributes underpinning models of FCC and partnership-in-care.	Thirty studies were reviewed; antecedents of models related to unclear roles, entrenched professional practice and lack of guidelines supporting their implementation; with central attributes being building trust, listening to parent concerns and valuing parents' knowledge of their child. The key attributes are outlined in a practical framework of involvement which may promote parent-professional collaboration for families of children with long-term conditions.
27	Smith, J., Shields, L., Neil, S. and Darbyshire, P. (2017).	Australia and UK	Opinion paper	A discussion of twitter chats that focused on child and FCC	Two key themes emerged: <ul style="list-style-type: none"> • The lack of evidence that FCC improves the care of the child, young person and their families. • Whether FCC marginalises the voice of the child. Is it assumed that the child is somehow not part of the family or that FCC involves a hierarchy with parents at the top & child at bottom?

No.	Author/Year	Setting/Country of origin	Design	Aim of paper	Key conclusions
28	Söderbäck, M., Coyne, I. and Harder, M. (2011)	Sweden and Ireland	Discussion paper	This paper will help differentiate between a child perspective and the child's perspective in healthcare. The issues are supported with research which illustrates the different perspectives. Both are required to perceive & encounter children as equal human beings in child-centred health care settings.	Treating children with dignity and respect, acknowledging their competence and supporting their right to make informed decisions are of prime importance in today's healthcare settings, according to the UN Convention on the Rights of the Child (1989). The provision of quality healthcare tailored to children's preferences means that health professionals have a responsibility to ensure children's rights, and that the child is encouraged and enabled to make his/her view known on issues that affect them. The FCC approach needs to be redirected towards a CCC approach incorporating the rights of the child to participate in all aspects of healthcare delivery in conjunction with the family needs.
29	Tallon, M., Kendall, G. and Snider, P. (2015)	Australia	Discursive paper	This paper presents an alternative model of FCC that focuses on optimising the health and developmental outcomes of children through the provision of appropriate support to the child's family.	While there is no direct evidence showing that the implementation of this alternative model of FCC in the hospital setting improves the health & developmental outcomes of children who are seriously ill, there is a great deal of evidence from community nursing practice suggesting it is likely to do so. Application of these theoretical concepts to practice has potential to underpin a theory of nursing that is relevant for all nurses irrespective of the age of those they care for & the settings within which they work. The relevance, meaning & effectiveness of FCC have been challenged recently. Studies show that parents in hospital often feel unsupported, judged and uncertain about what care they should give to their child. With no convincing evidence relating FCC to improved health outcomes, it has been suggested that FCC should be replaced with a new improved model to guide care.
30	Uniacke, S., Browne, T. and Shields, L. (2018).	Australia	Discussion article	This article argues that different interpretations of FCC currently available are either not clearly distinguishable from earlier healthcare ideals or significantly problematic.	The current ambiguity surrounding FCC is unhelpful for health professionals or the children for whom they care. If FCC is to direct health professionals in how to approach the care of hospitalized children, then its underlying rationale, as well as what FCC implies & requires, must be clear. The language of FCC is appealing in its sentiment & its rationale, the language of FCC has also fostered confusion. A prominent understanding of FCC that regards family as collectively the unit of care can imply courses of action that do not aim to do what will best promote a hospitalized child's welfare.

Appendix 6 Inclusion and Exclusion Criteria for Literature Review

An objective list of inclusion and exclusion criteria was established prior to conducting systematic searches of the relevant databases. Clearly outlining the inclusion and exclusion criteria ensures the quality and similarity of the studies included in the review, and defines the boundaries of the review (Siddaway, 2014). The search strategy aims to conduct a search that is exhaustive and representative of all studies that have been conducted on the topic to date (Papaioannou, 2009). Establishing clear inclusion and exclusion criteria and applying them consistently to the studies identified from the searches is important in order to avoid bias and maintain the integrity of the review.

With the assistance of a subject librarian, keyword/search terms were developed based on my knowledge of the topic and in collaboration with my supervisors. Careful consideration was given to this task so that the keywords/search terms used, retrieved the appropriate data for inclusion in the review (Cronin *et al*, 2008).

The use of the acronym **P**opulation, **E**xposure, **O**utcomes and **S**tudy type (PEOS) was used as a guiding framework to identify inclusion and exclusion criteria, see Table 1 below.

Participants

The research question in this review included children/young people in hospital who have not yet reached their 16th birthday, their parents/guardians and children's nurses. Studies involving any or all of these populations were included in the review. Studies involving adult patients were excluded. Furthermore studies involving new-born infants and/or their parents/guardians in the neonatal/maternity setting were also excluded as the focus of this review is the child/young person as an in-patient in a children's unit in the acute hospital setting. Nurses working with children in the acute in-patient setting are also participants in this study. Studies exploring their perspectives/ understanding and experiences of family-centred care were also included.

Exposure

In the context of this literature review, exposure refers to the participants' perspectives/ understanding and experiences of family-centred care, either as in-patients and parents/guardians receiving care or as nurses delivering care to children and their families in the acute hospital setting. Articles were included which were peer-reviewed and relevant to family-centred care as it was applied to the care of children as in-patients in the acute hospital setting and their families.

Outcome

This review focuses on children's, parents'/guardians' and children's nurses' experiences and understanding of the concept of family-centred care. All peer reviewed studies which addressed the population's understanding, experiences, perceptions and expectations of family-centred care were included.

Study type

The review explored peer-reviewed studies which reported the participants' experiences and expectations of family-centred care during the 12-year period January 2007 to December 2018. Only journal articles based on original and empirical research were included. Descriptive studies, systematic reviews, reports of conceptual/theoretical analysis and narrative literature reviews were excluded. Publications such as commentaries, editorials, opinion articles, case studies and guidelines were also excluded. Due to the unavailability of translation services, only studies which were published in English were included.

Table 1 – Inclusion and Exclusion Criteria.

PEOS term	Inclusion Criteria	Exclusion Criteria
Population / Participants		
Children	Children aged from new-born to 16 years of age, including infants, toddlers, school children, adolescents and young persons up to 16 years of age who have been admitted as in-patients to a children's unit in the acute hospital setting.	Young people over 16 years of age. New-born infants in the neonatal / maternity setting.
Parents/ Guardians	Parents, including legal guardians acting in <i>loco parentis</i> of the above cohort.	Parents/guardians whose infants are in patients in the neonatal / maternity setting.
Children's Nurses	Children's nurses, including all those nurses working with children in the acute in-patient hospital setting.	Nurses not working with children. Nurses working with children but in the non-acute in-patient/ residential or home settings.
Exposure		
Family-centred care	All peer reviewed primary research articles relevant to children, their families and children's nurses' experiences and/or understanding of family-centred care as it applied to children and their families as in-patients in the acute hospital setting.	Articles which were not peer reviewed Articles relating to care in a setting other than in-patient for example: medical or surgical day-care units, care in the ED, care at home, care in the community, care in school, care in residential facilities or care in the neonatal unit.
Outcomes		
Understanding, perceptions or experiences of FCC by the above population	All peer reviewed studies which addressed the populations' experiences, perceptions, understanding and expectations of family-centred care.	Studies which did not address this populations' experiences were excluded.

Study Type		
Studies published within the 12 years prior to this review.	Peer-reviewed primary research studies only. Full text in English	Not peer reviewed Published prior to January 2007, unless considered seminal or landmark work. Not published in English Descriptive studies, systematic reviews, reports of conceptual/theoretical analysis and narrative reviews were excluded. Commentaries, editorials, opinion articles and guidelines were excluded.

Search terms

The following search terms were developed for use on three relevant databases in collaboration with the subject librarian.

General search for Ebsco databases:

((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))

AND

Hospital*

CINAHL Complete

(MH("Family Centered Care+") OR TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (MH(Hospitals+) OR TI(Hospital*) OR AB(Hospital*))

MEDLINE

(TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR CI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (MH(Hospitals+) OR TI(Hospital*) OR AB(Hospital*) OR CI(Hospital*))

PsycInfo

(TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR KW((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (TI(Hospital*) OR AB(Hospital*) OR KW(Hospital*)).

The initial systematic searching of the relevant electronic databases using the search terms described above was conducted on the 4th October 2018. The results are displayed in Table 2 below.

Table 2 – Results from database searches - 4th October 2018

Database	Articles retrieved
CINAHL Complete	1447
MEDLINE	842
PsychINFO	271

All articles were imported to EndNote Library, once duplicates were removed there were 1899 articles remaining to be screened by title and abstract.

Manual searches of journals that are specifically related to the topic of interest or those that are likely to cover the topic can also be performed.

A time frame of 12 years was placed on the age of the works to be included. Seminal or influential works are the exception to this rule. Remaining articles were identified through pearl growing.

Once searching of additional data sources was complete and the relevant studies identified, screening of the title and abstracts of all resultant studies was carried out. The above agreed inclusion and exclusion criteria were applied consistently throughout this process in order to arrive at an unbiased and objective final list of studies for inclusion in the review.

Following review and data extraction of the full text of the final studies included in the analysis, quality assessment of all studies was conducted in collaboration with my supervisors. Discussion and shared decision-making between my supervisors and I was a feature throughout this process.

References

Cronin, P., Ryan, F. and Coughlan, M. (2008) Undertaking a literature review: a step-by-step approach. *British Journal of Nursing*, **17**(1): 38-43.

Papaioannou, D., Sutton, A., Carroll, C., Booth, A. And Wong, R. (2009) Literature searching for social science systematic reviews: consideration of a range of search techniques. *Health Information and Libraries Journal*, **27**: 114-122.

Siddaway, A. (2014) What is a Systematic Literature Review and How Do I Do One? Available at: <https://pdfs.semanticscholar.org/2214/2c9cb17b4baab118767e497c93806d741461.pdf>
Last accessed on 13th November 2017.

Appendix 7 Key search words/terms used for literature review

Original search performed - 4th October 2018

General search for Ebsco databases:

((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))
AND
Hospital*

CINAHL Complete

(MH("Family Centered Care+") OR TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (MH(Hospitals+) OR TI(Hospital*) OR AB(Hospital*))

MEDLINE

(TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR CI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (MH(Hospitals+) OR TI(Hospital*) OR AB(Hospital*) OR CI(Hospital*))

PsycInfo

(TI((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR AB((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare)) OR KW((Family OR parent* OR child*) N2 (Centered OR centred) N2 (care OR healthcare))) AND (TI(Hospital*) OR AB(Hospital*) OR KW(Hospital*))

Systematic searches conducted on all three databases on 4th October 2018, inclusive of all publications in the English language from January 2007 through to October 2018.

Results displayed on Table 1 below.

Table 1 – Outcome of database searches

Database	Articles retrieved
CINAHL Complete	1447
MEDLINE	842
PsycInfo	271
Total	2560

All articles imported to EndNote Library

Updated search performed - 26th October 2022

Systematic searches were repeated on all three databases on 26th Oct 2022, inclusive of all publications in the English language from January 2018 to October 2022.

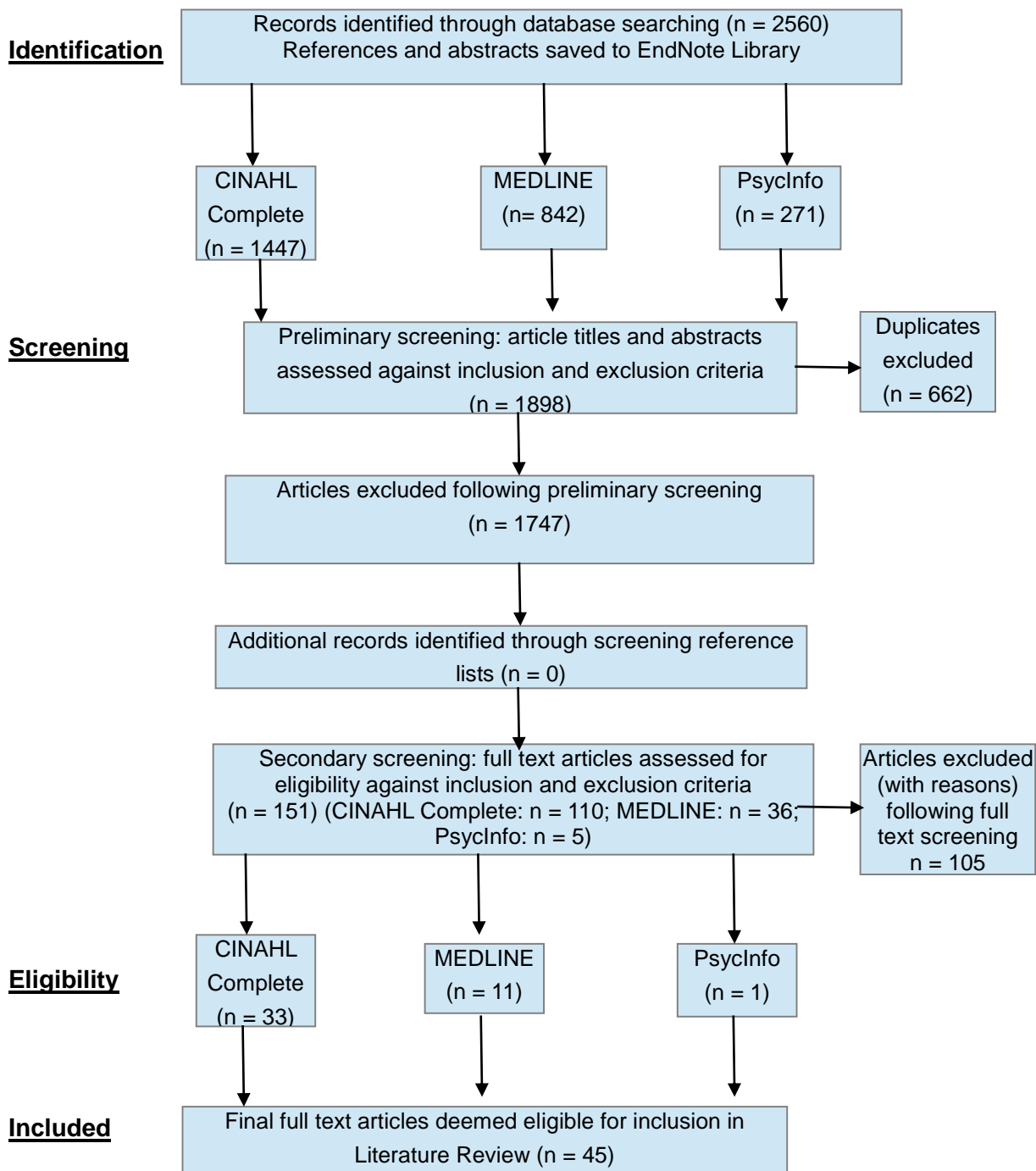
Results displayed on Table 2 below.

Table 2 – Outcome of database searches

Database	Articles retrieved	Articles removed after de-duplicating, reading titles & abstracts	Articles remaining	Articles removed after full text reading	Articles included in updated search of the literature
CINAHL Complete	607	532	75	63	12
MEDLINE	565	501	64	60	4
PsycInfo	136	128	8	7	1
Totals	1308	1161	147	129	17

All articles imported to EndNote Library

Appendix 8 - Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for literature review



Source: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097.

doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 9 - Assessment of studies (n=147) following full text reading for inclusion in literature review after updated search

Author / Year	Title	Decision
2019	Patient- and Family-Centered Care and the Role of the Emergency Physician Providing Care to a Child in the Emergency Department.	Exclude - Not applicable to in-patients in the acute hospital setting.
Abdel Razeq <i>et al</i> (2021).	Nurses' Perceptions and Attitudes toward Family-Centered Care in Acute Pediatric Care Settings in Jordan	Include MMAT 71% Moderate
Abela <i>et al</i> (2020).	Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review.	Exclude – not primary research
Aghajari <i>et al</i> (2019).	Cultural sensitivity in paediatric nursing care: a concept analysis using the Hybrid method.	Exclude – not primary research
Alabdulaziz <i>et al</i> (2019).	Corrigendum to "Paediatric nurses' perceptions and practices of family-centred care in Saudi hospitals: A mixed methods study"	Exclude – not primary research
Alvarez, M. B. (2020).	A phenomenological study of how the experiences of Spanish-speaking parents/family caregivers in a pediatric intensive care unit compare to the principles of patient- and family-centered care.	Exclude - Not applicable to in-patients in the acute hospital setting.
Andrade, <i>et al</i> (2022).	Parental psychosocial needs in Brazilian paediatric intensive care units.	Exclude – not relevant to FCC as it is applied to children in hospital
Andrist <i>et al</i> . (2020).	Paved With Good Intentions: Hospital Visitation Restrictions in the Age of Coronavirus Disease 2019.	Exclude – not primary research
Angelhoff <i>et al</i> . (2018).	Sleep quality and mood in mothers and fathers accommodated in the family-centred paediatric ward.	Exclude – not relevant to FCC as it applies to children in hospital
Angelhoff <i>et al</i> . (2020).	"Like Walking in a Fog"-Parents' perceptions of sleep and consequences of sleep loss when staying overnight with their child in hospital.	Exclude – not relevant to FCC as it applies to children in hospital
Arabi <i>et al</i> (2018).	Parents' experiences of Family Centred Care practices.	Exclude – already included in original review
Arigliani <i>et al</i> (2018).	Measuring empathy in pediatrics: validation of the Visual CARE measure	Exclude - not relevant to FCC as it applies to children in hospital
Arslan <i>et al</i> (2019).	The FCC Assessment Scale: Development and Psychometric Evaluation in a Turkish Sample.	Exclude – A scale to measure FCC
Bannerman <i>et al</i> (2021).	Parental perceptions of the impact of COVID-19 restrictions on family-centred care at a paediatric intensive care unit.	Exclude – not relevant to FCC as it applies to children in hospital
Barnes <i>et al</i> (2020).	Effectiveness and family experiences of interventions promoting partnerships between families and pediatric and neonatal intensive care units: a mixed methods systematic review protocol.	Exclude – Review protocol

Author / Year	Title	Decision
Barratt <i>et al</i> (2022).	Children living with long-term conditions and their experiences of partnership in nursing care: An integrative systematic review.	Exclude – systematic review
Bassett <i>et al</i> (2021).	Parent Preferences for Transparency of Their Child's Hospitalization Costs.	Exclude – not relevant to FCC as it applies to children in hospital.
Batista Ferreira <i>et al</i> (2019).	Nursing Care for the Families of Hospitalized Children and Adolescents.	Exclude - not relevant to FCC as it applies to children in hospital.
Bianchi, A. & Greenberg, R. (2019).	Deceased-directed donation: Considering the ethical permissibility in a multicultural setting.	Exclude – not primary research
Blake, S. (2019).	Supporting paediatric patients: Parental presence in the anaesthetic journey.	Exclude – not relevant to hospitalised children in the in-patient setting
Bordessoule, <i>et al</i> (2022).	In situ simulation training for parental presence during critical situations in PICU: an observational study.	Exclude - not relevant to FCC for hospitalised children in the in-patient setting
Bouchoucha, S.L. & Bloomer, M.J. (2021).	Family-centered care during a pandemic: The hidden impact of restricting family visits	Exclude – not primary research
Bowden, <i>et al</i> (2022).	Caregiver experiences during their child's acute medical hospitalization for a mental health crisis.	Exclude - not relevant to FCC for hospitalised children in the in-patient setting
Campbell-Yeo, <i>et al</i> (2022).	Parental perspectives on technology use to enhance communication and closeness during the COVID-19 parental presence restrictions.	Exclude – NICU setting
Cartland, <i>et al</i> (2018)	The Role of Hospital Design in Reducing Anxiety for Pediatric Patients	Exclude - not relevant to FCC as it applies to children in hospital
Chen, <i>et al</i> (2022).	Clinical Study of Mobile Application- (App-) Based Family-Centered Care (FCC) Model Combined with Comprehensive Iron Removal Treatment in Children with Severe Beta Thalassemia.	Exclude - not relevant to FCC as it applies to children in hospital
Chong, <i>et al</i> . (2022).	Compassionate Healthcare for Parents of Children with Life-limiting Illnesses: A Qualitative Study.	Exclude - not relevant to FCC as it applies to children in hospital
Chow, <i>et al</i> (2022).	Families' healthcare experiences for children with inherited metabolic diseases: protocol for a mixed methods cohort study.	Exclude – Protocol for a study
Chow, <i>et al</i> (2021).	Family experiences with care for children with inherited metabolic diseases in Canada: A cross-sectional survey.	Exclude - not relevant to FCC for hospitalised children as in-patients
Coats, <i>et al</i> . (2018).	Nurses' Reflections on Benefits and Challenges of Implementing Family-Centered Care in Pediatric Intensive Care Units.	Include MMAT 100% Good
Coombes, <i>et al</i> (2022).	Achieving child-centred care for children and young people with life-limiting and life-threatening conditions-a qualitative interview study.	Exclude - not relevant to FCC for hospitalised children in the in-patient setting
Dadlez, <i>et al</i> (2018).	Understanding Parental Preferences for Participants in Medical Decision-making for Their Hospitalized Children.	Exclude - not relevant to FCC for hospitalised children in the in-patient setting

Author / Year	Title	Decision
Dall'Oglio, et al (2018).	Practices and Perceptions of Family Centered Care among Healthcare Providers: A Cross-sectional Study in a Pediatric Hospital.	Exclude – already included original literature review
D'Aprano, et al (2020).	Important components of a programme for children with medical complexity: An Australian perspective.	Exclude - not relevant to FCC for hospitalised children as in-patients.
Vainberg, et al (2019).	The Experiences of Parents of Children Undergoing Surgery for Congenital Heart Defects: A Holistic Model of Care.	Exclude - not relevant to FCC as it applies to children in hospital
Davison, et al. (2021).	How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis.	Exclude – scoping review, not primary research
Dean, et al (2021).	Assessment of an Educational Tool for Pediatric Cardiac Nurses on Individualized Family-Centered Developmental Care.	Exclude - not relevant to FCC as it applies to children in hospital
Destino, et al (2019).	Family-Centered Rounds: Past, Present, and Future.	Exclude – not primary research
Diskin, et al (2021).	The Secondary Consequences of the COVID-19 Pandemic in Hospital Pediatrics.	Exclude – not relevant to FCC as it applies to children in hospital
Done, et al (2020).	Pediatric Nurses' Perspectives on Family-Centered Care in Sri Lanka: A Mixed-Methods Study.	Exclude - A duplicate of Gangodage Done, et al. (2020) below
Dorfman, et al (2021).	Strategies to maintain a family-centered care approach in the era of COVID-19: Experiences of a Canadian pediatric cardiology program.	Exclude – Not primary research
Efendi, et al (2022).	Nursing care recommendation for pediatric COVID-19 patients in the hospital setting: A brief scoping review.	Exclude – not primary research
Evans, M. (2018).	Supporting parents with children hospitalized in the pediatric intensive care unit.	Exclude – already included in original review
Everhart, et al (2019).	Patient- and Family-Centered Care: Leveraging Best Practices to Improve the Care of Hospitalized Children.	Exclude – not primary research
Farokhzadian, et al (2021).	Mothers and nurses' perceptions of the family-centered care barriers in pediatric departments of an educational hospital in Iran.	Include MMAT 57% Moderate
Ferentzi, et al (2021).	Family-Centered Care at Pediatric Cardiac Intensive Care Units in Germany and the Relationship With Parent and Infant Well-Being: A Study Protocol.	Exclude – a study protocol re neonatal care
Ferrari, et al. (2021).	The impact of PPE and social distancing on communication and relation between nurses, caregivers and children: a descriptive qualitative study in a maternal and child health hospital.	Exclude - not relevant to FCC for hospitalised children in the in-patient setting
Fisk, et al (2022).	Parent Perception of Their Role in the Pediatric Cardiac Intensive Care Unit.	Include MMAT 100% Good

Author / Year	Title	Decision
Foster, et al (2022).	Family presence in Canadian PICUs during the COVID-19 pandemic: a mixed-methods environmental scan of policy and practice.	Exclude - not relevant to FCC as it applies to children in hospital. Re family presence in ICU during C19
Foster, et al (2022).	Children's voices on their participation and best interests during a hospital stay in Australia.	Exclude - not relevant to FCC as it applies to children in hospital.
Foster, M., & Whitehead, L. (2019).	Using drawings to understand the child's experience of child-centred care on admission to a paediatric HDU.	Exclude - not relevant to FCC. Child's' experience of CCC
Foster, et al (2019).	Development and validation of the needs of children questionnaire: An instrument to measure children's self-reported needs in hospital.	Exclude - not relevant to FCC as it applies to children in hospital. An instrument development study.
Foster, M., et al (2019).	Parents' and Staff Perceptions of Parental Needs During a Child's Hospital Admission: An Australian Study.	Include MMAT 57% Moderate
Frechette, et al (2020).	When the paediatric intensive care unit becomes home: A hermeneutic-phenomenological st	Exclude - not relevant to FCC. Nurses' experience of caring following major hospital transformation.
Gangodage Done, et al. (2020).	Pediatric Nurses' Perspectives on Family-Centered Care in Sri Lanka: A Mixed-Methods Study.	Include MMAT 57% Moderate
Gibbs, et al (2020).	Caring for Children with Non-Accidental Head Injuries: A Case for a Child-Centered Approach.	Exclude - not relevant to FCC as it applies to children in hospital.
Gill, et al. (2018).	Barriers and facilitators to implementing a process to enable parent escalation of care for the deteriorating child in hospital.	Exclude - not relevant to FCC as it applies to children in hospital.
Gill, M. A. (2020).	Making Space for Siblings in Family-Centered Care.	Exclude – not primary research
Girch, et al (2022).	The German EMPATHIC-30 Questionnaire Showed Reliability and Convergent Validity for Use in an Intermediary/General Pediatric Cardiology Unit: A Psychometric Evaluation.	Exclude – checking validity of a tool
Glick, et al (2019).	Health Literacy in the Inpatient Setting: Implications for Patient Care and Patient Safety.	Exclude - not relevant to FCC as it applies to children in hospital.
Hart, et al (2020).	Family-Centered Care During the COVID-19 Era	Exclude – not primary research
Hengeveld, et al (2021).	Nursing competencies for family-centred care in the hospital setting: A multinational Q-methodology study.	Exclude - not relevant to FCC as it applies to children in hospital.
Hill, et al (2018b).	Parent perceptions of the impact of the Paediatric Intensive Care environment on delivery of family-centred care.	Exclude - already included original literature review.

Author / Year	Title	Decision
Hill, C., et al (2018a).	Family-Centered Care From the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review.	Exclude – not primary research
Hogan, C. (2020).	Understanding parent perspectives to improve family-centered care in an inpatient pediatric rehab: A quality improvement project.	Exclude – not relevant to FCC as it applies to children in hospital - not acute care setting
Iqbal, et al (2022).	Appellation Preferences of Parents of Children Attending Hospital.	Exclude - not relevant to FCC as it applies to children in hospital
Johnson, et al (2019).	Children, young people's and families' experiences of integrated care within a paediatric tertiary setting in Australia.	Exclude - Study protocol
Johnson, et al. (2020).	Understanding Young People and Their Care Providers' Perceptions and Experiences of Integrated Care Within a Tertiary Paediatric Hospital Setting, Using Interpretive Phenomenological Analysis.	Exclude – not relevant to FCC as it applies to children in hospital
Kaplan, et al (2022).	The role of parental health and distress in assessing children's health status.	Exclude – not relevant to FCC as it applies to children in hospital
Kaslow, et al. (2020).	Collaborative patient- and family-centered care for hospitalized individuals: Best practices for hospitalist care teams.	Exclude – not primary research
Khaksar, et al (2022).	Reducing Maternal Stress in Pediatric Hospitalization during the COVID-19 Pandemic by Improving Family-Centered Care with Bedside Telehealth: A Pilot Randomized Clinical Trial.	Include MMAT 43% Poor
Koch, et al (2021).	Multiple Roles of Parental Caregivers of Children with Complex Life-Threatening Conditions: A Qualitative Descriptive Analysis.	Exclude - not relevant to FCC as it applies to children in hospital
Kozkowski, R., & Wayman, K. (2021).	Family Matters. Applying Family-Centered Care to Food Insecurity During COVID-19.	Exclude - not primary research
Krisnana, et al (2019).	Reducing acute stress disorders in mothers of leukemic children by means of the family centred empowerment module (FACE)	Exclude - not relevant to FCC as it applies to children in hospital
Lessa, et al (2022).	Impact of the COVID-19 Pandemic on Patient- & Family-Centered Care and on the Mental Health of Health Care Workers, Patients & Families.	Exclude - not primary research
Lewis, H., et al (2022).	A Qualitative Study of Clinicians and Parents of Children with Severe Neurological Impairment on Tools to Support Family-Centered Care.	Exclude – not relevant to FCC as it applies to children in acute care setting
Lewis, et al (2019).	A qualitative study of nurses' perspectives of caring for children with intellectual disability and their families in a paediatric acute care setting.	Exclude – not relevant to FCC as it applies to children in hospital.
Leyenaar, et al (2018).	Paediatric hospital admission processes and outcomes: a qualitative study of parents' experiences and priorities.	Exclude - not relevant to FCC as it applies to children in hospital.

Author / Year	Title	Decision
Lindkvist, et al (2021).	"In a Way We Took the Hospital Home"-A Descriptive Mixed-Methods Study of Parents' Usage and Experiences of eHealth for Self-Management after Hospital Discharge Due to Pediatric Surgery or Preterm Birth.	Exclude – neonatal care
Loureiro,et al (2021).	Theoretical nursing conceptions in hospitalized child care: scoping review.	Exclude - not primary research
Love, et al (2022).	Lessons learned in the development of a nurse-led family centered approach to developing a holistic comprehensive clinic and integrative holistic care plan for children with cerebral palsy.	Exclude – not primary research
Lulgjuraj, D., & Maneval, R. E. (2021).	Unaccompanied Hospitalized Children: An Integrative Review.	Exclude – not primary research
Lundgren, et al. (2020).	Adolescents' Experiences of Staying Overnight at Family-Centered Pediatric Wards.	Exclude - not relevant to FCC as it applies to children in hospital
Luque-Coqui, et al (2021).	Implementation of guidelines to integrate the caregiver as a co-assistant of health-care personnel during the hospital stay of COVID-19 pediatric patients: adaptation in a Mexican public pediatric hospital.	Exclude – not primary research
Lyon, et al (2020).	Effect of Family CEntered (FACE®) Advance Care Planning on Longitudinal Congruence in End-of-Life Treatment Preferences: A Randomized Clinical Trial.	Exclude - not relevant to FCC as it applies to children in hospital
Lyu, et al (2020).	Perceived family impact during children's hospitalization for treatment of acute lymphoblastic leukemia: A cross-sectional study.	Exclude - not relevant to FCC as it applies to children in hospital
Mackie, et al (2021).	Exploring family participation in patient care on acute care wards: A mixed-methods study.	Exclude - not relevant to FCC as it applies to children in hospital.
Mahooti, et al (2018).	Effect of organizational citizenship behavior on family-centered care: Mediating role of multiple commitment.	Exclude - not relevant to FCC as it applies to children in hospital.
Maragakis, et al (2021).	Promoting a holistic family care model: Ethical and practical considerations for treating adult caregivers in integrated pediatric settings.	Exclude - not relevant to FCC as it applies to children in hospital.
Marshall, et al (2020).	Family-Centered Management of Birth Defects Diagnosis and Referral in Hospital Settings in Florida.	Exclude - not relevant to FCC as it applies to children in hospital.
Matziou, et al (2018).	Evaluating how paediatric nurses perceive the family-centred model of care and its use in daily practice.	Exclude – already included in original literature review
McCann, C. L. (2018).	Negotiation Intervention Between the Family and the Nurse of a Hospitalized Child.	Include PhD study MMAT 43% Poor
McKevitt, et al (2019).	Seeking normality: Parents' experiences of childhood stroke.	Exclude - not relevant to FCC as it applies to children in hospital.

Author / Year	Title	Decision
McLaughlan, R. (2018).	Psychosocially Supportive Design: The Case for Greater Attention to Social Space Within the Pediatric Hospital.	Exclude - not relevant to FCC as it applies to children in hospital.
Michel, et al (2020).	Caregiver and Adolescent Patient Perspectives on Comprehensive Care for Inflammatory Bowel Diseases: Building a FCC Delivery Model.	Exclude – not relevant to FCC as it applies to children in hospital
Minion, et al (2022).	The lived experience by patients and family members of extracorporeal membrane oxygenation: A qualitative study.	Exclude – not relevant to FCC as it applies to children in hospital.
de Sales Norte, et al (2018).	Empowerment of the mothers of children in a pediatric intensive care unit.	Exclude – not relevant to FCC as it applies to children in hospital.
Murrell, et al (2018).	Identifying Opportunities to Provide Family-centered Care for Families With Children With Type 1 Spinal Muscular Atrophy.	Exclude – already included in original literature review
Nicholas, et al (2020).	Patient- and Family-Centered Care in the Emergency Department for Children With Autism.	Exclude - not relevant to FCC as it applies to children in hospital.
North, et al (2020).	Distinctive nursing practices in working with mothers to care for hospitalised children at a district hospital in KwaZulu-Natal, South Africa: a descriptive observational study	Include MMAT 100% Good
O'Connor, et al (2019).	Family first.	Exclude – not primary research
O'Connor, et al (2019).	Family-centred care of children and young people in the acute hospital setting: A concept analysis.	Exclude – not primary research
Ohene, L. A., Power, K. J., & Raghu, R. (2020).	Health Professionals' Perceptions and Practice of Family Centred Care for Children Injured in Road Traffic Accidents: A Qualitative Study in Ghana.	Include MMAT 100% Good
Olwell, K. (2018).	Engaging families: A continuing education course on Family Centered Care principles and practice.	Exclude - not relevant to FCC as it applies to children in hospital.
O'Neill, et al (2022).	Exploring the impact of the COVID-19 environment on nursing delivery of family-centred care in a paediatric hospital.	Exclude – explores nurses experiences of delivering care during Covid-19
Paraszczuk, et al (2021).	Psychometric Testing of Family Centered Care (FCC) Instrument: A Mixed Methods Analysis of Pediatric Nurses and Their Workplace Perceptions of FCC.	Exclude - not relevant to FCC as it applies to children in hospital. Testing an instrument
Pazarcikci, F., & Efe, E. (2022).	Effect of care programme based on Comfort Theory on reducing parental anxiety in the paediatric day surgery: RTC.	Exclude - not relevant to FCC as of children in hospital.
Phiri, et al (2020a).	Parents' Perception regarding Their Participation in the Care of Hospitalised Children at a Tertiary Government Hospital in Blantyre, Malawi.	Include MMAT 100% Good
Phiri, P., Chan, C., & Wong, C. L. (2020b).	The Scope of Family-Centred Care Practices, and the Facilitators and Barriers to Implementation of Family-Centred Care for Hospitalised Children and their Families in Developing Countries: An Integrative Review.	Exclude – not primary research

Author / Year	Title	Decision
Phiri, et al (2022).	Discrepancies between nurses' current and perceived necessary practices of family-centred care for hospitalised children and their families: A cross-sectional study	Include MMAT 85% Good
Phiri, et al (2019).	Exploring Paediatric Nurses' Experiences on Application of Four Core Concepts of Family Centred Nursing Care in Malawi: Findings from a Resource Limited Paediatric Setting	Include MMAT 85% Good
Pilevar, et al. (2019).	Effect of Implementing Family-centered Empowerment Model on the Quality of Life in School-age Children Diagnosed with Rheumatoid Arthritis.	Exclude – not relevant to FCC as it applies to children in hospital. Day care setting.
Pouraboli, et al (2019).	The Effect of Relaxation Techniques on Anxiety, Fatigue and Sleep Quality of Parents of Children with Leukemia under Chemotherapy in South East Iran.	Exclude – not relevant to FCC as it applies to children in hospital. Day care setting.
Prasopkittikun, et al. (2019).	Thai nurses' perceptions and practices of family-centered care: The implementation gap.	Include MMAT 57% Moderate
Pretorius, et al (2021).	Stakeholders' perceptions of family-centred care in the intensive care unit: An associative group analysis.	Exclude – not relevant to FCC as it applies to children in hospital.
Quaye, et al (2021).	How are children's best interests expressed during their hospital visit?-An observational study.	Exclude – not relevant to FCC as it applies to children in hospital
Quaye, et al (2019).	Children's active participation in decision-making processes during hospitalisation: An observational study.	Exclude – not relevant to FCC as it applies to children in hospital.
Richards, et al. (2018).	Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care.	Exclude – not relevant to FCC as it applies to children in hospital.
Roney, et al (2021).	An Interprofessional Approach to Family-Centered Child Protective Services Referral: A Case Report.	Exclude – not primary research
Ryerson Espino, et al (2018).	It is a marathon rather than a sprint: an initial exploration of unmet needs and support preferences of caregivers of children with SCI	Exclude – not relevant to FCC as it applies to children in hospital.
Salvador, Á., Crespo, C., & Barros, L. (2019).	The Benefits of Family-Centered Care for Parental Self-Efficacy and Psychological Well-being in Parents of Children with Cancer.	Exclude – not relevant to FCC as it applies to children in hospital.
Saria, et al. (2019).	Parents and nurses telling their stories: the perceived needs of parents caring for critically ill children at the Kilimanjaro Christian Medical Centre in Tanzania.	Include MMAT 100% Good
Scharping, et al (2022).	Unmet Needs of Parents of Children with Urea Cycle Disorders	Exclude – not relevant to FCC as it applies to children in hospital. Day care setting.

Author / Year	Title	Decision
Shaibu, et al (2019).	Comparison of Intensive Care Units (ICUs) Nurses' and Families' Perception of Compliance with Patient and Family Centered Care Principles in ICUs in Ghana.	Exclude – not relevant to FCC as it applies to children in hospital. Day care setting. Adult ICU
Shepley, et al. (2021).	Rationale, Development, and Description of a Brief Family-Centered Service Provision Model for Addressing Children's Severe Behavior.	Exclude – not primary research
Shields, et al (2018).	International commentary on Phiri et al. 'Registered nurses' experiences pertaining to family involvement in the care of hospitalised children at a tertiary government hospital in Malawi'.	Exclude – not primary research. Commentary
Simione, et al. (2020).	Family-centered Outcomes that Matter Most to Parents: A Pediatric Feeding Disorders Qualitative Study.	Exclude – not relevant to FCC as it applies to children in hospital.
Smith, T. S. (2022).	Standardized Postoperative Cardiac Surgery Educational Process: Improving FCC.	Exclude – not primary research. QIP
Smith, W. (2018).	Concept Analysis of Family-Centered Care of Hospitalized Pediatric Patients	Exclude – not primary research.
Stephen, J. M. (2021).	Pediatric Nurses' Experiences in Caring for Non-English Speaking Patients and Families.	Exclude – not relevant to FCC as it applies to children in hospital.
Sundal, H., & Vatne, S. (2020).	Parents' and nurses' ideal collaboration in treatment-centered and home-like care of hospitalized preschool children – a qualitative study.	Exclude – not relevant to FCC as it applies to children in hospital.
Tallent, et al (2022).	Extending the radius of family-centered care in the pediatric cardiac intensive care unit through virtual rounding.	Exclude - not primary research. QIP
Taranto, et al (2021).	Parents' experience of family-centred care in the post-anaesthetic care unit during non-clinical delays: A qualitative study.	Exclude – not relevant to FCC as it applies to children in hospital.
Tedesco, et al (2021).	Challenges to delivering family-centred care during the Coronavirus pandemic: Voices of Italian paediatric intensive care unit nurses.	Exclude - not primary research.
Terp, et al. (2021).	Parents' Views of Family-Centered Care at a Pediatric Intensive Care Unit-A Qualitative Study.	Include MMAT 85% Good
Tollit, et al (2018).	Patient and Parent Experiences of Care at a Pediatric Gender Service	Exclude – not relevant to FCC as it applies to children in hospital.
Tyack, et al (2021).	Improving the patient-centred care of children with life-altering skin conditions using feedback from electronic patient-reported outcome measures: protocol for a hybrid effectiveness-implementation study (PEDS-ePROM)	Exclude - not primary research. Study protocol
Uniacke, et al. (2018).	How should we understand family-centred care?	Exclude - not primary research.
Uuksulainen, et al (2022).	Translation and cultural adaptation of the Family Centered Care Assessment Scale (FCCAS) for Finnish pediatric nursing.	Exclude – not primary research. Instrument development

Author / Year	Title	Decision
Vance, et al (2021).	Visitor Guidelines in US Children's Hospitals During COVID-19.	Exclude – not primary research.
Vasey, et al (2019).	Tokenism or true partnership: Parental involvement in a child's acute pain care	Include MMAT 100% Good
Vasli, P. (2018).	Translation, Cross-Cultural Adaptation, and Psychometric Testing of Perception of Family-Centered Care Measurement Questionnaires in the Hospitalized Children in Iran.	Exclude - not relevant to FCC as it applies to children in hospital. Development of a tool
Velez, et al (2022).	Facilitating Engagement on Family-Centered Rounds for Families With Limited Comfort With English.	Exclude - not relevant to FCC as it applies to children in hospital.
Williams, et al (2019).	Pediatric psychosocial care: Historical context and a theoretically informed practice model.	Exclude – not primary research.
Yin, Y., et al (2020).	Experiences of family caregivers caring for critically ill children hospitalized in a pediatric intensive care unit: a qualitative systematic review protocol.	Exclude – not primary research. A study protocol
Yoo, S. Y., & Cho, H. (2020).	Exploring the Influences of Nurses' Partnership with Parents, Attitude to Families' Importance in Nursing Care, and Professional Self-Efficacy on Quality of Pediatric Nursing Care: A Path Model.	Exclude - not relevant to FCC as it applies to children in hospital.
Zhou, et al (2022).	Management experience of a designated hospital for children with coronavirus disease 2019.	Exclude – not primary research.
Zimmermann, E., & Alfes, C. M. (2019).	Simulating the Role of the Parent: Promoting Family-Centered Nursing Care.	Exclude – not primary research.

Appendix 10 Three completed data extraction forms

Data Extraction Template amended from JBI Data Extraction Form for Systematic Reviews

Study Details: Shields, L., Young, J., & McCann, D. (2008). The needs of parents of hospitalized children in Australia. *J Child Health Care*, 12(1), 60-75. doi:10.1177/1367493507085619

Author/Year	Shields, Young & McCann (2008)
Aims / Objectives	The aim of this study is to investigate, in an Australian setting, parents' perceptions of their needs when they have a child who is hospitalized, and to compare them with staff's perceptions of the parents' needs.
Participants (characteristics / total number)	Parents and staff (nurses, doctors and allied health staff) at a paediatric hospital participated. A convenience sample in paediatric facilities in From 139 staff and 188 parent surveys distributed, 79 staff and 130 parent questionnaires were returned, yielding a response rate of 57% and 69% respectively.
Country of origin	Australia
Setting / Context	A tertiary referral children's hospital
Description of interventions / phenomena of interest	A widely used and validated tool was used
Type of study	a cross-sectional survey design
Key findings / results	<p>Some differences were found between parents and staff for scores for perceived importance of the 51 needs included in the questionnaire, and whether or not they were being met satisfactorily during children's hospital admission, although there were no consistent patterns.</p> <ul style="list-style-type: none"> • Parents indicated that they did not need as much help as the staff supposed, illustrating that parents of hospitalized children are more independent than staff perceive them to be. • More staff than parents are aware of the importance of each need, demonstrating that staff are cognisant of the needs of parents of hospitalized children and their families. Parents are more likely to be able to meet their needs themselves rather than rely on staff to assist them. • Parents declared themselves more independent than the staff perceived them to be. • Cultural differences may influence the findings. • it is time for a review of this tool, as societies around the world have changed since it was last reviewed in 1995
Implications for practice / future research	<p>These findings facilitate improvements in communication between parents and staff and can be included in education programmes for both. The study results highlighted several areas requiring improvement in communication between staff and parents.</p> <p>This study is being conducted in Indonesia at present, and a study in Iran is under negotiation. Differences and similarities in cross-cultural comparisons will provide a rich source of information on which to base care for people from differing cultural backgrounds.</p> <p>of interest to see if the needs of children old enough to be involved in such research differ from those of their parents and/or differ from staff perceptions of the children's needs.</p>

Appraisal

Appraisal instrument used	MMAT
Appraisal rating	71% Moderate

Summary of key points

- Family-centred care is a central tenet of paediatrics and should encompass all aspects of the child and family's experience of hospitalization. Important to this are the needs of parents when their children are hospitalized.
- Participation by families in their child's care promotes normality of the family unit, continues the normal routines of the child's life within the limitations of the hospital setting and reduces emotional stress for the child
- Nurses fail to incorporate elements of this concept consistently into their daily practice
- Involvement of parents in daily planning and assessment is often on an ad hoc basis, rather than a negotiated plan based on assessment of needs.
- Parents of hospitalized children have physical and psychosocial needs which must be met to enable them to stay with their children during the child's admission;
- Assumptions are made in clinical practice that parents' needs are similar across all countries and cultures.

Data Extraction Template amended from JBI Data Extraction Form for Systematic Reviews

Study Details: HUGHES M (2007) Parents' and nurses' attitudes to family-centred care: an Irish perspective. *Journal of Clinical Nursing* **16**, 2341–2348.

Author/Year	Hughes, M. (2007)
Aims / Objectives	The aim of the study was to examine the attitudes of parents & nurses to Casey's (1988) partnership model of care delivery on an in-patient children's unit in a regional general hospital.
Participants (characteristics / total number)	The sample of parents was chosen using a simple random sampling plan. The Hospital Information System was accessed to identify all the children admitted to the unit over a 3 month period. The target population for this study included both mothers & fathers who stayed overnight with their sick child. A significant percentage of resident parents were chosen, based on mean values for the previous 3-year admission figures (n = 100). The eligibility criteria for the parent sample included the ability of parents to read & write English. It was ensured that none of the parents selected had been bereaved of their child during or after the period of hospitalization. All the nurses employed on the unit were included in the nurse sample, the accessible population were the qualified, state-registered nurses. The target population included permanent, temporary and job-sharing members of staff at staff nurse and clinical nurse manager level. This ensured that all nurses working on the unit were selected to participate, regardless of the grade and length of service (n = 44).
Country of origin	Ireland
Setting / Context	An in-patient children's unit in a regional general hospital.
Description of interventions / phenomena of interest	This study set out to examine parents' & nurses' attitudes regarding the facilitation & empowerment of parents in caring for their sick child in hospital by nurses, examining the facilities available to parents on the unit. The research question is: 'What are the attitudes of parents and nurses to parent participation in care?'
Type of study	The study was carried out using two self-designed questionnaires.
Key findings / results	<ul style="list-style-type: none"> • The entire nurse group (n=28) agreed that parents should be cared for as well as the sick child who is in their care. All nurse respondents agreed that it was important for parents to be present with their sick child in hospital. • The entire parent group (n=43) felt that they were included in the care of their sick child by the nurses on the unit. • 57.1% (n=16) of the nurse respondents believed they were good at teaching parents new skills while only 27.9% (n = 12) of the parent group believed so. • 69.9% (n=30) of parents were dissatisfied with the facilities available to them; 78.5% (n=21) of the nurse sample disagreed with the statement. The need for improved facilities was agreed by 82.1% (n=22) of the nurse sample and 55.8% (n=24) of the parents. • 40% (n=11) of the nurses believed that parents did not know what was expected of them when a child is admitted to hospital. Over half of the parent group (55.8%, n = 24) admitted that they did not know what was expected of them & 34.9% (n = 15) of parents felt they had to stay with their sick child because the nurses looked too busy. • Both the parent (58.1%, n=25) and nurse (75%, n=21) groups felt that the cost for parents of staying with a child

	<p>in hospital were too high.</p> <ul style="list-style-type: none"> The nurses recognize that it is advantageous for both the child & the parent if they can be resident with their child & that the parent needs to be cared for also.
Implications for practice / future research	The area where both groups agreed needed improvement was in the facilities available to parents on the unit.

Appraisal

Appraisal instrument used	MMAT
Appraisal rating	57% Moderate

Summary of key points

- FCC requires a partnership approach, with negotiation & shared care planning that leads to the empowerment of parents to become stronger advocates for their sick children (Casey 1988, Darbyshire 1994, Smith 1995, Valentine 1997).
- Central to the philosophy of FCC is the view that care is negotiated and respect for the wishes of the family is defended (Casey 1988, Tomlinson et al. 2002, Franck & Callery 2004).
- Involving parents as partners in care is a major component of promoting a FCC approach, though it is an area identified as being problematic for both nurses and parents (Taylor 1996, Kristensson-Hallstrom & Elander 1997). Each views the other as encroaching on their care-giving role, their traditional areas of expertise.
- Hutchfield (1999) & Franck & Callery (2004) suggest that the skill level & competency of the nurse influences the degree to which FCC is practiced. It appears that the level of participation varies greatly, depending on the nurse more so than the parent. Alsop-Shields and Mohay (2001) suggest that this is the result of a lack in guidance, direction, support and confidence from management in the autonomy and ability of nurses to undertake their new role in practicing FCC.
- A therapeutic relationship between patient and nurse requires a change in the traditional role of dominant expert and passive recipient of care. For nurses to empower patients, the relationship must be based on mutual respect, trust and equality of worth.
- Kawik (1996) suggests that there are occasions where there is meaningful partnership with parents, but this is at the discretion of the nurse and is more through convenience than by planned negotiation.
- Dunst & Trivette (1996) suggest that, by facilitating parents in caring for their child in hospital, there is a decrease in the feelings of frustration, powerlessness and guilt parents experience.
- Taylor & Daniel (2000) suggested that fathers feel disempowered by excluding them from caring for their sick child. Taylor and Daniel (2000) found that nurses overlooked fathers as a resource when caring for sick children. They suggest that this is the result of parenting being seen as a predominantly maternal occupation.

Data Extraction Template amended from JBI Data Extraction Form for Systematic Reviews

Study Details: MacKay, L. J., & Gregory, D. (2011). Exploring Family-Centered Care Among Pediatric Oncology Nurses. *Journal of Pediatric Oncology Nursing*, 28(1), 43-52.

Author/Year	MacKay, L. J., & Gregory, D. (2011).
Aims / Objectives	The purpose of this study was to understand the experiences of pediatric oncology nurses in relation to FCC; identify how pediatric oncology nurses implemented FCC into their practice; identify what facilitated and enabled them to implement FCC; and discern the barriers and challenges that were present in their setting when implementing FCC.
Participants (characteristics / total number)	Nurses (N=20) were recruited through purposeful convenience sampling and were then interviewed.
Country of origin	Canada
Setting / Context	Western Canadian children's hospital
Description of interventions / phenomena of interest	This study entailed naturalistic inquiry (Polit & Hungler, 1999) and person-centered interviewing (Hollan, 2005; Levy & Hollan, 1998). The participants described the extent to which they practiced FCC, explained what FCC meant to them and shared their personal experiences implementing such philosophy in their nursing practice.
Type of study	A qualitative approach utilizing person-centered interviewing was used to collect data. Interviews were guided by a semistructured interview guideline created from the core concepts of FCC.
Key findings / results	<ul style="list-style-type: none"> ● The demographic data were examined with respect to the findings, no patterns or relationships were identified. ● Five major themes were identified from the data set: Hospital support of FCC, How participants defined FCC, Establishing FCC, Enhancing FCC, and Barriers and Challenges to providing FCC. <ul style="list-style-type: none"> ◦ The majority of participants (80%, N = 16) stated that "yes" the hospital supported FCC in their setting ◦ All of the participants identified that FCC meant incorporating and encompassing the whole family in the care provided to the child. ◦ The notion of teamwork and the family's place on that team fostered collaboration. ◦ Flexibility involved being open to negotiation and having a willingness to compromise when care procedures would occur. Education empowered the patient-family to be involved in decision making, participate in care and equipped to ask questions. ◦ A barrier to FCC was the lack of understanding and knowledge regarding the patient-family's culture.
Implications for practice / future research	<ul style="list-style-type: none"> ● To gain a deeper understanding of FCC further research among patients and families is needed. ● Recommendations for future research and implications for practice and education are offered.

Appraisal

Appraisal instrument used	MMAT
Appraisal rating	100% Good

Summary of key points

- Family-centered care (FCC) is important within pediatric oncology nursing. However, pediatric oncology nurses often face challenges and barriers when attempting to provide FCC.
- At the heart of FCC in pediatrics is the understanding that the child's family is the primary source of strength and support for her or him (American Academy of Pediatrics, 2003).
- However FCC lacks clarity in both the literature and practice contexts (MacKean, Thurston, & Scott, 2005).
- To implement FCC into their practice, pediatric oncology nurses must attain particular skills, knowledge, and experiences. Such information does not appear to have been given consideration within the FCC model of care (Baker, 1995).
- According to Shields (2007), "healthcare practitioners must critically examine family-centered care and how it is delivered" (p. 869).
- In order to provide FCC nurses must be comfortable interacting and creating relationships with patient families, which is an expertise that is acquired over time with experience.
- "Simply espousing a philosophy of family-centered care does not ensure that the philosophy will be practiced" (Bruce & Richie, 1997; p. 220).
- Benzein, Johansson, Arestedt, and Saveman (2008) found in their descriptive study that newly graduated registered nurses viewed the family as a burden because they did not have time to take care of them. Also, they found that newly graduated RNs focused on the individual patient more than the family.
- FCC was deemed important and valuable within pediatric oncology nursing, but it did not come without considerable barriers and factors that undermined its implementation.
- A FCC philosophy that takes into account and embraces the strengths of the nurse and the patient-family with flexibility in the delivery and adaptability in its evaluation

Appendix 11 Summary of the studies included in literature review.

Qualitative studies (n = 22)

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Ames, K.E., Rennick, J.E., and Baillargeon, S. (2011). Canada	To gain an in-depth understanding of parents' perceptions of their role when their child is critically ill and admitted to a Paediatric Intensive Care Unit (PICU).	7 parents (5 mothers and 2 fathers) who had a child hospitalized in PICU & whose child was being prepared for discharge from PICU. Children were aged from 13 days to 16 years. 5 children had unplanned admissions to the critical care unit	PICU in a tertiary care, Canadian university-affiliated pediatric hospital.	Qualitative study: descriptive and interpretive inquiry. Each parent participated in a semi-structured, audiotaped interview lasting 25-60 minutes. The interview tool, composed of 8 open-ended questions. Data were coded and clustered into themes. Analysis revealed statements describing the parental role and facilitators of that role.	Participants revealed that their overall parental role was to ensure that their child was well cared for and that they were doing something important for their child in hospital. Three dimensions to this parental role, each with sub roles, emerged: (1) being present and participating in care by (a) just being there, providing comfort (b) active caring (c) providing explanations/reassurances to their child; (2) forming a partnership of trust with PICU healthcare team by (a) sharing their expertise as a parent, (b) building trust with the team (c) taking care of themselves; (3) being informed of their child's progress and treatment plan as the person who knows the child best by (a) knowing their child's status, (b) understanding the care provided to their child (c) knowing what to expect next.	100% Good
Avis, M. and R. Reardon (2008). United Kingdom (UK)	To explore parents' views on how their child with additional needs had been cared for by hospital nursing staff.	Purposive sampling strategy was used to recruit parents from one National health Service (NHS) Children's Centre in the UK	One NHS Children's Centre providing respite care for approximately 50 parents and children with learning disabilities and complex healthcare needs.	A qualitative study	Four themes were developed: prior experiences of hospital care; communication with staff; nurse-parent relationships; and perceptions of nurses and nursing care. Parents placed a high value on "direct" communication between nurse and child. Often the child can understand more than nurses assumed. Nurses need to "communicate better with parents". Parents acknowledged that they were deemed the "experts" by nurses. Their involvement was expected rather than negotiated, leaving them feeling unable to leave the bedside. An understanding of cultural issues was mentioned, with an Asian father noting that fathers can have "little to do with children in our culture".	100% Good

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Baird, J., Davies, B., Hinds, P. S., Baggott, C., & Rehm, R. S. (2015). USA	To understand interactions, processes & the creation of meaning for the parents of children with complex chronic conditions & nurses in the PICU.	There were a total of 19 participants in the study, 7 parents (5 mothers and 2 fathers, all parents of different children) and 12 nurses (all female).	A single PICU in a large, urban teaching hospital in the western United States.	A qualitative, grounded theory study. Parents who agreed to participate allowed the investigator to observe their interactions with nurses from the child's room at various times over one week.	The existence of hospital rules can impact the extent to which PFCC is delivered. The existence of explicit and implicit rules in a PICU negatively affected the family's ability to receive care that was attentive to their needs. The rules also placed the registered nurse in the challenging position of serving as rule enforcer and facilitator of PFCC. Further work is needed to explore how to adapt the hospital environment to better meet families' needs.	100% Good
Boztepe, H., and Kerimoğlu Yıldız, G. (2017). Turkey	To explore the views of nurses regarding the practice of FCC and their perceptions of the barriers to implementing this practice.	Purposive sampling was adopted to include participants according to their work experience. In-depth interviews were conducted with 18 nurses to obtain detailed information about their perspectives on FCC activities.	Three different units (the PICU, pediatric surgery unit and general pediatric unit) of a children's hospital in Istanbul, Turkey.	A descriptive qualitative study. They also commented on some of the challenges and barriers to FCC practice.	Two main themes emerged with sub-themes. Almost all nurses had positive views of FCC stating continuity of the family's presence in a child's life was important. The second included their views on parents' participation during nursing rounds "nurses could feel uncomfortable about the parents' inclusion...., a mother may interfere by interrupting our conversation". Majority of nurses did not agree that parental participation in nursing bedside rounds was beneficial. They believed that if parents knew everything about their child, they could become anxious, would negatively affect the nurses and their care activities, so they only provided necessary information. Nurses thought that parental participation in nursing bedside report increased their workload. In Turkey, cultural aspects might have caused some challenges. Nurses stated families' cultural characteristics were an obstacle. To implement FCC, nurses should not only understand the model but also understand the rights, roles, responsibilities of parents. Nurses need to have sufficient resources, appropriate education and support from their managers to implement FCC.	100% Good

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Coyne, I. and Cowley, S. (2007) UK	To explore children's, parents' and nurses' views on participation in care in order to uncover the core issues and to develop explanatory theory.	Participants (11 children, 10 parents and 12 nurses) were obtained through purposeful sampling. Children were aged 7–14 years and had a range of acute and chronic illnesses.	Four paediatric wards in two hospitals in England, UK.	A grounded theory study.	Most nurses assumed that parents would participate in care, viewing their role as facilitators. Nurses reported that the ideology of partnership with parents did not accurately reflect their relationships. Parents felt compelled to be there and to be responsible for their child's welfare in hospital. They all experienced considerable disruption to their worlds and had difficulty with participation in care. Parents felt their physical presence provided emotional support for their child rather than being involved in giving physical care. While being present was a moral imperative for parents, they also reported feeling compelled to be there because they lacked confidence in nurses. Children talked about how their parent provided companionship by chatting and playing games, which helped towards relieving boredom.	100% Good
Coyne, I. (2013). Ireland	To explore parents', children & nurses' perspectives & experiences of FCC & to understand how parents, children & nurses negotiate roles & relationships in the hospital setting.	Children (n=18) were purposively sampled to ensure that children with acute & chronic illnesses were represented as experiences may differ. Parents (n=18) were also included. Nurses (n=18) who were present & delivering care for the families were purposefully sampled to ensure a range of grades	Two general medical & surgical wards in two children's hospitals & one surgical children's ward in a district general hospital in Ireland.	The qualitative method used was guided by a constructivist approach and elements of grounded theory.	The key themes identified were: (i) Expectations, (ii) Relying on parents help, (iii) Working out roles, and (iv) Barriers to FCC. Nurses and parents saw parents' presence as helping, provide reassurance, comfort and security for the child. Nurses felt it was important that parents had a choice about participation, FCC could place unrealistic expectations on parents because of family commitments and work responsibilities. Parents and nurses appeared to work out their roles in an <i>ad hoc</i> way rather than from an open and full discussion of expectations. Both parents and nurses stated that over-reliance on parents and lack of communication were the main barriers to effective FCC. Overall parents wanted to participate in the usual childcare needs, which their child required and to comfort their child.	100% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Curtis, P. and Northcott, A. (2017). UK	To explore the experiences and perceptions of hospitalised children, their parents and health professionals with respect to children's everyday care and activities of daily living, and to understand how formal and informal care interactions took place in both single and shared rooms.	Phase 1 observation within four wards of a specialist children's hospital. Phase 2; interviews with 17 children aged 5-16 years & 60 parents/carers. Sixty nursing and support staff also took part in interviews and focus group discussions.	One specialist paediatric hospital in the north of England, two years prior to relocation into a new-build hospital extension.	A focused qualitative ethnographic study (Morse 1987) in two phases over a 10 month period.	Two themes emerged: "role expectations" and "family-nurse interactions". The later theme comprised 3 subthemes: "family support needs", "monitoring children's well-being" and "survey-assess-interact within spatial contexts". Spatial configurations within hospital wards significantly impacted the relationships and interactions between children, parents and nurses, which played out differently in single and shared rooms. Single rooms within wards is therefore likely to directly affect how FCC manifests in practice. Shared rooms were associated with greater sociability and single rooms with greater privacy, but also lower sociability and increased boredom for children & parents, agree with findings from other studies (Birch <i>et al</i> , 2007; Austin <i>et al</i> , 2013; Lambert <i>et al</i> , 2014). Nurses' concerns that families in single rooms liable to make additional calls on nurses' time to meet their social support needs. Nurses need to be aware of spatial characteristics, particularly of single and shared rooms, on families' experiences of children's hospital wards. Nurses' contribution to and experience of FCC can be expected to change significantly when spatial characteristics of wards change and as hospitals maximise the provision of single rather than shared rooms.	100% Good

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de Macedo, I. F., de Souza, T. V., dos Santos Oliveira, I. C., Alves Cibreiros, S., de Cássia Melão de Moraes, R., & Coelho Vieira, R. F. (2017) Brazil	Describe nursing team care and discuss the nursing team's conception of companion families of hospitalized children.	14 members of a nursing team were interviewed through an unstructured group interview.	A pediatric inpatient unit of a public university hospital in Rio de Janeiro, Brazil.	A qualitative study	Nurses considered that family participation in care provision is necessary. One nurse considered agreement regarding family participation in care provision must be established first, especially during the night. All nurses believed that family presence is beneficial to the child's emotional needs during hospitalization. Most participants conceived families as an important element in the development of habitual & maintenance care regardless of the child's clinical condition. The literature justifies this conception, as families have been shown to provide emotional security to their children & help nursing teams, especially considering staff shortage. The nurses believed that families often need psychological support to endure their hospital experience.	100% Good
Foster, M. and Whitehead, L. (2017). New Zealand	To explore parent and staff perceptions of FCC.	A convenience sample of 91 parents resident with their child & 66 staff working within a paediatric High Dependency Unit (HDU).	A paediatric HDU in one New Zealand hospital.	A descriptive qualitative cross-sectional design seeking written responses for one open ended question	The parents' responses generated three themes (family, treatment and relationships) and the staff's responses generated two themes (family and treatment). The importance of meeting the family's needs which included involvement of the family into the daily care of the child & the practical support the family required in hospital to fulfil this role was most frequently described by parents. Staff described meeting the child's needs more often than meeting the family's needs. Whilst there were similarities in describing the meaning of FCC between parents and staff, their views on the central focus of this differed.	71% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Higham, S., & Davies, R. (2013) UK	To gain an increased understanding of fathers' experiences during their child's stay in hospital following an unplanned admission for acute illness or injury and to gain an increased understanding of nurses' experiences of working with fathers.	A purposive approach to sampling was taken, consistent with ethnographic research - 12 fathers and 7 qualified children's nurses were interviewed.	Two children's wards of a district general hospital of an acute NHS Trust in the South of England.	A qualitative field study involving 150 hours of ethnographic observation and interviews.	Fathers wanted to be with their sick child in hospital & made essential contributions to the family's experience. Three aspects of the fathers role in caring for their sick child were identified: protecting - Fathers were observed undertaking a range of protective behaviours & discussed the importance of protecting their children & partners; providing for the family - ensuring others' needs were met, providing care & working; participating in care - Fathers participated by: sharing the caring, assisting with clinical care & in decision-making. Parents & nurses assumed that a parent would be with the child throughout the hospital stay. Fathers were not always involved as equal partners in their child's care & FCC appeared to relate to mothers or resident parents, rather than the whole family.	100% Good
Hill, C., Knafl, K. A., Docherty, S. and Santacroce, S. J. (2018b). USA	To examine parent perception of how the physical and cultural environment of PICU impacted the implementation of FCC as outlined by the IPFCC.	61 interviews with 3 mothers and 3 fathers of infants with complex congenital heart defects treated in a PICU were subjected to secondary analysis via content analysis.	A PICU in a major academic children's hospital in South-eastern USA	A qualitative descriptive design utilizing secondary analysis from a longitudinal study.	FCC core concepts of information sharing, participation, respect & dignity were present in parents' data. They indicated that the physical & cultural environment of PICU impacted on their perceptions of how each of the concepts was implemented. The unit environment impacted both positively & negatively on how parents experienced their infant's hospitalisation. Operationalisation of FCC differed from actual parent experiences. The impact of physical & cultural environment should be considered in the delivery of care, as the environment was shown to impact implementation of each of the core concepts.	71% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Lee, R. L. and Lau, V. W. (2013). China	To examine Chinese mothers' experience of caring for their hospitalized sick child.	Semi-structured interviews were conducted with 15 mothers caring for their hospitalized sick children with acute injury or illness.	Two hospitals in the New Territories of Hong Kong	An interpretive phenomenological approach using thematic analysis.	The prevailing concept identified through analysis was the 'constant vigilance' that mothers developed. Interpretation of data resulted in the identification of four key themes: 'being sensitive to others', 'providing helping hands', 'monitoring health conditions', and 'maintaining dialogues'. The findings highlight Chinese mothers' desire for participation in caring for their hospitalized child, their unexpressed needs for communication, and concern about being uncared by the busy health professionals, which affect their care for the child's health outcomes.	100% Good
Livesley, J. and Long, T. (2013). England, UK	To develop insight into children's subjective interpretations and knowledge of being hospital in-patients.	A purposive sample was employed of 15 children over 2 phases: six (9–15 years) at home in a reconnaissance first phase, and nine (5–14 years) in hospital in phase 2.	A nephro- urology ward in a tertiary referral children's hospital	Critical ethnography.	The ward was a place in which children struggled to find a space for their competence to be recognised and voice heard. Children's voice became manifest in what they said, also through the non-verbal mechanisms of resisting, turning away and being silent. All the children experienced being in trouble, recognition of their competence was fluid and contingent on their relationships with the nurses and other factors. The children worked hard to maintain their position as knowledgeable individuals. When they could not do so they relied on supportive adults, in the absence of supportive adults they became marooned and received bare minimum care. Quiet, sick and shy children who were alone were most likely to have their needs overlooked.	85% Good

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Macdonald, M. E., Liben, S., Carnevale, F. A. and Cohen, S. R. (2012). USA	To examine the experience of families whose children were hospitalized in a PICU using in-depth prospective qualitative methods to better understand how the PICU is experienced by patients and families.	Purposive sampling of families of children needing high-acuity care in order to target those whose stay would most likely be protracted and therefore who would be more able to provide extensive data - 25 families were eligible for recruitment, of which 18 participated.	A PICU in a tertiary care hospital in a large North American urban center.	A 12-month prospective ethnographic study	Findings revealed a disconnect between the espoused model of FCC and quotidian (daily) professional practices. Two main themes emerged: Transformation: From a "child & parent" to a "patient & visitor" & The "family" in family-centered care. Together these themes suggest that the goals of FCC may be greatly challenged by quotidian practice in the PICU. This divergence emerged in the authors' analysis as a heuristic that contrasts a professional "office" to a sick child's "bedroom." PICU practices & protocols transformed the child into a patient & parents into visitors; issues such as noise, visitation, turf & privacy could favor staff comfort & convenience over that of the child & family.	85% Good
Mackay, L. J. and Gregory, D. (2011) Canada	To understand the experiences of pediatric oncology nurses in relation to FCC; identify how they implemented FCC in practice; identify what facilitated and enabled them to implement FCC; and discern the barriers and challenges that were present when implementing FCC.	Nurses (N=20) were recruited through purposeful convenience sampling.	Western Canadian children's hospital	A qualitative approach using person-centered interviewing to collect data.	Five major themes were identified: <ul style="list-style-type: none"> • Hospital support of FCC - 80% of participants stated that the hospital supported FCC. • How participants defined FCC - All participants identified FCC meant incorporating & encompassing the whole family in care provided to the child. • Establishing FCC - Teamwork & the family's place on that team fostered collaboration. • Enhancing FCC - Flexibility involved being open to negotiation & having a willingness to compromise when care procedures would occur. Barriers and challenges to providing FCC - A barrier to FCC was the lack of understanding & knowledge regarding patient-family's culture.	100% Good

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Moore, M., Robinson, G., Mink, R., Hudson, K., Dotolo, D., Gooding, T., . . . Vavilala, M. S. (2015). USA	To examine the family experience of critical care after pediatric traumatic brain injury (TBI) in order to develop a model of specific factors associated with FCC.	Fifteen mothers of children who had an acute hospital stay after TBI within the last 5 years were interviewed about their experience of critical care & discharge planning. Participants who were primarily English, Spanish or Cantonese speaking were included.	Two level 1 trauma centres in Washington, USA.	Qualitative methods with semi-structured interviews were utilized. Content analysis was used to code the transcribed interviews and develop the family-centered care model.	Three major themes emerged: 1. Thorough, timely & compassionate communication. 2. Capacity building for families, providers & facilities. 3. Co-ordination of care transitions. Participants valued detailed & frequent communication that set realistic expectations & prepared them for decision-making & outcomes. Areas for capacity building included strategies to increase provider cultural humility, parent participation in care & institutional flexibility. Co-ordinated care transitions, including continuity of information & maintenance of partnerships with families & teams were highlighted. Participants who were not primarily English speaking reported particular difficulty with communication, cultural understanding & co-ordinated transitions.	85% Good
Murrell, D. V., Crawford, C. A., Jackson, C. T., Lotze, T. E., & Wiemann, C. M. (2018). USA	To understand, from the parent perspective, the experience of the family whose child has Type 1 spinal muscular atrophy (Type 1 SMA), in the emergency center, hospital & clinical care settings to identify opportunities for improved FCC.	Nineteen families with 22 children with Type 1 SMA participated.	Texas Children's hospital	A qualitative descriptive design with individual or small group interviews guided by a semi-structured questionnaire. Framework analysis was used to identify gaps in the provision of FCC & opportunities for improvement.	Eight basic tenets of FCC were identified. Family-to-family interactions strongly impacted participants' decision-making & perceived level of support. Participants valued strong family/ HCP partnerships, feeling heard and respected by their HCPs, and receiving complete education regarding disease trajectory. Analysis revealed both successful application of FCC & gaps in care where FCC could have been used to benefit families who have children with Type 1 SMA. As a chronic illness affects the whole family, FCC is important in maintaining the HCPs' focus on the family during child's care.	85% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Rasmussen, S., Water, T. and Dickinson, A. (2017) New Zealand	To ask children to share the narratives of their experience of hospital and hospitalisation in New Zealand, in order to consider multiple factors influencing their experience in hospital.	11 family interviews were completed; however, only 9 were included when it became apparent through the interview that two did not fulfil the inclusion criteria of the child having at least one night stay in hospital (the two related to day-stay surgeries).	8 interviews were conducted in participants' homes, while 1 took place at University. The home setting allowed families to be in their own environment with the interviewer as a guest.	A narrative qualitative study design involving face-to-face interviews with families (adults and children) was used. Families were free to determine who they included in the interview. Interviews with mother only (n=4), Interviews with mother and child (n=1), two parents (n=2), two parents with children (n=2).	The research findings offer insights into how children make meaning of hospital experience & how their roles are influenced by adults. Themes evident are that parent & child experience may be different; children's stories may not be consistent with family narratives; and children's agency in hospital is variable. Children's stories provide insights to the interconnectedness of personal, familial & societal narratives & their influence on experience of hospitalisation. Nurses and families are able to both constrain & enable children's participation in hospital care. Families reported a wide spectrum of experience including the hospitalisation of premature infants, acute illness and injury, and chronic illness; in one case, the child had died as a result of cancer.	85% Good
Rosignano, C. I. (2016). <u>USA</u>	Aim not clearly outlined. Research questions (a) What are parents trying to tell us about how they wish to be considered & treated in early acute care after children's moderate & severe TBI? (b) How do parents perceive caring from the nurses they met? (c) Do parents' narratives confirm Swanson's theory described by the five caring processes, or do parents' narratives expand what should be considered re the caring processes in this context & with these parents?	The sample for this analysis consisted of 29 parents of children with severe traumatic brain injury (TBI) from 25 families.	The 29 parents from 25 families came from 9 of the 50 United States and were cared for at 14 different acute care hospitals in the USA.	Descriptive qualitative study where parents of children with severe TBI (n = 25) described their appraisals of nurse caring & uncaring behaviors in early acute care. Swanson's theory of caring was used in data analysis.	A child's severe TBI creates a family crisis requiring extensive cultural, informational, psychological & environmental support. Nurses need to understand parents' expectations of caring so they can tailor their attitudes, beliefs & behaviors appropriately to accommodate family's needs. Caring nurse encounters included (a) involving parents in the care of their child & reflecting on sociocultural factors shaping family resources (knowing); (b) respecting that family grief can be co-mingled with resilience & parents are typically competent to be involved in decision making (maintaining belief); (c) actively listening & engaging parents to fully understand family values & needs (being with); (d) decreasing parents' workload to provide a safe cultural, psychological and physical environment for the family (doing for); & (e) providing anticipatory guidance to navigate the care system & giving assistance to learn & adjust to their situation (enabling).	100% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Schalkers, I., Parsons, C. S., Bunders, J. F. G., & Dedding, C. (2016). The Netherlands	To investigate healthcare professionals' perspectives on child participation in paediatric hospital care and their opinions on improving participation practices.	Healthcare professionals (n = 32) participated.	10 hospitals that were geographically spread across the Netherlands (two teaching hospitals and eight regional hospitals).	Qualitative descriptive design. Semi-structured interviews were conducted with healthcare professionals. Shier's Pathways to Participation model (2001) was used to guide the interviews.	Participation is not a term that is frequently used by professionals; however, they feel familiar with the ideas underlying the term, and it is perceived as being at the core of their work. Professionals believe that high levels of participation are possible in basic care for children. Participation in medical decision-making is considered to be more complex and subject to a number of reservations and restrictions. The participants expressed a strong need to enhance child participation in service evaluation and to increase the respect for and understanding of the rights of children to participate outside of the paediatric unit, including in the surgery and emergency departments. The type of decisions being made, the child's medical condition and his/her age (with related individual competences) greatly influence the extent to which professionals are willing to actively involve children in healthcare decisions. Professionals are more likely to enable a high level of participation in decisions that have a relatively low impact on the child's health, a tokenistic form of participation. The views and preferences of chronically ill children are more likely to be taken into account than those of children with acute conditions. The authors argue for a situational approach to participation in decision-making that considers each child's own contributions in each specific situation. Creative methods that support the role of children in evaluating and improving the quality of paediatric hospital care and services should be developed. Professionals have a duty to facilitate child participation in hospital care.	100% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study/Data collection methods	Key findings / Implications for practice	MMAT Score
Segantini Felipin, L. C., de Fátima Garcia Lopes Merino, M., Ayres Baena, J., Oliveira, R. B. S. R., Barbosa Alves Borghesan, N., & Harumi Higarashi, I. (2018). Brazil	To know the perception of nurses of neonatal & pediatric intensive care unit on FCC.	The target population of this study were nurses (n = 19) who were working on the day of the interview in a Pediatric Neonatal Intensive Care Unit of a municipality located in the Northwest of the state of Paraná, Brazil.	A Neonatal and Pediatric Intensive Care Unit of a private hospital.	Qualitative descriptive study that has a theoretical reference the FCC, which has as a background to support the family, stimulating the effective participation of the parents in the care process, as well as their insertion in the decisions about the behaviors. Thematic analysis was used to analyse the data.	Two themes emerged: "FCC in the perception of the nurse that provides intensive care to the child" and "the challenges of incorporating FCC in practice daily: gap between theory and practice. The study revealed the persistence of gaps between the theory & practice of FCC, which is seen as an aim by professionals, but still far from being fully understood & achieved, due to organizational & training obstacles. Conceptual assistance is necessary to promote reflections about the feasibility of this model, evidencing its potential in the qualification of the assistance, making it more holistic and humanized.	71% Moderate
Vasli, P., Dehghan-Nayeri, N., Borim-Nezhad, L., and Vedadhir, A. (2015) Iran	To examine the culture of FCC in the PICU.	Data collection strategy was participant observation, fieldwork & interviews with main actors of the PICU, namely supervisors, nurses & parents.	This study took place in one PICU in a hospital in Tehran, Iran.	Focused ethnography. Ethnography as a qualitative approach is studying a specific group of people regarding a specific topic.	The results were in the main named as paternalism & were presented as five themes: "non-possessed environment" (neither the child nor his/her family had the feeling of belonging) "separation of the children from their parents" (there were no facilities for parents' to stay or even sit by their child) "non-interactive communication" (an unequal & superior-inferior relation between staff & parents) "limited participation" (parents had very little participation in ward affairs & received inadequate information & education) & "affection & sympathy combined with superiority." (staff seemed cruel & dominant at times, some would have hidden or clear sympathy with the parents & communicated with them based on their needs). The prevailing atmosphere in care was paternalistic, there was a huge gap between conceptually or theoretically accepted application of FCC in PICU & what is practically administrated.	85% Good

Quantitative research articles (n = 18)

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Abdelkader, R., Arabiat, D. H., Holmes, S. L. and Hamdan-Mansour, A. (2016). Jordan	To investigate the relative contributions and predictive value of parents' & children's demographics on parents' participation in care.	A convenience sample of 294 parents of children 12-years old or less were recruited. Parents were eligible to participate if they were more than 18-years old, were the main caregivers for the hospitalized child and if they remained at the bedside for at least 24 hours.	Four major hospitals in a metropolitan area in Amman, Jordan, including one public hospital, one university-affiliated hospital and two private hospitals.	Quantitative Parents' participation in care was measured using the Index of Parent Participation/Hospitalized Child (IPP/HC) (Melnik <i>et al.</i> , 2004). The article states that data were collected through semi-structured interviews, but fails to describe the findings of same.	Four variables were identified as the optimal set of predictors for parent participation in care: hospital experience, type of illness, child's age & type of hospital. Parents at the public hospital and university-affiliated hospital reported significantly higher participation levels than parents in the private hospitals. The participation score of parents of infants was significantly lower than that of parents of older children, and the participation score of the parents of children aged three to six-years old was significantly higher than that of parents of older children. There was a significant negative association between child's age and parents' participation. There was a significant positive association between the number of previous hospitalizations and parents participation.	43% Poor
Bellin, M. H., Osteen, P., Heffernan, C., Levy, J. M. and Snyder-Vogel, M. E. (2011). USA	To examine the practice of FCC from two key stakeholder perspectives: parents of children with special health care needs (CSHCN) and interdisciplinary health care professionals.	A random sample of 132 families of CSHCN receiving care at the hospital (response rate 40%). A convenience sample of 69 healthcare professionals was also invited to participate (43 (62%) responded).	A large, urban U.S. children's hospital.	A cross-sectional quantitative study	No significant differences emerged between the two stakeholder groups. The data suggest that health professionals are generally meeting families' needs for specific communication & are respectful of parents' expertise. Parents & professionals alike indicated the need for continued professional growth in the area of providing holistic, comprehensive services to advance FCC.	43% Poor

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Cimke, S. and Mucuk, S. (2017). Turkey	To explore the relationship between overall parent satisfaction and FCC perception, parent participation and demographic characters.	285 parents (all mothers) were recruited using convenience sampling method.	A tertiary children's hospital, and the only medical specialist hospital for children and adolescents in the city.	A descriptive study. Data were collected using Family Descriptive Questionnaire Form, Pediatric Quality of Life Inventory Health Care Satisfaction Scale and Family-Centered Care Scale.	PedsQL HCSS and FCCS scores were found to increase at significant levels when the mothers are informed about the healthcare activities provided for their children, they were shown how to do these activities, & when they are given feedback as a follow-up to the care activity. There is a positive relationship between parents' healthcare satisfaction & FCC. The nurses should do their best to involve the parent in care of their children in accordance FCC principles. The most common practices that the mothers participate in are feeding the child orally, changing clothes and accompanying the child in painful procedures. The more mothers were involved in care of their children, the higher their satisfaction with the health care was.	57% Moderate
Coyne, I., Murphy, M., Costello, T., O'Neill, C. and Donnellan, C. (2013). Ireland	To investigate the practices and perceptions of pediatric nurses toward FCC in Ireland and to examine the factors that influence those perceptions.	All nurses in working in the 7 units were invited to participate. The sample consisted of 250 nurses working in children's hospitals or wards in Ireland, The response rate was moderate at 33%.	The study aimed to recruit nurses working in 7 of the 19 pediatric units across Ireland (n = 750).	A non-experimental survey design, the FCCQ-R developed by Bruce and Ritchie (1997) was used.	With the exception of design of the health care system, nurses felt that elements of FCC were present in their current practice. Nurses reported that they practiced FCC but there were significant differences between their practices and perceptions of FCC. They did not consistently apply the FCC elements in their actual practice. Emotional and financial support for families was the FCC element most frequently practiced.	71% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Dall'Oglio, I., Di Furia, M., Tiozzo, E., Gawronski, O., Biagioli, V., Di Ciommo, V. M., . . . Raponi, M. (2018). Italy	To: (1) investigate the extent to which FCC principles are currently applied in clinical practice by healthcare providers working in inpatient units; (2) evaluate the extent to which FCC principles are perceived as necessary; & (3) examine the associations between FCC principles & socio-demographic & job characteristics of participants.	Data from 469 healthcare providers were used for analysis.	A large pediatric hospital using the Italian version of the FCC Questionnaire Revised (FCCQ-R).	A cross-sectional study was conducted using the Italian version of the FCC Questionnaire Revised (FCCQ-R). Univariate & multivariate analyses were performed.	Scores for current FCC daily practices were significantly lower than those for their perceived necessity. Participants who were male, younger, with work experience >20 years & working in rehabilitation reported a significantly higher perception of current FCC activities than others. The older & the more educated the participants, the greater was the perceived necessity of FCC activities. Female, older & less experienced participants employed by the hospital but not working in the rehabilitation setting perceived a greater gap between Necessary & Current activities of FCC. Scores for the Current & Necessary activities of FCC were lower than those reported in other studies. The lower scores in the Current activities & the significant gap can be due to organizational barriers or lack of skills, but the lower scores in the Necessary activities should be interpreted as a deficit of knowledge about FCC.	57% Moderate
Evans, M. (2017). USA	To a) evaluate the impact of nursing education re parent support on nurses' knowledge of PFCC, (b) determine whether parent-support nursing education affected parents' perception of FCC and (c) parents' perceived care satisfaction.	A convenience sample of 67 nurses from one PICU, a 60-minute pre- & post-test educational intervention. A convenience sample to survey 40 parents with children in the PICU pre nurse education, & 39 different parents were surveyed after education.	PICU in the USA	A quasi-experimental pre-intervention-post-intervention design.	Nurses' knowledge increased significantly with post-test scores. No statistically significant changes occurred with parents' perception of PFCC nursing or parents' perceived satisfaction with their PICU nursing experience. There was a statistically significant difference with parent gender for importance and consistency scores. This is useful evidence of the ways parents perceived PFCC nursing care in a PICU & suggest a need for better reciprocal communication between nurses & parents & enhanced inclusion in participation. This translational research project provided nurses with a better understanding of parental experiences to inform expanded implementation of PFCC to support parenting role in PICU.	71% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Feeg, V. D., Paraszczuk, A. M., Çavuşoğlu, H., Shields, L., Pars, H., & Al Mamun, A. (2016). USA, Turkey & Australia	To (a) describe and measure how health providers perceive FCC and theoretically define the underlying construct of “family centeredness” from this perception; (b) compare differences between and among providers from three countries with varied health care systems that may explain cultural/ contextual issues in implementation; (c) explore a measure to determine providers' affective understanding of “family centeredness;” and (d) identify characteristics of providers that relate or differ in their “family centeredness” perceptions.	In each country, the researchers arranged for the distribution and collection of pencil to paper surveys following protocols approved by their respective hospitals. Participants included a range of nurses, physicians, allied health professionals and ancillary staff working in pediatrics (n = 476). Convenience samples of above professionals were invited to participate.	Two hospitals in the USA (n = 154); two hospitals in Australia (n = 117) and one hospital in Turkey (n = 205).	A multi-site comparative non-experimental design using survey questionnaires, translated when appropriate, designed to elicit participants' perceptions of caring for hospitalized children and their parents.	Healthcare providers report a significantly higher score for working with children than working with parents. Findings suggest that those who are older and/or are parents of children may be more compassionate about the parents' situations when their children are hospitalized. Further analyses revealed family-centeredness scores to be significantly different between nurses and physicians and significantly correlated with age, number of children and education.	57% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Frost, M., Green, A., Gance- Cleveland, B., Kersten, R. and Irby, C. (2010). USA	Discusses the results of a survey of parents and staff re their perceptions of FCC, discuss the initiatives to improve practice, and results of a follow- up survey	A convenience sample of 39 parents of hospitalized infants and toddlers and 76 staff members were recruited over a 4-week period for both the pre- and post-test phases.	A 35-bed medical– surgical unit serving infants and toddlers up to 3 years of age, as well as children requiring long-term mechanical ventilation.	Survey design. Intervention: comprehensive mandatory FCC education programme, the introduction of a FCC Framework and environmental changes as suggested by parents and staff in the pre-test survey	<p>Pre-test findings - concerns to parents included the need for more child-friendly decor, privacy for breast-feeding mothers, lack of continuity of care, lack of input into pain assessment, a place for families to lock personal belongings, parent showers in patient rooms and improvement in staff interaction with/inclusion of fathers. Staff concerns included unit appearance, unit congestion and environmental stimulation. Both parents and staff identified need for improved planning and preparation for discharge and need for a private place for families to talk to medical team.</p> <p>Post-test findings - From the staff's perspective, there was significant improvement in unit appearance and privacy for staff/parent discussions. Staff reported improvements in inclusion of fathers, recognition of parents as primary decision makers, and supportive measures to resolve disagreements. Parents noted improvements in unit congestion, availability of a secure place to store belongings, staff interactions, educational resources, feeling welcome and respect for decisions.</p>	43% Poor

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Hughes, M. (2007) Ireland	To examine the attitudes of parents & nurses to Casey's (1988) partnership model of care delivery on an in-patient children's unit in a regional general hospital	Sample of parents was chosen using a simple random sampling plan. Target population included parents who stayed overnight with their child. All nurses working on the unit were selected, regardless of the grade and length of service (n = 44).	An in-patient children's unit in a regional general hospital in Ireland.	Data were collected using two self-designed questionnaires.	All nurses (n=28) agreed parents should be cared for as well as child. All nurses agreed it was important for parents to be present with their child. All parents (n=43) felt they were included in the care of their child. 57% (n=16) of the nurses believed they were good at teaching parents new skills while only 28% (n=12) of the parents believed so. The need for improved facilities was agreed by 82% (n=22) of nurses & 56% (n= 4) of parents. 40% (n=11) of the nurses believed parents did not know what was expected of them. Over half of the parents (56%, n=24) said that they did not know what was expected of them, 35% (n=15) of parents felt they had to stay with their child because nurses looked too busy. Parents (58%, n=25) and nurses (75%, n=21) felt the cost for parents of staying with child was too high.	57% Moderate
Kuntaros, S., Wichiencharoen, K., Prasopkittikun, T. and Staworn, D. (2007). Thailand	To examine the effects of FCC on mothers' self-efficacy in participatory involvement in child care & satisfaction with nursing care.	32 eligible mothers (16 for each group of control and experimental) whose children were admitted to PICU.	PICU at Phramongkutklao Hospital, Bangkok. Thailand	A quasi-experimental study. The control group received usual nursing care & the experimental group received the FCC approach.	The results revealed that, at Day 5 after the PICU admission, the mothers' self-efficacy in participatory involvement in child care and satisfaction with nursing care in the experimental group who had received FCC practices were significantly higher than that in the control group.	57% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Kurtulus, N., Yildiz, K., Korucu, E. and Ozyazicioglu, N. (2018). Turkey	To determine attitudes of nurses working in pediatric clinics regarding FCC.	304 nurses working in three different hospitals' pediatric clinics.	Three different hospitals' pediatric clinics in Thailand	A descriptive study using survey data obtained by questionnaire of socio-demographic profile of nurses and Parent Participation Attitude Scale (PPAS).	It was found that there is no statistically significant difference between the mean scores of parent participation attitude scale & socio-demographic characteristics of the nurses included in the study. Clinics where nurses work & scores of Parent Participation Attitude Scale (PPAS) were found to have a significant difference. When this difference was analyzed, it was determined that nurses working in paediatric intensive care clinic had the lowest score on the parent participation attitude scale (PPAS). In this study, PPAS scores of nurses working in paediatric intensive care clinic were found to be low. It is recommended paediatric intensive care nurses co-ordinate visits to increase active involvement of family in the child's care, organize in-service training for subjects & improve hospital policy to improve care	57% Moderate
Matziou, V., Manesi, V., Vlachioti, E., Perdikaris, P., Matziou, T., Chliara, J. I. and Mpoutopoulou B. (2018). Greece	To assess nurses' perceptions of FCC & how they applied the family-centred model of care in everyday practice.	A 'convenience' sample of 183 nurse participants completed the Family-Centered Care Questionnaire - Revised,	A paediatric hospital in Athens	Survey questionnaire based on the Family-Centred Care Questionnaire-Revised (FCCQ-R). The questionnaire consisted of 45 items.	Nurses considered a care philosophy that puts the focus on the family as important. Factors that had significant correlation with whether nurses implemented FCC included educational level, experience, age, marital status & if they had children. Nurses aged 20-30 years, those with children, & those who had up to 10 years experience, communicated with parents more frequently compared with those aged over 31 years, those who did not have children or whose experience was more than 11 years. ICU nurses recognised uniqueness of each family more than nurses in paediatric wards. Nurses who worked for more than 10 years were less aware of children's developmental needs than those who had less experience. Co-operation between parent & nurse were the most important factor for FCC. Nurses did not think it was essential to apply all its aspects in daily practice.	57% Moderate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Mortensen, J., Simonsen, B. O., Eriksen, S. B., Skovby, P., Dall, R., & Elklit, A. (2015). Denmark	To: investigate the association between parents' experience of nursing care and levels of stress, identify potential gender differences and examine the relationships among the severity of a child's illness, parents' fear of losing their child and development of symptoms of acute stress.	90 parents of children admitted to PICU completed a self- report questionnaire at the time of their child's discharge from PICU and transfer to another ward in the hospital.	PICU at the University Hospital of Aarhus, Denmark.	A cross-sectional survey study.	Studies show that traumatic stress symptoms are common in parents of children admitted to PICU. FCC has shown promising potential in reducing levels of traumatic stress in this group of parents. The experience of support from nurses was high in parents and was associated with acute stress disorder. About one-third of the parents had acute stress disorder or subclinical acute stress disorder. No significant gender differences existed when symptoms were measured dimensionally. When measured categorically, 17% of the mothers and 7% of the fathers had acute stress disorder. Mothers with very young children had higher levels of acute stress; fathers whose children had high illness severity scores exhibited more acute stress.	71% Moder- ate
Okunola, I., Olaogun, A. A., Adereti, S. C., Bankole, A., Oyibocho, E. and Ajao, O. (2017). Nigeria	To examine parents and nurses' perceptions of Family Centered Nursing care behaviours to be most and least important.	Purposive sampling technique was adopted to select 323 parents while simple random sampling used to recruit 176 nurses who participated in the study.	University College Hospital, Ibadan and Massy Street Children Hospital, Lagos State, South-West Nigeria.	A descriptive design was used. A modified Family Centered Care Scale (FCCS) was used for data collection.	Nurse-caring behaviours mostly perceived as caring by the parents was "Use my suggestions about how to care for your child" while nurses perceived "Parents are given detail explanations about changes they could expect from their condition as the most important". Age and education influenced parents' perception of FCC behaviours and length of hospital stay did not influence it. Nurses' age did not influence their perception of FCC behaviours but years of paediatric experience influenced it. There was no significant statistical difference in the Parents and Nurses perception of FCC behaviours. Parents and nurses perceived these items to be important for FCC which should be incorporated into nursing practice and nursing education in Nigeria.	57% Moder- ate

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Romaniuk, D., O'Mara, L., & Akhtar- Danesh, N. (2014). Canada	To measure parents' actual & desired level of participation in care of their hospitalized child & to examine the congruency between them. Introduce the concept of congruency between parents' actual and desired participation in the care of their hospitalized child and to report a study that examined congruency.	A convenience sample of 191 parents, mostly mothers, was recruited consecutively over a 1 year period. A total of 230 questionnaires were distributed, with a response rate of 83%. Parents could participate if they spoke & read English, if their child was 12 years or younger & had been on the unit at least 1 day prior to data collection.	Two acute-care inpatient units in a pediatric tertiary hospital in southern Canada. Children in these units required care for a wide variety of medical & surgical conditions. FCC was an integral part of nursing practice on both units.	A cross-sectional design	Study results indicate a significant difference between parents' actual and desired participation. The majority of parents expressed a desire to increase their participation. Parents participated in providing comfort, assisting with activities of daily living and advocating for their child. FCC is integral to pediatric nursing practice and includes supporting parents to participate in their hospitalized child's care. Research to date suggests that parents' actual participation in care may differ from their desired participation in care, and that such discrepancies may cause parental distress. Supporting parental participation in a way that facilitates congruency between actual and desired participation may contribute to a satisfying experience for families of hospitalized children.	71% Moderate
Rostami, F., Hassan, S. T. S., Yaghmai, F., Ismaeil, S. B. and Suandi, T. B. (2015a). Iran	To determine the effects of FCC on the satisfaction of parents of hospitalized children.	Parents of 70 hospitalized children aged 1-3 years & suffering diarrhoea, vomiting or pneumonia were conveniently sampled, & divided randomly into groups, a control group (routine care) and an experimental group (FCC).	The pediatric ward at Razi Hospital in Chaloos, Iran.	Quasi-experimental study. SPSS Statistics 14 software was used to analyse the data.	In the FCC group, the mean score of satisfaction among parents was 20 out of 90 pre-intervention, after the FCC method was used satisfaction increased to 83 out of 90. A significant difference was found between satisfaction scores for the control & experimental groups. All parents in the experimental group expressed high satisfaction. The practice of FCC in caring for sick children can increase parental satisfaction significantly. The role of the family's involvement is critical in every component of the intervention efforts, as shown by the constructs of participatory support, educational support, & psychological support. Implementation of a FCC approach increased satisfaction & quality of care.	14% Poor

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Rostami, F., Syed Hassan, S. T., Yaghmai, F., Ismaeil, S. B., & BinSuandi, T. (2015b). Iran	To determine nurses' attitudes toward the importance of FCC before and after an educational intervention programme. The following hypothesis was tested: Nurses' attitudes toward the provision of FCC are different before and after the educational intervention (3 months).	Multi-stage random-sampling method was used to select 200 nurses, 100 were randomly assigned to each group. There were 200 participants during the study period at baseline & 196 at 3 months (99 in the intervention group and 97 in the control group).	Pediatric wards of hospitals affiliated with Shahid Beheshti University of Medical Sciences in Tehran.	Experimental study. Data were gathered using a questionnaire with 31 items which was completed in 3 stages: before intervention, after intervention (post-test) and 3 months after intervention (follow-up). Data were analysed via SPSS using descriptive and analytical methods, the Spearman Correlation Co-efficient, and Repeated Measure Analysis (the Bonferroni method).	There was a significant increase in the mean score of attitude after intervention. There was no significant relationship between the nurses' socio-demographic characteristics & their attitudes. In the intervention group in pre-test "The mother's participation helps a hospitalized child feel secure" had the highest mean score, followed by "The mother's participation comforts the child & takes care of her/his physical needs". In the post-test, "The mother's presence is adequate, & her participation in providing care for her child is not required" & "The mother's participation helps a hospitalized child feel secure" scored highest. The lowest score was for "The mother's participation shortens the length of the hospital stay". The results indicated that there was a significant increase in the mean score of attitude after intervention. Most subjects had neutral attitudes toward family participation in their child's care. Nurses' attitudes should be improved by taking part in continuous training programs.	29% Poor
Shields, Young & McCann (2008) Australia	To investigate parents' perceptions of their needs when they have a child who is hospitalized, & to compare them with staff's perceptions of the parents' needs.	A convenience sample of parents (n=130, response rate=69%) & staff (nurses, doctors & allied health staff), (n=79, response rate=57%) participated.	All units in a tertiary referral children's hospital except oncology and ICU.	A cross-sectional survey design. Data were collected using the Needs of Parents Questionnaire (NPQ), consisting of 51 statements with 3 scoring systems: importance score, fulfilment score & independence score.	Some differences were found between parents & staff for scores for perceived importance, there were no consistent pattern. Parents indicated that they did not need as much help as staff supposed, illustrating that parents of hospitalized children are more independent than staff perceive them to be. More staff than parents are aware of the importance of each need, demonstrating that staff are cognisant of the needs of parents of hospitalized children & their families. Parents are more likely to be able to meet their needs themselves rather than rely on staff to assist them. Cultural differences may influence the findings. It is time to review this tool, as societies have changed since it was last reviewed in 1995.	71% Moderate

Mixed methods research articles (n=5)

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Alabdulaziz, H., Moss, C., & Copnell, B. (2017). Jeddah, Saudi Arabia	To explore FCC in the Saudi context from the perspectives of paediatric nurses.	In the quantitative phase a convenience sample of 234 nurses from completed the FCC Questionnaire. The qualitative phase involved 140 hours of non-participant observation of paediatric nurses' practice using a convenience sample of 14 nurses. Additionally, 10 face-to-face semi-structured interviews were conducted with a purposeful sample of 10 nurses.	Six hospitals in, Saudi Arabia (quantitative phase). One hospital in Saudi Arabia (qualitative phase).	A mixed methodology was utilised with an explanatory sequential design. Quantitative data were collected via questionnaires, while qualitative data were collected via interview and observation. The findings from both phases were integrated in the final analysis.	Results indicated that participants identified most elements of FCC as necessary for its practice. They were less likely to incorporate them into their practice. These findings were supported by the observation data, which revealed that, while several elements of FCC were frequently practised, others were implemented either inconsistently or not at all. Findings from the interview data indicated that participants had limited & superficial understanding of what FCC means as a model of care; rather, they worked with the elements as a set of core tasks. There were similarities between what has been found in the Saudi context and findings from other studies using the same tool in western contexts. There is general agreement regarding the differences between theory and practice. Nurses believe and acknowledge the importance of FCC however, they struggle with implementing the model in their everyday work. Many factors contributed to this, including language barriers, communication issues, cultural issues and hospital policies. Western concepts of FCC appear to be accepted by paediatric nurses in Saudi Arabia. However, full adoption of FCC in keeping with western values is likely not to be appropriate or successful in the Saudi context where both nurses and families have a non-western culture. The western model of FCC requires cultural modification and further development to fit Saudi and Middle Eastern cultures.	85% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Arabi, D., Whitehead, L., Foster, M., Shields, L. and Harris, L. (2018). Australia	To gain knowledge and understanding of how parents experience FCC using a relatively new tool and identify aspects of FCC for further development	A convenience sample of 48 parents of hospitalised children.	A paediatric health facility in Australia.	A cross-sectional study where participants completed a seven-item instrument measuring importance and consistency of the core aspects of FCC, also an open-ended question about what FCC means to the parent.	85% of parents reported positive experiences of receiving FCC practice from nurses, with lower consistency reported in parents' feelings of being seen as important in their child's care, feeling valued as a team member, or well cared for by nurses. Parents' definition of FCC included informal expressions such as allowing parents to stay with their hospitalised child, family inclusion in child's care and care for the whole family. Although recent debates represent the 'unit of care' in FCC as 'a child within the family context', parents' view of FCC places themselves as care recipient with a strong understanding of the ideals of partnership-in-care.	71% Moderate
Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B. and Kersten, R. (2007). USA	To evaluate parent and staff perceptions of care provided to meet the needs of the family unit on an infant-toddler unit. Research questions were: (1) How do families & staff perceive the FCC delivered on the unit? (2) How do the family & staff perceptions compare?	Convenience sampling was used. All members of the multidisciplinary team were asked to participate – 75 of approx. 125 staff members completed the surveys. Parents of children hospitalized at least 24 hours were asked to participate – 38 of the 39 families approached agreed to participate in the survey.	An inpatient 35-bed medical/surgical unit caring for infants and toddlers with acute and chronic medical needs, including a nine-bed pulmonary ward for ventilator-dependent patients.	A mixed method design using a survey & qualitative data. An experienced qualitative interviewer, surveyed the parents in person & recorded comments as well as survey responses. The qualitative data were analysed using content analysis.	In general, family responses were more positive than staff responses. Families were most concerned about educational issues, the staff were most concerned about unit environment. More than half of both families & staff felt nursing care & clinical needs were being met. 30% of families reported concerns with continuity of care because their child did not have the same nurse several days in a row. Only 5% of staff reported this concern. Overwhelmingly, both staff and families responded positively to questions about respect and equality. Families indicated that they had concerns with how fathers were treated. Approximately 50% of both parents & staff expressed concern over the lack of a private place for families & staff to speak. Nearly 75% of staff expressed concerns that the roles of all team members are unclear to families.	29% Poor

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Seliner, B., Latal, B., and Spirig, R. (2016). Switzerland	To assess parental burden of care, satisfaction with FCC, & quality of life (HRQoL) of parents & their hospitalized children with profound intellectual & multiple disabilities (PIMD), and to determine the relationship among these factors.	The sample of parents was selected by reviewing inpatient entry lists from October 2011 to September 2013. 117 parents (98 mothers, 19 fathers)	In six pediatric units of a Swiss University Children's Hospital.	A cross-sectional study using printed questionnaires and a semi-structured interview focusing on the parent's experience of children with PIMD being hospitalized. SPSS version 20 for Windows was used to analyze data from all quantitative sources. All interview data were transferred into the qualitative data management system ATLAS.ti 7.5. Data were analyzed using content analysis (Mayring, 2007).	The participants indicated a substantial impact on burden of care & parental health-related quality of life. The highest scores were observed in the domains of "general negative impact" & "financial strain". "Personal strain" & "coping" were also measured. FCC received moderately satisfactory ratings. The domain "general information" received a lower satisfaction rating while "respectful & supportive care" dimension received the highest. Three qualitative concepts evolved: concerns for the child's well-being, parents' effort & support needs. Most of the parents worried about their child's safety & well-being while hospitalized. They felt responsible for the child while in hospital. The perception of the child's well-being & the degree of the parents' efforts determine parental support needs. When parents were familiar with the ward & nurses, & vice versa, parents developed trust & felt a lessening of their work load. Respectful open communication & participation in discussions helped to overcome parents' worries & provided them with a feeling of security. The child's well-being was associated with parental well-being. Easing parents' burden & fostering confidence in the child's well-being requires co-ordination of care provided by advanced nurse specialists, with an institutional framework that clarifies parental collaboration.	86% Good

Author/Year/ Country	Aim/Objective	Sample	Setting	Type of study / Data collection method	Key findings/ Implications for practice	MMAT Score
Uhl, T., Fisher, K., Docherty, S. L., & Brandon, D. H. (2013). USA	To describe parents' care experiences during hospitalization of their child to identify strategies that could improve the provision of PFCC.	Nine parents participated in one of three semi-structured focus groups during Phase 1. During Phase 2, 134 parents completed the inpatient hospital experience survey.	A south-eastern academic children's hospital (178 beds) with 89% of admissions from within the state & the remainder from around the world.	A two-phase mixed-method descriptive design	Three themes were identified in the focus group data: apprehending the reality where parents moved through the initial shock of their child's hospital admission & processed the impact that hospitalization had on their lives. engaging adversity - how parents experienced their parental role during hospitalization. advancing forward when parents transitioned from the hospital environment back to their home. Survey findings are organized into 8 content areas: care from nurses, care from doctors, working together, child's experience, hospital environment, child medications (safety), arriving at & leaving the hospital, and overall ratings of the experience. The findings support the importance of ongoing evaluation of PFCC initiatives to identify strengths and weaknesses.	71% Moderate

Appendix 12 Four completed Mixed Methods Appraisal Tool (MMAT) Forms (Hong *et al*, 2018)

The 2018 Mixed Methods Appraisal Tool (MMAT) Checklist (Hong *et al*, 2018)

Study for appraisal: Curtis, P. & Northcott, A. (2017) The impact of single and shared rooms on family-centred care in children's hospitals. *Journal of Clinical Nursing* 26(11/12): 1584-1596.

Primary studies	Methodological quality criteria	Response			
		Yes	No	Can't tell	Comment
Screening questions (for all types of studies)	Are there clear research questions (or objectives)?	Yes			
	Do the collected data address the research questions (objectives)?	Yes			Data collected from children, parents and nurses/HCPs
<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>					
Qualitative questions	Is the qualitative approach appropriate to answer the research question?	Yes			
	Are the qualitative data collection methods adequate to address the research question?	Yes			
	Are the findings adequately derived from the data?	Yes			Data analysis well described
	Is the interpretation of results sufficiently substantiated by data?	Yes			
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes			

Overall quality score of the study: 7/7 = 100% Good

The 2018 Mixed Methods Appraisal Tool (MMAT) Checklist (Hong *et al*, 2018)

Study for appraisal: Uhl, T., Fisher, K., Docherty, S. L., & Brandon, D. H. (2013). Insights into patient and family- centered care through the hospital experiences of parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns* 42(1): 121-131.

Primary studies	Methodological quality criteria	Response			
		Yes	No	Can't tell	Comment
Screening questions (for all types of studies)	Are there clear research questions (or objectives)?	Yes			
	Do the collected data allow to address the research question (objective)?	Yes			
<i>Further appraisal may not be feasible or appropriate when the answer is "No" or "Can't tell" to one or both screening questions</i>					
Mixed methods questions	Is there an adequate rationale for using a mixed methods design to address the research question?			Can't tell	The rational for using mixed methods is not clearly addressed in the paper.
	Are the different components of the study (qualitative and quantitative data/results) effectively integrated to answer the research question?	Yes			
	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes			
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?		No		Limitations were discussed but not in the context of those associated with integration of qual and quant data.
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes			

Overall quality score of the study: 5/7 = 71%

Moderate

The 2018 Mixed Methods Appraisal Tool (MMAT) Checklist (Hong et al, 2018)

Study for appraisal: Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B. and Kersten, R. (2007). Family centered care within an infant-toddler unit. *Pediatric Nursing* 33(6): 481-485.

Primary studies	Methodological quality criteria	Response			
		Yes	No	Can't tell	Comment
Screening questions (for all types of studies)	Are there clear research questions (or objectives)?	Yes			Outlined on p. 481.
	Do the collected data address the research questions (objectives)?			Can't tell	Content of the survey not addressed in the paper.
<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>					
Questions for Quantitative (descriptive) studies	Is the sampling strategy relevant to address the research question?		No		Convenience sampling used.
	Is the sample representative of the target population?		No		Target population not described in the paper.
	Are the measurements appropriate (ie clear origin, or validity known, or standard instrument)?			Can't tell	Validity & reliability of the instrument used to collect data not addressed in the paper.
	Is the risk of non-response bias low (ie is there an acceptable response rate (60% or above)?	Yes			38 of the 39 parents invited to participate completed the survey. All staff were asked to participate, 75 staff completed the survey, the total population was not outlined in the paper.
	Is the statistical analysis appropriate to answer the research question?	Yes			Descriptive statistics and chi-square were used to analyse quant data while content analysis was used to analyse qual data.

Overall quality score of the study: 3/7 = 43%

Poor

The 2018 Mixed Methods Appraisal Tool (MMAT) Checklist (Hong *et al*, 2018)

Study for appraisal: Terp, K., Weis, J., & Lundqvist, P. (2021). Parents' Views of Family-Centered Care at a Pediatric Intensive Care Unit-A Qualitative Study. *Frontiers in pediatrics*, 9, 725040. doi:10.3389/fped.2021.725040.

Primary studies	Methodological quality criteria	Response			
		Yes	No	Can't tell	Comment
Screening questions (for all types of studies)	Are there clear research questions (or objectives)?	Yes			To describe parents' views of family-centered care at a PICU
	Do the collected data address the research questions (objectives)?	Yes			Data collected from 70 parents using the EMPATHIC questionnaire
<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>					
Qualitative questions	Is the qualitative approach appropriate to answer the research question?	Yes			Data gathered using a questionnaire, spontaneous responses were analysed using thematic analysis.
	Are the qualitative data collection methods adequate to address the research question?			Can't tell	Interviews may have been a better source of raw data.
	Are the findings adequately derived from the data?	Yes			Data collection and analysis described on p. 3.
	Is the interpretation of results sufficiently substantiated by data?	Yes			Many direct participant quotes used to explain the findings.
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes			

Overall quality score of the study: 6/7 = 85% Good

STANDARD APPLICATION FORM

ADAPTED VERSION (AUGUST 2018)

EDITED (31 August 2018)

For the Ethical Review of
Health-Related Research Studies,
which are not Clinical Trials of
Medicinal Products For Human Use
as defined in S.I. 190/2004

DO NOT COMPLETE THIS APPLICATION FORM
IF YOUR STUDY IS A CLINICAL TRIAL OF A MEDICINAL PRODUCT

Title of Study: Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Application Version No: _____

Application Date: _____

For Official Use Only – Date Stamp of Receipt by REC:

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This Application Form is divided into Sections.

*Sections A, B, C, D, E, J and K are **Mandatory**.

(Sections F, G, H, I and L are optional. Please delete Sections F, G, H, I and L if these sections do not apply to the application being submitted for review.)

IMPORTANT NOTE: Please refer to **Section I** within the form before any attempt to complete the Standard Application Form. **Section I** is designed to assist applicants in ascertaining if their research study is in fact a clinical trial of a medicinal product.

IMPORTANT NOTE: This application form permits the applicant to delete individual questions within each section depending on their response to the preceding questions. Please respond to each question carefully and refer to the accompanying *Guidance Manual* for more in-depth advice prior to deleting any question.

PLEASE ENSURE TO REFER TO THE ACCOMPANYING GUIDANCE MANUAL WHEN COMPLETING THIS APPLICATION FORM.

SECTION A GENERAL INFORMATION

SECTION A IS MANDATORY

A1 TITLE OF THE RESEARCH STUDY:

Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

A2 (a) Is this a multi-site study? No

IF YOU CHOSE 'YES' PLEASE DELETE QUESTIONS A2 (E) AND (F), IF YOU CHOSE 'NO' PLEASE DELETE QUESTIONS A2 (B) (C) AND (D)

A2 (e) If no, please name the principal investigator with overall responsibility for the conduct of this single-site study.

Title: Ms. **Name:** Siobhán O'Connor
Qualifications: RGN, RCN, MSc (Education & Training)
Position: PhD student,
Dept: School of Nursing & Midwifery,
Organisation: TCD
Address: 6th Floor, Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.
TEL: 087.9977843 **E-MAIL:** aconns49@tcd.ie

A2 (f) For single-site studies, please name the only site where this study will take place.

Children's Health Ireland at Crumlin.

A3. DETAILS OF CO-INVESTIGATORS:

NAME OF SITE (IF APPLICABLE):

Title: Prof. **Name:** Imelda Coyne

QUALIFICATIONS: RCN, RGN, PhD

POSITION: Professor of Children's Nursing & Co-Director of Trinity Research in Childhood Centre, Trinity College Dublin, Ireland

Dept : School of Nursing & Midwifery

ORGANISATION: Trinity College Dublin

Address: School of Nursing & Midwifery, Trinity College Dublin, the University of Dublin College Green Dublin 2

TEL: 01.8964071 **E-MAIL:** coynei@tcd.ie

ROLE IN RESEARCH E.G. STATISTICAL / DATA / LABORATORY ANALYSIS:

The central theme underpinning Prof Coyne's research programme is valuing children's and young people's voices and promoting their participation in matters that affect their lives. Her research focuses on: child participation rights, shared decision-making, child and family centred care, technological interventions for chronic illness management and transition from child to adult services. She has more than 200 publications in peer-reviewed journals and has co-authored over 150 conference abstracts.

Title: Dr. **Name:** Maria Brenner

QUALIFICATIONS: RCN, RGN, RNT, BSc, MSc, PhD

POSITION: Associate Professor of Children's Nursing & Director of Research, School of Nursing & Midwifery, Trinity College Dublin, Ireland

Dept: School of Nursing & Midwifery

ORGANISATION: Trinity College Dublin

Address: Trinity College Dublin, the University of Dublin College Green Dublin 2

TEL: 01.8963901 **E-MAIL:** brennerm@tcd.ie

ROLE IN RESEARCH E.G. STATISTICAL / DATA / LABORATORY ANALYSIS:

Dr. Brenner's research is focused on the care of children living with complex care needs and their families. She recently completed a three and a half year programme of research as part of the Models of Child Health Appraised (MOCHA) project. She is currently exploring the initiation of technology dependence in

children with complex care needs (TechChild), in a 5 year programme of research funded by the European Research Council.

A4. Lead contact person who is to receive correspondence in relation to this application or be contacted with queries about this application.

Name: Siobhán O'Connor

POSITION: PhD student, School of Nursing & Midwifery, TCD

ORGANISATION: TCD

Address for Correspondence: 6th Floor, Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.

TEL (WORK): Answer **TEL (MOB.):** 087.9977843 **E-MAIL:**
aconns49@tcd.ie

A5 (A) IS THIS STUDY BEING UNDERTAKEN AS PART OF AN ACADEMIC QUALIFICATION? Yes

If answer is No, please delete remaining questions in Section A

A5 (b) IF YES, please complete the following:

Student Name(s): Siobhán O'Connor

Academic Course: PhD

Academic Institution: School of Nursing and Midwifery, TCD

A5 (c) Academic Supervisor(s):

Title: Prof.

Name: Imelda Coyne

Qualifications: RCN, RGN, PhD

Position: Professor of Children's Nursing & Co-Director of Trinity Research in Childhood Centre, Trinity College Dublin, Ireland

Dept: School of Nursing & Midwifery

ORGANISATION: Trinity College Dublin

Address: School of Nursing & Midwifery, Trinity College Dublin, The University of Dublin College Green Dublin 2

TEL: 01.8964071 **E-MAIL:** coynei@tcd.ie

Title: Dr.

Name: Maria Brenner

Qualifications: RCN, RGN, RNT, BSc, MSc, PhD

Position: **Associate** Professor of Children's Nursing & Director of Research

Dept : School of Nursing & Midwifery

ORGANISATION: Trinity College Dublin

Address: School of Nursing & Midwifery, Trinity College Dublin, The University of Dublin College Green Dublin 2

TEL: 01.8963901 **E-MAIL:** brennerm@tcd.ie

SECTION B IS MANDATORY

B1. What is the anticipated start date of this study?

It is anticipated that data collection will start in October 2019

B2. What is the anticipated duration of this study?

Data collection will continue over 4 to 6 months from October 2019 until data saturation is reached.

B3. Please provide a brief lay (plain English) description of the study. Please ensure the language used in your answer is at a level suitable for use in a research participant information leaflet.

Nurses and healthcare professionals working in children's services consider that family-centred care (FCC) is the preferred model of care for hospitalised children and their families, both in Ireland (Coyne, 2013) and internationally (Feeg *et al*, 2016). FCC involves parents being supported to take part in their child's care in hospital, parents and children being included as partners with the healthcare team, the healthcare team keeping the family informed of progress as it is happening and the entire family being included in care as needed. However there is no internationally agreed definition for FCC for hospitalised children. This lack of definition has been cited as contributing to an inconsistent application of FCC in practice (Coyne *et al*, 2011; Feeg *et al*, 2016).

This study will explore children's and parents' experiences and expectations of their roles while in hospital and develop knowledge to explain the involvement of the child and parent in care in hospital. Information will be collected through in-depth semi-structured interviews with hospitalised children and their parents to gather information about their experiences and expectations of their roles while in hospital. This new knowledge will create the evidence needed to promote consistent implementation of a model of care that is truly child- and family-centred.

B4. Provide brief information on the study background.

There are 1,100,153 children under 16 years of age living in Ireland, accounting for 23.1% of the population (Central Statistics Office, 2017). With the European Union (EU) average standing at 18.8%, Ireland has the highest proportion of children in its population. While the vast majority of our children are healthy, on average over 100,000 children in Ireland spend more than 3 nights in hospital per year, 75% of these children are under four years of age, the majority are unplanned admissions (Children in Hospital Ireland, 2017).

Evidence-based models of nursing care guide nurses' critical thinking and decision-making and support them in the implementation and evaluation of quality patient care. Since the mid-1990s CHI at Crumlin have been using the Roper, Logan and Tierney (1990) model, while both CHI at Temple St and CHI at Tallaght have been using a modified version of the Nottingham Model (Smith *et al*, 1995). The Roper, Logan and Tierney model is not child or family focused, rather it is a framework to guide care which is adult focused. While the Nottingham model is child focused, it is not explicitly family-centred. Evidence-based nursing care plans informally include parents/guardians in the care of their child in hospital, however they do not explicitly address FCC. FCC has evolved in an unstructured and unco-ordinated fashion, without any formal theory or process of evaluation.

Following an extensive literature review it is evident that parents wish to participate actively in the care of their child in hospital, the degree to which they wish to do so varies and must be negotiated between the nurse and the parent and child (Coyne, 2013; Feeg *et al*, 2016). There is also evidence that children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. There is no hard evidence to inform healthcare professionals if the application of a

family-centred approach to care makes a difference to the child's health outcomes or the families' healthcare experience. Furthermore the voice of the child is noticeably absent from existing research on the topic. A lack of attention to cultural and societal changes which impacts not only on those receiving care, but also on those delivering care, was also highlighted.

Further research must examine the experiences and expectations of hospitalised children and their parents. This research must reflect cultural diversity and social norms, and examine the outcomes of FCC for hospitalised children and their families. Questions which must be answered with empirical evidence to inform practice include: does FCC support parents to care for their child in hospital, does FCC support parents to make informed healthcare decisions and what are the hospitalised child's and parent's experiences and expectations of FCC. This knowledge will promote a move away from the current *ad hoc* implementation of the model to a more systematic and evidence-based approach. Such research must be carried out in the context of the current evolving healthcare delivery system which is the current reality in Ireland. Increased day-case activity, early discharge and increased patient throughput results in reduced time spent in hospital and increased patient acuity. Identification of the role children play in their own care and the role their parents play in caring for them in hospital is crucial to quality care and consistent with the National Model of Care for Paediatric Healthcare Services in Ireland (Nicholson and Murphy, 2015).

B5. List the study aims and objectives.

The aim of this study is to explore children's and parents' experiences and expectations of their roles while in hospital.

These aims will be achieved through the following objectives:

- To identify children's experiences and expectations of their parents' and nurses' role in their care in hospital.
- To explore children's experiences of engagement and role preferences in their own care while in hospital.
- To explore parents' experiences and expectations of their role and the nurses' role in their child's care in hospital.
- To explore parents' perspectives of their child's role in their own care while in hospital.
- To develop a theory to explain the involvement of the child and parent in care in hospital.

B6. List the study endpoints / measurable outcomes (if applicable).

Not applicable

B7. Provide information on the study design.

Constructivists believe in the value of observed and perceived phenomena, that many truths may surround the same phenomenon, that different people may have different interpretations of the same phenomenon and that to be understood phenomena must be studied in context (Johnson and Webber, 2014; Parahoo, 2014). This research project will take a constructivist approach.

Typically a qualitative approach is used in constructivist research, where the researcher seeks to understand the world in which the participants live and work (Lincoln *et al*, 2018). In the healthcare context, qualitative research is exploratory in nature, aiming to explore a phenomenon from the participants' perspective (Parahoo, 2014). The qualitative researcher listens to the participants and seeks a deeper understanding of their experience based on what he/she has heard and how he/she interprets what has been heard. Constructivist grounded theory (Charmaz, 2000) acknowledges the researcher's subjectivity, identifying preconceptions rather than denying them. In constructivist grounded theory, meaning and theory are constructed as a collaboration between the researcher and the participants. There is a focus on representation of the participants and reflexivity about the researcher's role in the

process (Charmaz *et al*, 2018). A pathway to help the researcher navigate the research process in grounded theory is included in Appendix 1.

This study will take a constructivist exploratory approach, using constructivist grounded theory methodology. Qualitative data will be collected retrospectively. Data collection and data analysis will occur simultaneously.

B8. Provide information on the study methodology.

Data collection methods

Open-ended, semi-structured interviews focus on the topic to be explored, and allow the participant to express his/her views and insights in a safe and non-threatening space (Charmaz, 2014). Data for this study will be collected through semi-structured interviews with pre-teenage children aged 9-12 years and with adolescents aged 13-16 years. Parents of the children will also be interviewed. All interviews will be audio-recorded and the contents transcribed by the Principal Investigator. Third party transcription services will not be used. The participants will be offered an opportunity to read the transcription of their interview and confirm that it reflects accurately what they said. They will be allowed to add and/or remove content from the transcription if they believe it does not reflect what they said during the interview. In this way the experiences and expectations of both cohorts of children and their parents will be explored.

Sampling methods

The number of participants recruited to a grounded theory study is determined by the data analysis from previous participants, this is known as theoretical sampling (Chiobitti and Piran, 2003). Theoretical sampling is the purposeful selection of participants at the early stages of a study (Coyne, 1997). It involves simultaneously collecting, analysing and coding data through constant comparison analysis, in order to inform what further data are needed (Coyne, 1997). This process continues until data saturation is reached, when the new raw data being collected replicate what is already identified by earlier participants and no new categories emerge (Charmaz, 2014). The purpose is to seek relevant data to develop and refine the emerging categories. This study will initially use purposeful sampling to recruit participants, aiming to be as inclusive as possible of varied family types from varied socio-cultural backgrounds and ages. Following analysis of the data, theoretical sampling will be employed until data saturation is achieved. The aim is to develop a detailed understanding of the phenomenon. It is expected that 15-20 interviews of children and of their parents will be required before data saturation occurs.

Data analysis

In grounded theory data collection and data analysis must occur simultaneously so that the researcher will know when saturation is reached. Data **are** always analysed using the constant comparison method (Corbin and Strauss, 2015). Constant comparison involves breaking data down into manageable pieces and each piece of data compared for similarities and differences. Data with similar characteristics are grouped together into codes and themes which are common across the data sources, then categorised into more refined units of information (Creswell and Creswell, 2018). The raw data may be reviewed again to determine if more evidence is needed to support each identified theme and whether additional data needs to be collected. NVivo 12, a software tool for qualitative data analysis, will be used to assist in managing the data analysis.

B9. Provide information on the statistical approach to be used in the analysis of your results (if appropriate) / source of any statistical advice.

Not applicable

B10 (a) Please justify the proposed sample size and provide details of its calculation (including minimum clinically important difference).

A sample size should be large enough to sufficiently describe the phenomenon of interest and address the research question. Qualitative research focuses on relatively

small samples, even single cases, selected purposefully to examine the phenomena being researched (Patton, 1990). In qualitative research an adequate sample size is one that allows in-depth analysis and produces a new and rich understanding of the phenomenon being studied (Sandelowski, 1995). Improving our understanding of a complex human phenomena is more important than generalising the findings (Marshall, 1996). It is expected that 15-20 interviews of purposefully selected hospitalised children and 15-20 interviews of their parents will be required before saturation occurs.

B10 (b) Where sample size calculation is impossible (e.g. it is a pilot study and previous studies cannot be used to provide the required estimates) then please explain why the sample size to be used has been chosen.

Not applicable

B11. How many research participants are to be recruited in total?

30 – 40 depending on when data saturation is reached.

B12 (a) How many research participants are to be recruited in each study group (where applicable)? Please complete the following table (where applicable).

Name of Study Group:	Name of Study Group:	Name of Study Group:	Name of Study Group:	Name of Study Group:
Answer	Answer	Answer	Answer	Answer
Number of Participants in this Study Group:	Number of Participants in this Study Group:	Number of Participants in this Study Group:	Number of Participants in this Study Group:	Number of Participants in this Study Group:
Answer	Answer	Answer	Answer	Answer

B12 (b) Please provide details on the method of randomisation (where applicable).

Not applicable

B13. How many research participants are to be recruited at each study site (where applicable)? Please complete the following table.

Site:	Number of Research Participants at this site:
CHILDREN'S HEALTH IRELAND AT CRUMLIN	15-20 CHILDREN/ADOLESCENTS 15-20 PARENTS

SECTION C STUDY PARTICIPANTS

SECTION C IS MANDATORY

C1 PARTICIPANTS – SELECTION AND RECRUITMENT

C1.1 How will the participants in the study be selected?

This study will initially use purposeful sampling to select participants, aiming to be as inclusive as possible of varied family types from varied socio-cultural backgrounds and ages. Following analysis of the initial data, theoretical sampling will be employed until theoretical saturation of data is achieved. The purpose of theoretical sampling is to seek relevant data to develop and refine the emerging categories (Charmaz, 2014).

C1.2 How will the participants in the study be recruited?

A Gatekeeper has been nominated (Ms Fionnuala O'Neill, Nurse Practice Development Co-ordinator) who will advise which ward areas will be most appropriate to access the

required participants. She will also introduce me to the ward manager of each ward as I enter the clinical area. Then a verbal approach will be made to invite potential participants to take part in the study. The researcher will only approach a child/adolescent if his/her parent is present at the bedside at the time. No child/adolescent will be approached to recruit to the study without the presence of one parent. The Principal Investigator and the Gatekeeper will always aim to ensure that the research process will cause as little disruption as possible to the working day of the ward staff and the healthcare experience of the child/adolescent and parent.

Three Participant Information Leaflets have been developed, aimed at the three participant populations, children aged 9-12 years, adolescents aged 13-16 years and parents. See accompanying documentation.

A poster will also be designed to bring the study to the attention of hospitalised children/ adolescents and their parents.

C1.3 What are the inclusion criteria for research participants? (Please justify, where necessary)

Inclusion criteria:

Hospitalised children/adolescents aged between 9 and 16 years.

Children/adolescents who are fluent in the English language.

Children/adolescents who can articulate their experiences and expectations of FCC in English

Parents of hospitalised children aged between 9 and 16 years.

Parents who are fluent in the English language

Parents who can articulate their experiences and expectations of FCC in English

C1.4 What are the exclusion criteria for research participants? (Please justify, where necessary)

Exclusion criteria:

Children/adolescents who are not in-patients at the time of the study

Children/adolescents who do not speak English.

Children/adolescents who are unable to articulate their experiences and expectations of FCC due to their illness, a communication difficulty or a learning disability.

Children/adolescents who are in-patients with a mental health diagnosis.

Children/adolescents who are in-patients with a diagnosis of a life-limiting condition.

Children/adolescents who are in-patients and who live in a residential care environment outside of hospital.

Parents whose children are not in-patients at the time of the study

Parents who do not speak English

Parents who are unable to articulate their experiences and expectations of FCC in English due to a communication difficulty or language barrier.

Parents whose child/adolescent is an in-patient with a mental health diagnosis.

Parents whose child is an in-patient with a diagnosis of a life-limiting condition.

C1.5 Will any participants recruited to this research study be simultaneously involved in any other research project? Not to my knowledge

C2 PARTICIPANTS – INFORMED CONSENT

C2.1 (a) Will informed consent to take part in the research be obtained?

Yes

C2.1 (c) If yes, please outline the consent process in full. (How will consent be obtained, when, by whom and from whom etc.)

The Principal Investigator will seek written informed consent from all potential parent participants.

Participant Information Leaflets will inform the participants, in plain English, about the study and what will be required of them as participants. Voluntary, written and informed consent to participate will be sought only after detailed information in plain English has been shared with each potential parent participant. They will also be given an opportunity to ask questions and seek clarification about any aspect of the study they may be unclear about. The right to refuse to participate in the study will be explained. The parent will be reassured that their decision not to participate in the study will be respected in full and will not affect the care their child receives in any way.

The Participant Information Leaflet for parents will include a statement about what will happen if their child/adolescent discloses any information to the researcher that they are at significant risk of harm. It will also include information about the process to be followed if a participant discloses any information which indicates a significant safety and quality issue for the child/adolescent while in hospital (see accompanying Participant Information Leaflet and Informed Consent Form).

All parent participants will be advised that they can withdraw from the study at any time with no repercussions to either them or their family member who may also be taking part in the study.

See Section C4 below for information re assenting children and adolescents for this study.

C2.2 (a) Will participants be informed of their right to refuse to participate and their right to withdraw from this research study? Yes

C2.2 (b) If no, please justify.

Not applicable

C2.3 (a) Will there be a time interval between giving information and seeking consent? Yes

C2.3 (b) If yes, please elaborate.

Not applicable.

C2.3 (c) If no, please justify and explain why an instantaneous decision is reasonable having regard to the rights of the prospective research participants and the risks of the study.

It is recognised that giving potential research participants a reasonable period of time to reflect and make a decision about whether they will take part in a study is best practice in order to allow them time to discuss participation with their family. However, since participation in this study poses minimal risk to participants, it is considered that the participants will not need an extended time period to decide if they wish to participate or not. Being an in-patient in the hospital at the time of the study is an inclusion criteria, hence a decision to participate will need to be made promptly, in light of early discharges and shorter length of stay. The child/adolescent and the parent will be provided with an age-appropriate Participant Information Leaflet in plain English and their informed written consent/assent to take part in the study will be obtained. Furthermore participants will have the opportunity to decline from participating and to withdraw from the study at any time. For these reasons a period of reflection is not thought to apply. However, if a child/adolescent or parent wishes to think about participation for a period of time this can be facilitated for up to two hours on the day they have been approached to take part.

C3 ADULT PARTICIPANTS (AGED 18 OR OVER) - CAPACITY

C3.1 (a) Will all adult research participants have the capacity to give informed consent? YES

If answer is Yes, please delete remaining questions in Section C3

C4 PARTICIPANTS UNDER THE AGE OF 18

C4.1 (a) Will any research participants be under the age of 18 i.e. Children? Yes

If answer is No, please delete remaining questions in Section C4

C4.1 (b) If yes, please specify:

Persons < 16 Yes

Persons aged 16 – 18 Possibly Yes if they are in-patients

Children in care No

C4.1 (c) If yes to persons < 16, please specify:

Pre-term neonates No

Full-term neonates No

Infants and Toddlers 0 - 4 No

Children 5 - 8 No

Children 9 – 12 Yes

Adolescents 13 -15 Yes

C4.2 Is this research of such a nature that it can only be carried out on children? Please elaborate.

Following an extensive literature review on the topic, it is evident that parents wish to participate in the care of their child in hospital. However there is no evidence to support the contention that children wish to have their parents participate in their care in hospital, or if they wish to participate in their own care while in hospital. This is especially important for older children/adolescents, who are developing skills of independence and autonomy, often wishing to be independent of their parents in many aspects of care, particularly personal care. The voice of the child was noticeably absent from the research reviewed. For this reason it is considered imperative that further research must listen to their voice and the findings represent their views, experiences and expectations. The knowledge generated will promote consistent and effective implementation of a model of care that is truly reflective of the needs of hospitalised children and their parents.

C4.3 Is the purpose of the research to generate knowledge about the health or social care needs of children?

The purpose of the study is to explore the hospitalised child's experiences and expectations of their role while an in-patient in hospital, thus generate new knowledge about the needs of children and their parents while in hospital in Ireland.

C4.4 Is the research expected to provide direct benefit to child participants, or if there is no prospect of direct benefit, are the risks no more than minimal? Please elaborate.

The findings from this research will contribute to the consistent and effective implementation of FCC to future children who are in-patients in a children's hospital in Ireland and their parents/guardians. Furthermore the risks associated with this research to participants are minimal.

C4.5 Will each child receive information about the risks and benefits of the study according to his/her capacity to understand? Please elaborate and provide copies.

A Participant Information Leaflet and Assent Form in age-appropriate language and in plain English for children aged 9-12 years and another for adolescents aged 13-16 years will include information about the risks and benefits of the study. The Principal Investigator will also offer each potential child/adolescent participant an opportunity to clarify any issues they may have prior to consenting/assenting to take part.

C4.6 Will the explicit wish of the child who is capable of forming an opinion and assessing information to refuse to participate or to be withdrawn from the study be considered by the investigators? Please elaborate, outlining the assent process in full. (How will assent be obtained, when and by whom etc.)

The Principal Investigator will be responsible for recruiting potential child/adolescent participants.

Age-appropriate Participant Information leaflets in plain English will inform the potential child/adolescent participant about the study and what will be required of them as participants. For children aged 9-12 years of age, the age-appropriate Participant Information leaflet will be read with them, and they will be given an opportunity to seek clarification where necessary. Adolescents aged 13-16 years old will be asked to read the age-appropriate Participant Information Leaflet independently, and offered an opportunity to clarify any issues afterwards. In both cases the child/adolescent will be encouraged to have his/her parent present while he/she is reading the leaflet, as recommended in the HSE National Consent Policy (2017). The right to refuse to participate in the study will be explained and respected in full. Voluntary, written and informed consent/assent to participate will be sought only after detailed age-appropriate information in plain English has been shared with each potential child/adolescent participant and one parent. They will also be given an opportunity to ask questions and seek clarification about any aspect of the study they may be unclear about. For all children/adolescents who agree to participate in the study, written informed assent will be obtained. An Assent Form will be signed by the child/adolescent in the presence of one parent and co-signed by one parent, who will be involved in the process from the outset (see accompanying Participant Information Leaflets, Informed Consent Form and Assent Form).

If a child/adolescent who is approached to participate in the study declines to do so, his/her wish will be fully respected. He/she will be reassured that the decision not to take part in the study will have no affect their care while in hospital.

All participants will be advised that they can withdraw from the study at any time with no repercussions to either them or their family member who may also be taking part in the study.

C4.7 Please comment on the involvement of parents / legal guardians of the child in the consent process.

The Principal Investigator will be responsible for recruiting children, adolescents and parents to participate in this study. It is good practice to involve the parent in the assent process and in the research process itself. The parent's presence will provide an opportunity for them to act as an advocate for the child/adolescent and provide them with comfort and support. For this reason the parent's presence will be encouraged throughout the consent/assent and research process.

The child/adolescent will be offered the choice of having his/her parent present when he/she is reading the Participant Information Leaflet. However, in order to obtain informed assent/consent for the child or adolescent to take part in the research, the parent must be present and must co-sign the Assent Form.

C4.8 Please explain your approach to consenting research subjects if they reach the age of 18 during the course of the study.

Participants in this study will be recruited and interviewed on the same day. For this reason this issue will not arise during this study.

C4.9 Please comment on what will occur if the researcher discovers that a child is at risk during the course of this study?

This study will adhere to the principles outlined in the Department of Children & Youth Affairs (2012) document [Guidance for developing ethical research projects involving children](#).

The Principal Investigator is familiar with the HSE publication [Children First: National Guidance for the Protection and Welfare of Children](#) (2017). I have also attended education and training on the child protection. Before collecting any data I will complete the Garda Vetting process, familiarise myself with the appropriate hospital policy on child safety and be aware of who the Child Safety Protection Officer is within the hospital. Should a child/adolescent disclose an incident of a child protection nature during the course of the interview or if I become aware that a child/adolescent may be at risk of harm, I will, as is my duty to protect the child/adolescent participant, discuss with him/her, and his/her parent if appropriate, in a sensitive manner, my obligation to divulge this information to the appropriate authority in the hospital. Having done so I will discuss the incident promptly with the Child Safety Protection Officer and complete any written reports as required and within the required time frame. Information on the possibility of this happening will be included in the Participant Information Leaflet for parents.

C5 PARTICIPANTS - CHECKLIST

C5.1 Please confirm if persons from any of the following groups will participate in this study. This is a quick checklist to assist research ethics committee members and to identify whether study participants include persons from vulnerable groups and to establish what special arrangements, if any, have been made to deal with issues of consent. It is recognised that not all groups in this listing will automatically be vulnerable or lacking in capacity. Please refer to the HSE's National Consent Policy, particularly Part 3, Section 5.

Committees are particularly interested to know if persons in any of these groups are being targeted for inclusion, as per the inclusion criteria.

(a) Healthy Volunteers No

(b) Patients Yes

- **Unconscious patients** No
- **Current psychiatric in-patients** No
- **Patients in an emergency medical setting** No

(c) Relatives / Carers of patients Yes (Parents)

(d) Persons in dependent or unequal relationships No

- **Students** No
 - **Employees / staff members** No
 - **Persons in residential care** No
 - **Persons highly dependent on medical care**
- No

(e) Intellectually impaired persons No

(f) Persons with a life-limiting condition No
(Please refer to guidance manual for definition)

(g) Persons with an acquired brain injury No

C5.2 If yes to any of the above, please comment on the vulnerability of the research participants, and outline the special arrangements in recognition of this vulnerability (if any).

Children/adolescents and their parents will be made aware during recruitment that they can decide not to participate in the study and that doing so will have no impact on the care they receive. Both cohorts will be consented/assented separately. They will also be aware that they can withdraw from the study at any stage without any repercussions to them or their family member.

The Principal Investigator is not a nurse in CHI at Crumlin and will not be known to the child/adolescent or the parent. I will be an outsider coming to the clinical area to explore with participants what their experiences and expectations of FCC are. Once the interview is complete I will be leaving the area and will not be involved in their care thereafter.

C5.3 Please comment on whether women of child-bearing potential, breastfeeding mothers, or pregnant women will be included or excluded in this research study.

Parents who are women of child-bearing potential, who are breastfeeding or who are pregnant may be included as participants in this study. Voluntary informed consent to take part in the study will be sought and the parent will be advised that they can withdraw from the study at any time with no repercussions to either them or their family member. Data collection is by means of interview. Hence there is minimal risk only to the participant, to the breastfeeding mother and child or to the unborn baby.

SECTION D RESEARCH PROCEDURES

SECTION D IS MANDATORY

D1 (A) What activities, procedures or interventions (if any) are research participants asked to undergo or engage in for the purposes of this research study?

For the purposes of this research study parent and child/adolescent participants will be asked to participate in one semi-structured interview, which will be audio-recorded and is expected to last approximately 1 hour (see accompanying Interview Guide).

D1 (B) WHAT OTHER ACTIVITIES (IF ANY) ARE TAKING PLACE FOR THE PURPOSES OF THIS RESEARCH STUDY E.G. CHART REVIEW, SAMPLE ANALYSIS ETC?

Not applicable

D2. Please provide details below of any potential harm that may result from any of the activities, procedures, interventions or other activities listed above.

The risk of harm occurring in this study is not quantifiable.

Inconvenience: participation in this study may cause inconvenience to the child/adolescent and the parent in terms of the time spent receiving and processing the study information and the time spent taking part in the interview. However this inconvenience is transient and will be minimised by agreeing a time and place suitable to the child/adolescent and parent to conduct the interview.

Risk to personal data: while it is unlikely that personal data will be misplaced all measures will be taken to mitigate against such a risk. In line with the Data Protection Act (2018) and best practice, minimal personal data will be collected. Personal data will be coded in such a way that only the Principal Investigator will recognise the data. Dates of birth will not be recorded, instead the child's/adolescent's age will be recorded in years and months. Additionally numbers and letters in code format will be used to record the participants' names and interview numbers, (e.g. Adolescent Interview1 14yrs & 5mths; Parent (of 9yrs & 4mths child)

Interview6). Hard copies of all data, including Consent and Assent Forms, will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Only the Principal Investigator will have access to this locked press. Electronic data will be coded and stored in the Principal Investigator's personal profile on a TCD desktop PC which is password protected. Only the Principal Investigator will have access to this profile.

Interviews will be audio recorded, recordings will be stored securely in the same manner as the personal data until they have been transcribed in full and the content of the transcriptions agreed by the individual participant. For this reason the personal email address of each parent participant will be collected so that the draft interview transcription can be emailed to the participant for confirmation of content. Interview recordings will be retained in a secure press in the Principal Investigator's office until the successful completion of the PhD. At that stage they will be shredded and disposed of in a confidential waste disposal unit at the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. The thesis and all reports and papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full. Personal data will be retained until successful completion of the PhD, at that point they will be shredded and disposed of in confidential waste unit.

Psychological distress: it is possible that during the course of an interview either a child, an adolescent or a parent may become distressed. Such an event is a low risk, but nonetheless must be considered in advance of data collection. If this occurs the child, adolescent or parent will be cared for in a sensitive manner and supported through their distress. They will be given an opportunity to end the interview immediately and withdraw from the study if they wish. They will be informed that appropriate person(s) in the clinical area, i.e. the Clinical Nurse Manager/Nurse in Charge of the shift and the Registered Nurse responsible for the child's or adolescent's nursing care, will be informed with their permission. Before leaving the child, adolescent or parent I will ensure that any necessary support is in place, as needed.

D3. What is the potential benefit that may occur as a result of this study?

There is no direct benefit identified for the participants as a result of participating in this research study. However, the benefits to future hospitalised children and their parents/ guardians will be evident following the implementation of the findings.

The Principal Investigator will benefit if the research is approved and a PhD is awarded. If this is the case there may be possible career opportunities for the researcher.

The new knowledge generated from this research will benefit Children's Hospital Ireland in terms of the outcomes that consistent and effective implementation of a child - and family-centred approach to nursing care will bring to hospitalised children and their parents/guardians.

D4 (A) WILL THE STUDY INVOLVE THE WITHHOLDING OF TREATMENT?

NO

D5 (A) HOW WILL THE HEALTH OF PARTICIPANTS BE MONITORED DURING THE STUDY, AND WHO WILL BE RESPONSIBLE FOR THIS?

Not applicable

D5 (B) HOW WILL THE HEALTH OF PARTICIPANTS BE MONITORED AFTER THE STUDY, AND WHO WILL BE RESPONSIBLE FOR THIS?

Not applicable

D6 (A) WILL THE INTERVENTIONS PROVIDED DURING THE STUDY BE AVAILABLE IF NEEDED AFTER THE TERMINATION OF THE STUDY? NON-APPLICABLE

D6 (B) IF YES, PLEASE STATE THE INTERVENTION YOU ARE REFERRING TO AND STATE WHO WILL BEAR THE COST OF PROVISION OF THIS INTERVENTION?

Not applicable

D7. PLEASE COMMENT ON HOW INDIVIDUAL RESULTS WILL BE MANAGED.

Not applicable

D8. PLEASE COMMENT ON HOW AGGREGATED STUDY RESULTS WILL BE MADE AVAILABLE.

This study is being carried out as part of a PhD programme. The final thesis will be submitted to the School of Nursing and Midwifery, at TCD as part fulfillment for that programme.

It is planned that local dissemination within the children's nursing community in Dublin and regionally in Ireland will occur through poster and verbal presentations at nursing conferences, seminars and meetings. It is also planned that the findings of this study will be written up for publication in a peer-reviewed journal, which will be widely circulated internationally.

D9. WILL THE RESEARCH PARTICIPANT'S GENERAL PRACTITIONER BE INFORMED THAT THE RESEARCH PARTICIPANT IS TAKING PART IN THE STUDY (IF APPROPRIATE)? NON-APPLICABLE

D10. WILL THE RESEARCH PARTICIPANT'S HOSPITAL CONSULTANT BE INFORMED THAT THE RESEARCH PARTICIPANT IS TAKING PART IN THE STUDY (IF APPROPRIATE)? NON-APPLICABLE

SECTION E DATA PROTECTION

SECTION E IS MANDATORY

E1 DATA PROCESSING - CONSENT

E1.1 (A) WILL EXPLICIT CONSENT BE SOUGHT FOR THE PROCESSING OF DATA? YES

E1.1 (B) IF NO, PLEASE ELABORATE. PLEASE NOTE EXPLICIT CONSENT IS MANDATORY UNDER THE DATA PROTECTION ACT 2018 (SECTION 36 (2)) (HEALTH RESEARCH) REGULATIONS 2018 UNLESS THE DATA IS ANONYMOUS OR A 'CONSENT DECLARATION HAS BEEN OBTAINED'

Not applicable

E2 DATA PROCESSING – GOVERNANCE AND PROCEDURE

YOU MUST ANSWER ALL QUESTIONS IN THIS SECTION AS THEIR FULFILLMENT IS A MANDATORY REQUIREMENT UNDER THE DATA PROTECTION ACT 2018 (SECTION 36(2)) (HEALTH RESEARCH) REGULATIONS 2018

E2.1 PLEASE SPECIFY WHICH arrangements are in place to ensure that personal data will be processed as is necessary; a) to achieve the objective of the health research and; b) to ensure that shall not be processed in such a way that damage or distress to the data subject?

In line with the Data Protection Act (2018) and best practice, minimal personal data will be collected for the purposes of this research study. Personal data which will be collected include the participants' first and second names. In the case of the child/adolescent, his/her age in years and months will also be collected. This data will be associated with his/her parent's interview data. All data will be coded in such a way that only the researcher will recognise the data. Numbers will be used to record the participants' names and interview numbers, (e.g. Adolescent Interview1 14yrs & 5mths; Parent (of 9yrs & 4mths child) Interview6). Hard copies of all data will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Only the Principal Investigator will have access to this locked press. Electronic data will be coded and stored in the Principal Investigator's personal profile on a TCD desktop PC which is password protected. Only the Principal Investigator will have access to this electronic profile. Online cloud data storage platforms will not be used at any stage during this research study. Interviews will be audio recorded, recordings will be stored securely in the same manner as the personal data until they have been transcribed in full and the content of the transcriptions agreed by the individual participant. At that stage they will be destroyed and disposed of in a confidential waste disposal unit at the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Third party transcription services will not be used. The thesis and all reports/papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full. Furthermore, the data collection site will be referred to as "a children's teaching hospital in Dublin" of which there are three, in order to avoid any risk of identification of same.

E2.2 PLEASE specify the data controller; joint data controllers (if applicable) and any data processors involved in the research.

Data controller:

The University of Dublin, Trinity College, Dublin 2.

Data processor:

Siobhán O'Connor, PhD student, School of Nursing & Midwifery, TCD.

Address: 6th Floor, Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.

Telephone: 087.9977843

Email: oconns49@tcd.ie

E2.3 PLEASE specify any person or organisation who provides funding for, or otherwise supports, the project.

This PhD study has been funded by the National Children's Hospital Foundation, based at Tallaght Hospital.

E2.4 PLEASE specify any person other than the named data controller, joint controllers or processors with whom it is intended to share any of the personal data collected (including where it has been pseudonymised or anonymised) and the purpose of such sharing.

It is not planned to share any of the personal data collected in this study with any third parties.

E2.5 THE provision of training in data protection law and practice to anyone involved in carrying out the health research is a mandatory legal requirement. Please specify the provision of training.

Siobhán O'Connor, Principal Investigator, has attended An Introduction to Good Clinical Practice ICH E6 (R2) for Investigators and Site Staff (Version 4.0) on 24th June 2019 at Tallaght University Hospital.

E2.6 HAS A "RISK ASSESSMENT" AND/OR "DATA PROTECTION IMPACT ASSESSMENT" BEEN CARRIED OUT, TAKING IN TO ACCOUNT LOCAL POLICY AND/OR LEGAL REQUIREMENTS?

A risk assessment has been carried out and found that the risk to participants is minimal as a result of this study. A data protection impact assessment is not required.

E2.7 PLEASE SPECIFY THE measures in place that demonstrate compliance with the data minimisation principle (Is it adequate, relevant and limited to what is necessary?)

The data to be collected will include:
Parent: First and second name only
Child/adolescent: First and second name and age in years and months.
A contact email address will also be collected to allow the participant to verify the content of the interview transcript.

E2.8 Please specify the controls in place to limit access to the personal data undergoing processing in order to prevent unauthorised consultation, alteration, disclosure or erasure of personal data.

All personal data will be coded in such a way that only the researcher will recognise the data. Numbers will be used to record the participants' names and interview numbers, (e.g. Adolescent Interview1 14yrs & 5mths; Parent (of 9yrs & 4mths child) Interview6). Hard copies of all data will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Only the Principal Investigator will have access to this locked press. Electronic data will be coded and stored in the Principal Investigator's personal profile on a TCD desktop PC which is password protected. Only the Principal Investigator will have access to this electronic profile. Online cloud data storage platforms will not be used at any stage during this research study. Interviews will be audio recorded, recordings will be stored securely in the same manner as the personal data until they have been transcribed in full and the content of the transcriptions agreed by the individual participant. At that stage they will be destroyed and disposed of in a confidential waste disposal unit at the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Contact email addresses will also be deleted from my PC. The thesis and all reports/papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full.

E2.9 Please specify the controls in place to log whether and by whom personal data has been consulted, altered, disclosed or erased.

Access to personal data will be allowed only by the Principal Investigator.

E2.10 Please specify measures to protect the security of the personal data concerned.

Electronic data will be stored on a TCD desktop PC in the personal profile of the Principal Investigator. This profile is password protected.

E2.11 Please specify the arrangements to anonymise, archive or destroy personal data once the health research has been completed.

The Principal Investigator will be responsible for pseudo-anonymising, storing and ultimately destroying the personal data of the research participants.

E.2.12 Please specify other technical and organisational measures designed to ensure that processing is carried out in accordance with the Data Protection Regulation, together with processes for testing and evaluating the effectiveness of such measures.

Not applicable

E2.13 Please specify which arrangements are in place to ensure that personal data is processed in a transparent manner.

Participants will be informed of what personal data will be collected, recorded and stored. The use of same will be included in the relevant Participant Information Leaflet. They will be assured of the confidentiality of data processing procedures.

Information included in the Information Leaflet includes: the purpose of the study, the personal data to be collected, how long the data will be retained, who the data will be shared with, and how the data will be disposed of.

E3 DATA PROCESSING - GENERAL

E3.1 WHAT MEDIA OF DATA WILL BE COLLECTED?

Hard copies of Informed Consent/Assent Forms will be collected.

Interview data will be audio-recorded and subsequently transcribed by the Principal Investigator. Transcriptions will be recorded and stored in electronic format only.

E3.2 (A) WOULD YOU CLASS THE DATA COLLECTED IN THIS STUDY AS anonymous, pseudonymised, coded or identifiable data?

Pseudonymised and coded.

E3.2 (B) IF 'PSEUDONYMISED', PLEASE CONFIRM WHO WILL RETAIN THE 'KEY' TO RE-IDENTIFY THE DATA?

The Principal Investigator, Siobhán O'Connor, will be the only person who can access the data which will allow re-identification of the participants.

E3.3 WHERE WILL DATA WHICH IS COLLECTED BE STORED?

Collected data will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Electronic data i.e. interview transcriptions, will be coded and stored in a personal profile in the personal profile of the Principal Investigator on a TCD desktop PC which is password protected. Only the Principal Investigator will have access to this locked press and the profile on the PC.

E3.4 (A) WILL DATA COLLECTED BE AT ANY STAGE LEAVING THE SITE(S) OF ORIGIN?

YES

E3.4 (B) IF YES, PLEASE ELABORATE.

Completed Consent/Assent Forms and recorded interview data will be collected by the Principal Investigator and transported in her personal car to her office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.

E3.5 WHERE WILL DATA ANALYSIS TAKE PLACE AND WHO WILL PERFORM DATA ANALYSIS (IF KNOWN)?

THE PRINCIPAL INVESTIGATOR, SIOBHÁN O'CONNOR, WILL PERFORM THE DATA ANALYSIS IN HER OFFICE IN THE INSTITUTE OF POPULATION HEALTH, RUSSELL BUILDING, TALLAGHT CROSS, DUBLIN 24.

E3.6 (A) AFTER DATA ANALYSIS HAS TAKEN PLACE, WILL DATA BE RETAINED?

YES

E3.6 (B) IF YES, FOR HOW LONG, FOR WHAT PURPOSE, AND WHERE WILL IT BE RETAINED?

Interview and participants' personal data will be retained until the successful completion of the PhD programme, which is expected by end of 2020. This data will be retained in the Principal Investigator's office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.

E3.7 PLEASE COMMENT ON THE CONFIDENTIALITY OF COLLECTED DATA.

No identifiable data will be disclosed to any third party during the course of this study. In the event of a participant disclosing information which leads the researcher to consider he/she is at risk of harm, the Principal Investigator will be obliged to share personal information with the relevant third party. The participant will be informed of this process prior to taking part in the research.

E3.8 (A) WILL ANY OF THE INTERVIEW DATA COLLECTED CONSIST OF AUDIO RECORDINGS / VIDEO RECORDINGS? YES (AUDIO RECORDINGS)

E3.9 (A) WILL ANY OF THE STUDY DATA COLLECTED CONSIST OF PHOTOGRAPHS/ VIDEO RECORDINGS? NO

E3.9 (B) IF YES, PLEASE ELABORATE.

Not applicable

E4 ACCESS TO HEALTHCARE RECORDS

E4.1 (A) DOES THE STUDY INVOLVE ACCESS TO HEALTHCARE RECORDS (HARD COPY / ELECTRONIC)? NO

If answer is No, please delete remaining questions in Section E3

SECTION F HUMAN BIOLOGICAL MATERIAL

F1 BODILY TISSUE / BODILY FLUID SAMPLES - GENERAL

F1 1 (a) Does this study involve human biological material? NO

If the answer is No, please delete Section F

SECTION G RADIATION

G1 RADIATION – GENERAL

G1.1 (a) Does this study/trial involve exposure to radiation? NO

If answer is No, please delete remaining questions in Section G

SECTION H MEDICAL DEVICES

H1 (A) IS THE FOCUS OF THIS STUDY/TRIAL TO INVESTIGATE/EVALUATE A MEDICAL DEVICE? NO

If answer is No, please delete remaining questions in Section H.

SECTION I MEDICINAL PRODUCTS / COSMETICS / FOOD AND FOODSTUFFS

I.1 NON-INTERVENTIONAL TRIALS OF MEDICINAL PRODUCTS

I1.1 (a) Does this study involve a medicinal product? No

If the answer is No, please delete remaining questions in subsection I1

I.2 COSMETICS

I2.1 (a) Does this study involve a cosmetic? No

If the answer is No, please delete remaining questions in subsection I2

I.3 FOOD AND FOOD SUPPLEMENTS

I3.1 (a) Does this study involve food or food supplements? No

If the answer is No, please delete remaining questions in subsection I3

SECTION J INDEMNITY AND INSURANCE

SECTION J IS MANDATORY

J1 PLEASE CONFIRM AND PROVIDE EVIDENCE THAT APPROPRIATE INSURANCE/INDEMNITY IS IN PLACE FOR THIS RESEARCH STUDY AT EACH SITE.

THE PRINCIPAL INVESTIGATOR IS AN EMPLOYEE OF CHI AT TALLAGHT.

CHI HAS EMPLOYER'S LIABILITY INSURANCE (FOR PERSONAL INJURY TO ITS EMPLOYEES) AND PUBLIC LIABILITY INSURANCE (FOR PERSONAL INJURY TO MEMBERS OF THE PUBLIC) VIA THE STATE CLAIMS AGENCY. (WRITTEN PROOF OF SAME TO FOLLOW).

CHI ALSO HAS PROFESSIONAL LIABILITY INSURANCE (IN RESPECT OF CLAIMS FOR LOSS AND INJURY CAUSED FOLLOWING PROFESSIONAL ADVICE ETC.). CLINICAL COVER, FOR STUDIES INVOLVING CLINICAL ACTIVITIES AND CLINICAL

DATA, IS PROVIDED VIA THE STATE-SPONSORED CLINICAL INDEMNITY SCHEME. HOWEVER SINCE THIS STUDY WILL NOT INCLUDE ANY CLINICAL DATA OR CLINICAL ACTIVITY, IT IS NOT ENVISAGED THAT PROFESSIONAL OR CLINICAL LIABILITY WILL BE REQUIRED.

J2 PLEASE CONFIRM AND PROVIDE EVIDENCE THAT APPROPRIATE INSURANCE/INDEMNITY IS IN PLACE FOR THIS RESEARCH STUDY FOR EACH INVESTIGATOR.

CHI EMPLOYEES ARE COVERED BY EMPLOYER'S LIABILITY INSURANCE AND PUBLIC LIABILITY INSURANCE VIA THE STATE CLAIMS AGENCY.

J3.1 Please give the name and address of the organisation / or individual legally responsible for this research study?

School of Nursing & Midwifery, Trinity College Dublin, 24 D'Olier St., Dublin 2.

J3.2 Where an organisation is legally responsible, please specify if this organisation is:

- A pharmaceutical company NO
- A medical device company NO
- A university YES
- A registered charity NO
- Other YES / NO If yes, please specify: Answer

J3.3 PLEASE CONFIRM AND PROVIDE EVIDENCE OF ANY SPECIFIC ADDITIONAL INSURANCE / INDEMNITY ARRANGEMENTS WHICH HAVE BEEN PUT IN PLACE, IF ANY, BY THIS ORGANISATION / OR INDIVIDUAL FOR THIS RESEARCH STUDY?

Professional Indemnity Insurance and Public Liability Insurance cover are provided to the School of Nursing & Midwifery at TCD by Willis Towers Watson, see accompanying letters as evidence.

SECTION K COST AND RESOURCE IMPLICATIONS, FUNDING AND PAYMENTS

SECTION K IS MANDATORY

K1 COST AND RESOURCE IMPLICATIONS

K1.1 PLEASE PROVIDE DETAILS OF ALL COST / RESOURCE IMPLICATIONS RELATED TO THIS STUDY (E.G. STAFF TIME, OFFICE USE, TELEPHONE / PRINTING COSTS ETC.)

All costs incurred as a result will be funded by the NCH Foundation and TCD School of Nursing & Midwifery.

K2 FUNDING

K2.1 (a) Is funding in place to conduct this study?

YES

K2.1 (b) If no, has funding been sought to conduct this study? From where? Please elaborate.

NOT APPLICABLE

K2.1 (c) If yes, please state the source of funding (industry, grant or other), the name of the funder, the amount of funding and duration of funding.

Source of funding (industry, grant or other):
Grant
Name of Funder:
National Children's Hospital Foundation at Tallaght Hospital
Amount of Funding:
Salary of Principal Investigator, PhD fees, ongoing additional educational needs of the student and any extra funding required in terms of stationery, publication fees etc
Duration of Funding
3 years from October 2017

K2.1(d) Please provide additional details in relation to management of funds.

Funding is managed by the National Children's Hospital Foundation office based at Tallaght University Hospital.

K2.1(e) Is the study funded by a 'for profit' organisation? NO

K2.2 (a) Do any conflicts of interest exist in relation to funding or potential funding? NO

K2.2 (b) If yes, please elaborate.

Not applicable

K3 PAYMENTS TO INVESTIGATORS

K3.1 (a) Will any payments (monetary or otherwise) be made to investigators? NO

K3.1 (b) If yes, please provide details of payments (including amount).

Not applicable

K4 PAYMENTS TO PARTICIPANTS

K4.1 (a) Will any payments / reimbursements (monetary or otherwise) be made to participants? NO

K4.1 (b) If yes, please provide details of payments / reimbursements (including amount).

Not applicable

SECTION L ADDITIONAL ETHICAL ISSUES

L1 (a) Does this project raise any additional ethical issues? NO

If answer is No, please delete remaining questions in Section L.

PLEASE ENSURE THIS APPLICATION FORM IS FULLY COMPLETED AS INCOMPLETE SUBMISSIONS WILL NOT BE REVIEWED.

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ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE

Tel: + 353 (0) 1 408 6307/6243

Ms Siobhan O'Connor
School of Nursing and Midwifery - TCD
6th Floor,
Institute of Population Health
Russell Building
Tallaght Cross
Dublin 24

23rd August 2019

REC Reference: GEN/747/19

Care for hospitalised children and adolescents – The child's, adolescent's and parent's experience of involvement in care while in hospital – A grounded theory study

Dear Ms O'Connor

The Ethics (Medical Research) Committee meeting that took place on, 16th July 2019, reviewed and approved the above Study provided the following is adhered to:

- That the Investigators provide more information in relation to the process in place if a parent becomes distressed during the participation in the Study and who would engage to manage that event e.g. the Ward Manager.
- That in the 'Title of the Study' make it clear that the study is involved with only one discipline in the care of the patient i.e. 'nurse based'.
- That the Consent/Participant Information Leaflets should state the rights of the participants under GDPR legislation.
- That the Investigators check with Trinity College Dublin that the University is the Data Controller.
- That In Section E2.11 of the Application Form the data is pseudo-anonymised and not anonymised as stated.

The Committee would like to thank you for being present at the meeting and for speaking to this item.

Yours sincerely



Claire Rice
Secretary
Ethics (Medical Research) Committee



Appendix 14 Faculty of Health Sciences at TCD Research Ethics Committee Application and approval



**FACULTY OF HEALTH SCIENCES
RESEARCH ETHICS APPLICATION FORM**

PLEASE NOTE THE FOLLOWING:

- Incomplete and/or late applications will not be processed and will be returned to the applicants.
- Forms without the following signatures will not be processed: (1) Applicant(s), (2) Research Supervisor (applicable in student application), (3) all researchers named on the form.
- Forms without the checklist completed will not be processed.
- When collating please staple documents

Applicant Name	Siobhán O'Connor
Applicant Email	oonns49@tcd.ie
Are you a TCD staff member?	NO ID No:
Are you a TCD student?	YES ID No: 17323700
What School/Department are you affiliated to?	School of Nursing & Midwifery
Supervisor Name	Prof Imelda Coyne / Prof Maria Brenner
Supervisor Email	coynei@tcd.ie brennerm@tcd.ie
Working title of proposed study	Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study
is this a fasttrack application?	No N.B. If yes, the fasttrack cover sheet must be attached with your application
PLEASE IDENTIFY WHICH OF THE FOLLOWING APPLIES:	(A) AN UNDERGRADUATE PROJECT <input type="checkbox"/> (B) AN ELEMENT OF A TAUGHT POST -GRADUATE COURSE <input type="checkbox"/> (C) A FULL TIME POST-GRADUATE RESEARCH PROJECT <input checked="" type="checkbox"/> (D) STAFF RESEARCH PROJECTS <input type="checkbox"/>

RESEARCH APPLICATION INDEX

Section 1: Applicants Details

Section 2: Details of Research Study and Participant Selection

Section 3: Consent and Confidentiality (incl. Data protection)



Section 4: Risk, Benefit and Harm

Section 5: Funding and Payment

Section 6: Ethical Approval from Other Committees

Section 7: Declaration of Approval and Signatures

Please complete the application form and return one signed hard copy to
Faculty of Health Sciences,
Ground Floor, Chemistry Building ,
Trinity College, Dublin 2.

Please email your application in full to ethicscommittee@tcd.ie

If you have any queries regarding the completion of this application form please email
ethicscommittee@tcd.ie

Notes:

If your proposal has been approved by the ST JAMES'S HOSPITAL AND FEDERATED DUBLIN VOLUNTARY HOSPITALS JOINT RESEARCH ETHICS COMMITTEE (JREC), since this body includes representation from Trinity College there is no requirement to seek approval from the Faculty Ethics Committee.

The Faculty Ethics Committee does not process applications for approval of projects that assess the effect of a drug or therapeutic substance. Approval for such studies must be sought through the Irish Medicines Board and ethics clearance should be obtained from the JREC



RESEARCH APPLICATION CHECKLIST

To process your application form efficiently you are required to fill in the checklist below. Do not leave any blanks. If this checklist is not completed, your application will not be processed.

PLEASE TICK THE APPROPRIATE BOX	YES	NO
Are you undertaking the proposed research study in your capacity as: (a) a student of the Faculty of Health Sciences? Or	Yes	
(b) a staff member of the Faculty of Health Sciences?		No
1. Does the proposed research involve current students and / or staff of the Faculty of Health Sciences as research participants?		No
2. If you are a student, has your supervisor endorsed the completed form?	Yes	
IF APPROPRIATE TO THE STUDY YOU SHOULD ATTACH THE FOLLOWING:		
<ul style="list-style-type: none"> (a) the consent form you propose using (b) the letter(s) to prospective participants seeking their co-operation with the study (c) the participant information leaflet you propose using (d) for the purpose of your proposed study, if you require access to: (i) a site outside your home department/School, and/or (ii) the person who is responsible for the welfare of your proposed participants please attach the letter seeking access (e) If the study requires ethical approval by ethics committees of any other institutions, outside of the St. James's Hospital and Federated Dublin Voluntary Hospitals Joint Ethics Research Committee (J.R.E.C.), please attach a copy of the responses received from these committees (f) If relevant to this study please attach a copy of the tool(s) of data collection you propose using (Questionnaire / interview schedule / observation schedule/other) 		



TRINITY COLLEGE
Faculty of Health Sciences
RESEARCH ETHICS APPLICATION FORM
CONFIDENTIAL

Please complete all information relevant to your application

SECTION 1 – APPLICANTS’ DETAILS

1.1 Name, qualification and position of each person associated with this research project.

List details of all personnel involved with the research (excluding participants)

Investigator Title / First name / Surname	Title of Study	Postal Address (Please note that approval will be posted to this address)	Email address	Tel No Work / Home	Role in research	Primary Employer (Hospital / University / Other)	Current Occupation
Ms Siobhán O’Connor	Nursing care for hospitalised children and adolescents: the child’s, adolescent’s and parent’s experience of involvement in care while in hospital: a grounded theory study	6 th Floor, Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.	occonn49@tcd.ie	087.9977843	Principal investigator	National Children’s Hospital Foundation, Based at Tallaght University Hospital, Dublin 24.	Full time PhD Candidate
Supervisor (if investigator is a student)		Postal Address (Please note that approval will be posted to this address)	Email address	Tel No Work / Home	Role in research	Primary Employer (Hospital / University / Other)	Current Occupation
Prof. Imelda Coyne	As above	School of Nursing & Midwifery, Trinity College Dublin, the University of Dublin	coynei@tcd.ie	01.8964071	Academic supervisor	TCD	Professor of Children’s Nursing & Co-Director of Trinity



Prof Maria Brenner	As above	College Green Dublin 2	brennerm@tcd.ie	01.896390 1	Academic co- supervisor	TCD	Research in Childhood Centre, Professor of Children's Nursing & Director of Research, School of Nursing & Midwifery, Trinity College Dublin, Ireland
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SECTION 2 – DETAILS OF RESEARCH STUDY & PARTICIPANT SELECTION

2.1 Working title of proposed study

Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

2.2 Dates & Duration of Study

Proposed Start Date:

Data collection will start in October 2019
--

 Proposed End Date:

Until data saturation is reached anticipated March 2020

2.3 What are the primary location(s) for data collection? (e.g. classroom, participant's home, hospital/clinic, laboratory, place of convenience for participant)

In the Hospital setting at a place of convenience for the participant	

2.4 State research aim(s) and objective(s), research question or hypothesis (as appropriate)

The aim of this study is to explore children's and parents' experiences and expectations of their roles while in hospital.
These aims will be achieved through the following objectives:

1. To identify children's experiences and expectations of their parents' and nurses' role in their care in hospital
2. To explore children's experiences of engagement and role preferences in their own care while in hospital
3. To explore parents' experiences and expectations of their role and the nurses' role in their child's care in hospital
4. To explore parents' perspectives of their child's role in their own care while in hospital
5. To develop a theory to explain the involvement of the child and parent in care in hospital

2.5 Provide brief outline of the project (maximum 400 words, must include background, research approach, design, data collection methods, sampling, indicate the method of sampling you intend to use and the sample size)

Background
Since the mid-1990s Children's Health Ireland (CHI) at Crumlin, Temple St and Tallaght have been using models of nursing care which are not explicitly family-centred. Evidence-based nursing care plans in use informally include parents/guardians in the care of their child in hospital, however they do not explicitly address family-centred care (FCC). FCC has evolved in an unstructured and unco-ordinated fashion, without any formal theory or process of evaluation.
Parents wish to participate actively in the care of their child in hospital, the degree to which they wish to do so varies (Coyne, 2013; Feeg *et al*, 2016). Children's nurses have been applying some elements of FCC to their practice for decades, albeit inconsistently. There is no hard evidence to inform healthcare professionals if the application of FCC makes a difference to the child's health outcomes or the families' healthcare experience. Furthermore the voice of the child is noticeably absent from existing research on the topic. A lack of attention to cultural and societal changes was also highlighted.

Design
Constructivists believe that people continuously make sense of the world around them and may have different interpretations of the same phenomenon (Parahoo, 2014). They believe in the value of observed and perceived phenomena, and that to be understood phenomena must be studied in context (Johnson and Webber, 2014; Parahoo, 2014). The constructivist researcher is a participant observer who engages with the research participants and discerns the meanings of actions as they are expressed by the participants (Carr and Kemmis, 1986). This study is situated within the constructivist paradigm.



Research approach

Constructivist researchers typically use a qualitative approach. Qualitative researchers listen to the participants, seeking a deeper understanding of their experience based on what they have heard and how they interpret it. Constructivist grounded theory (Charmaz, 2000) acknowledges the researcher's subjectivity, identifying preconceptions rather than denying them. There is a focus on representation of the participants and reflexivity about the researcher's role in the process (Charmaz *et al*, 2018). This study will use constructivist grounded theory methodology.

Data collection methods

Qualitative data will be collected retrospectively through semi-structured interviews with pre-teenage children aged 9-12 years and with adolescents aged 13-16 years. Parents of the children will also be interviewed. The experiences and expectations of hospitalisation of both cohorts of children and their parents will be explored. An Interview Guide has been developed, (see Appendix 1).

Sampling

Theoretical sampling, the purposeful selection of participants (Coyne, 1997), will be used in this study, and will aim to be as inclusive as possible of varied family types from varied socio-cultural backgrounds and ages. Theoretical sampling involves simultaneously collecting, analysing and coding data through constant comparison analysis, in order to inform what further data is needed (Coyne, 1997). This process continues until data saturation is reached, when the new raw data being collected replicates what is already identified by earlier participants, with no new categories emerging (Charmaz, 2014). The aim is to develop a detailed understanding of the phenomenon. It is expected that 15-20 interviews of children/adolescents and 15-20 interviews with parents will be required before data saturation occurs.

2.6 If appropriate please identify how participants will be recruited and what steps you will take to access the sample, specifying details of people who will be contacted during this process:

The number of participants recruited to a grounded theory study is determined by the data analysis from previous participants, this is known as theoretical sampling (Chiobitti and Piran, 2003). Theoretical sampling is the purposeful selection of participants at the early stages of a study (Coyne, 1997). It involves simultaneously collecting, analysing and coding data through constant comparison analysis, in order to inform what further data is needed (Coyne, 1997). This process continues until data saturation is reached, when the new raw data being collected replicates what is already identified by earlier participants and no new categories emerge (Charmaz, 2014). The purpose is to seek relevant data to develop and refine the identified categories. This study will initially use purposeful sampling to recruit participants, aiming to be as inclusive as possible of varied family types from varied socio-cultural backgrounds and ages. Following data analysis, theoretical sampling will be employed until data saturation is achieved.

The Research Ethics Committee in CHI at Crumlin have reviewed the study at a Committee meeting in July last. The application was approved pending minor amendments which have been made (see Appendix 2). It is expected that data collection will commence in October 2019.

A Gatekeeper has been nominated who is a member of the senior nursing management team and will advise which in-patient clinical areas will be most appropriate to access the required participants. She will also introduce me to the Clinical Nurse Manager (CNM) of each ward as I enter the clinical area. Then a verbal approach will be made to invite potential participants to take part in the study. The researcher will only approach a child/adolescent if his/her parent is present at the bedside at the time. No child/adolescent will be approached to recruit to the study without the presence of one parent. The researcher and the Gatekeeper will always aim to ensure that the research process will cause as little disruption as possible to the working day of the ward staff and the healthcare experience of the child/adolescent and parent.

Three Participant Information Leaflets and Consent/Assent Forms have been developed, aimed at the three participant populations, children aged 9-12 years, adolescents aged 13-16 years and parents (see Appendix 3).

A poster will also be designed to bring the study to the attention of hospitalised children/adolescents and their parents.



2.7 List your exclusion/inclusion criteria for participant selection:

Inclusion criteria:

Hospitalised children/adolescents aged between 9 and 16 years
Children/adolescents who are fluent in the English language
Children/adolescents who can articulate their experiences and expectations of FCC in English.
Parents of hospitalised children aged between 9 and 16 years
Parents who are fluent in the English language
Parents who can articulate their experiences and expectations of FCC in English

Exclusion criteria:

Children/adolescents who are not in-patients at the time of the study
Children/adolescents who do not speak English
Children/adolescents who are unable to articulate their experiences and expectations of FCC due to their illness, a communication difficulty or a learning disability
Children/adolescents who are in-patients with a mental health diagnosis
Children/adolescents who are in-patients with a diagnosis of a life-limiting condition
Children/adolescents who are in-patients and who live in a residential care environment outside of hospital
Parents whose children are not in-patients at the time of the study
Parents who do not speak English
Parents who are unable to articulate their experiences and expectations of FCC in English due to a communication difficulty or language barrier.
Parents whose child/adolescent is an in-patient with a mental health diagnosis.
Parents whose child is an in-patient with a diagnosis of a life-limiting condition

References

- Carr, W. and Kemmis, S. (1986) *Becoming Critical Education, Knowledge and Action Research*, London: Falmer Press.
- Chiobitti, R.F. and Piran, N. (2003) Rigour and grounded theory. *Journal of Advanced Nursing* **44**(4): 427-435.
- Charmaz, K. (2000) Constructivist and objectivist grounded theory. In: N. Denzin and Y. Lincoln (Eds.) *Handbook of Qualitative Research* (2nd ed., pp. 509-535) Thousand Oaks, CA: Sage.
- Charmaz, K. (2014) *Constructing Grounded Theory* (2nd ed.) Los Angeles: Sage.
- Charmaz, K., Thornberg, R. and Keane, E. (2018) Evolving Grounded Theory and Social Justice Inquiry. In: N. Denzin and Y. Lincoln (Eds.) *The SAGE Handbook of Qualitative Research* (5th ed., pp. 411-443) Thousand Oaks, CA: Sage.
- Coyne, I.T. (1997) Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing* **26**(3): 623-630.
- Coyne, I. (2013). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations* **18**(5): 796-808.
- Feeg, V.D., Paraszczyk, A.M., Çavuşoğlu, H., Shields, L., Pars, H. and Al Mamun, A. (2016) How is Family Centered Care Perceived by Healthcare Providers from Different Countries? An International Comparison Study. *Journal of Pediatric Nursing*, **31**, 267-276.
- Johnson, B.M. and Webber, P.B. (2014) *An Introduction to Theory and Reasoning in Nursing* (4th ed.) New York: Lippincott Williams & Wilkins.
- Parahoo, K. (2014) (3rd ed.) *Nursing Research: Principles, Process and Issues*. London: Macmillan Press Ltd.



SECTION 3 – CONSENT, CONFIDENTIALITY (INCLUDING DATA PROTECTION)

3.1 Will informed consent be obtained from the research participants?

YES Yes NO

If yes, please give details of **who** will take consent and **how** it will be done.

(Please attach a copy of letter, consent form (if required) and information leaflet. See guidelines on how to prepare these documents in Appendices and adapt examples accordingly to suit your study and participants)

The Principal Investigator will seek written informed consent from all potential parent participants.

Participant Information Leaflets will inform the participants, in plain English, about the study and what will be required of them as participants. Voluntary, written and informed consent to participate will be sought only after detailed information in plain English has been shared with each potential parent participant. They will also be given an opportunity to ask questions and seek clarification about any aspect of the study they may be unclear about. The right to refuse to participate in the study will be explained. The parent will be reassured that their decision not to participate in the study will be respected in full and will not affect the care their child receives in any way.

The Participant Information Leaflet for parents includes a statement about what will happen if their child/ adolescent discloses any information to the researcher that they are at significant risk of harm. It also includes information about the process to be followed if a participant discloses any information which indicates a significant safety and quality issue for the child/adolescent while in hospital (see Appendix 3 - Participant Information Leaflets and Consent/Assent Forms).

All parent participants will be advised that they can withdraw from the study at any time with no repercussions to either them or their family member who may also be taking part in the study.

3.2 What is the time interval between giving information and seeking consent?

(It is recommended that a period of seven days be provided for reflection. If less than this, please justify).

There will be a 24 hour interval allowed for the potential participant to consider the information before written informed consent will be sought.

3.3 Will the participants be from any of the following groups (tick as appropriate)

	INVOLVEMENT	
	YES	NO
Children under 18 years of age	Yes	
Adults with learning disabilities		No
Adults with communication difficulties		No
Adults who are unconscious or very severely ill		No
Adults who have a terminal illness		No
Adults with mental illness		No
Adults suffering from dementia		No
Prisoners		No
Young Offenders		No
Those who could have been considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, students		No
Other groups who may be considered vulnerable (Please specify below)		



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3.4 If participants are to be recruited from any of the potentially vulnerable groups listed above, please give details of:

- (a) the extra steps taken to ensure that participants from any of these vulnerable groups are as fully informed as possible about the nature of their **involvement**;
The Principal Investigator will be responsible for recruiting all potential participants. Voluntary, written and informed consent/assent to participate will be sought only after detailed age-appropriate information has been shared with each potential child/adolescent participant and at least one parent. A Participant Information Leaflet in age-appropriate language and in plain English for children aged 9-12 years, and another for adolescents aged 13-16 years will inform the potential child/adolescent participant about the study and what will be required of them as participants. These leaflets also include information about the risks and benefits of the study. The Principal Investigator will read the age-appropriate Participant Information leaflet with children aged 9-12 years of age. Adolescents aged 13-16 years old will be asked to read the age-appropriate Participant Information Leaflet independently. In both cases the child/adolescent will be encouraged to have his/her parent present while he/she is reading the leaflet, as recommended in the HSE National Consent Policy (2017). Each potential child/adolescent participant will be offered an opportunity to ask questions and seek clarification about any aspect of the study he/she may be unclear about prior to consenting/assenting to take part. The right to refuse to participate in the study will be explained. If a child/adolescent who is approached to participate in the study declines to do so, his/her wish will be fully respected. He/she will be reassured that the decision not to take part in the study will not affect their care. All participants will be advised that they can withdraw from the study at any time with no repercussions to either them or their family member who may also be taking part in the study.
- (b) who will give consent;
The Principal Investigator will be responsible for recruiting children and adolescents to participate in this study. It is good practice to involve the parent in the assent process and in the research process itself. The parent's presence during the consent/assent process will provide an opportunity for them to act as an advocate for their child/adolescent and provide him/her with comfort and support. For this reason the parent's presence will be encouraged throughout the consent/assent and research process.
An Assent/Consent Form will be signed by the child/adolescent in the presence of at least one parent and co-signed by one parent, who will be involved in the process from the outset (see Appendix 3 - Participant Information Leaflets and Assent/Consent Forms). In order to obtain informed assent/consent for the child/adolescent to take part in the research, the parent must be present and must co-sign the Informed Assent/Consent Form.
- (c) how consent will be obtained (e.g. will it be verbal, written or visually indicated?)
Written informed assent will be obtained from all children/adolescents who agree to participate in the study. Age-appropriate Consent/Assent Forms have been developed and will be co-signed by at least one of the child's/adolescent's parents.
- (d) When consent will be obtained
It is recognised that giving potential research participants a reasonable period of time to reflect and make a decision about whether they will take part in a study is best practice in order to allow them time to discuss participation with their family. Since participation in this study poses only minimal risk to participants, it is considered that the participants will require no longer than 24 hours to consider if they wish to participate or not. Being an in-patient in the hospital at the time of the study is an inclusion criteria. As a result of early discharges and shorter length of stay in hospital, a decision to participate will need to be made while the child is still an in-patient.



Potential participants will have the opportunity to decline from participating and to withdraw from the study at any time. For these reasons a period of reflection of up to 24 hours is considered appropriate.

(e) The arrangements that have been made to inform those responsible for the care of the research participants of their involvement in research
 Each potential child/adolescent participant must co-sign the Informed Assent/Consent Form with at least one parent having read the age-appropriate Participant Information Leaflet and receiving any clarifications requested.
 The Clinical Nurse Manager or the Nurse in Charge in the clinical area and the nurse caring for the child/adolescent will be made aware that the child/adolescent has agreed to participate in the study and that the interview is in progress.

This study will adhere to the principles outlined in the Department of Children & Youth Affairs (2012) document *Guidance for developing ethical research projects involving children*.

The Principal Investigator has read in detail the HSE publication *Children First: National Guidance for the Protection and Welfare of Children* (2017). I have also attended education and training on the child protection. Before collecting any data I will complete the Garda Vetting process, familiarise myself with the hospital statement on child safeguarding and be aware of who the Child Protection Co-ordinator is. Should a child/adolescent disclose an incident of a child protection nature during the course of the interview or if I become aware that a child/adolescent may be at risk of harm, I will, as is my duty to protect the child/adolescent participant, discuss with him/her, and his/her parent if appropriate, in a sensitive manner, my obligation to divulge this information to the appropriate authority in the hospital. Having done so I will discuss the incident promptly with the Child Protection Co-ordinator and complete any written reports as required and within the required time frame. Information on the possibility of this happening is included in the Participant Information Leaflet for parents.

3.5 Will participants include women of childbearing potential?

YES	NO	IF NO, PLEASE EXPLAIN WHY NOTE: This information is required regardless of whether there are potential implications for the well-being of participants
Possibly		Parents who are women of child-bearing potential may be included as participants in this study. Voluntary informed consent to take part in the study will be sought and the mother will be advised that she can withdraw from the study at any time with no repercussions to either herself or her family member. Data collection is by means of interview. Hence there is minimal risk only to the participant, or to the unborn baby.

3.6 If women of childbearing potential are to be involved, do the study design and the participant information sheet address the 9 essential points listed in the accompanying checklist (Appendix 3)?

YES	NO	N/A	IF NO, PLEASE EXPLAIN WHY NOTE: This information is required regardless of whether there are potential implications for the well-being of participants
Yes			Qualitative data collection is by means of interview. A study drug will not be administered. Contraception advice and pregnancy testing will not be necessary.

3.7 During and after the study, what steps will you take to protect the confidentiality of:

(a) participant identities?
 In line with the Data Protection Act (2018) and best practice, minimal personal data will be collected. Personal data will be coded in such a way that only the Principal Investigator will recognise the data. Dates of birth will not be recorded, instead the child's/adolescent's age will be recorded in years and months. Additionally numbers and letters in code format will be used



to record the participants' names and interview numbers, (eg. Adolescent Interview1 14yrs & 5mths; Parent (of 9yrs & 4mths child) Interview6). Hard copies of all data, including Consent/ Assent Forms, will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24. Only the Principal Investigator will have access to this locked press. Electronic data will be coded and stored in the Principal Investigator's personal profile on a TCD desktop PC which is password protected. Only the Principal Investigator will have access to this profile. Online cloud data storage platforms will not be used at any stage during this research study.

(b) data collected and patient/client records?

Interviews will be audio recorded, recordings will be stored securely in the same manner as the personal data until they have been transcribed in full by the Principal Investigator and the content of the transcriptions agreed by the individual participant. For this reason the personal email address of each parent participant will be collected so that the draft interview transcription can be emailed to the participant for confirmation of content. Interview recordings will be retained in a secure press in the Principal Investigator's office until the completion of the PhD. At that stage they will be shredded and disposed of in a confidential waste disposal unit at the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24.

The thesis and all reports/papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full. Personal data will be retained until completion of the PhD, at that point it will be shredded and disposed of in confidential waste unit.

(c) hardcopy records?

Hard copies of Informed Consent/Assent Forms will be collected. These forms will contain the child/adolescent participant's full name, age and a contact email address. These will be stored securely in a locked press, in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24 for the duration of the study. Only the Principal Investigator will have access to this locked press.

Interview data will be audio-recorded and subsequently transcribed by the Principal Investigator. Transcriptions will be recorded and stored in electronic format only and destroyed on completion of the PhD. Third party transcription services will not be used.

3.8 Is there any potential confidentiality issue through identification of the study location?

The study location will be a children's university hospital in Dublin. For the purposes of this study it will be described as an urban children's university hospital in Ireland. There are three such hospitals in Dublin. Potential confidentiality through identification of the study location is not considered an issue.

3.9 If your data is to be held on computer, how will it be protected?

All electronic data associated with this study will be coded and stored in the Principal Investigator's personal profile on a TCD desktop PC which is password protected. This PC is located in a locked office in the Institute of Population Health, Russell Building, Tallaght Cross, Dublin 24 for the duration of the study. Only the Principal Investigator will have access to this password protected profile.

3.10 What other person(s) other than the researcher/team as listed will have access to the data collected and what steps will be done to protect confidentiality?

No other persons, other than the researcher and her academic supervisors, as outlined in this application, will have access to the raw interview data.

Only the researcher will have access to the participants' personal data, which will be coded and pseudonymised, so that it will only be identifiable by the Principal Investigator.



The personal data collected for the purposes of this study will not be shared with any third party.

3.11 Accepted best practice recommends secure retention of data for 5 years. If there is any reason to apply for variation from these guidelines, please give details and justify;

Not applicable

3.12 If identifiable data or material will be retained after the study is completed, is it stated on the informed consent form that this will be done and that material will not be used in future unrelated studies without further specific permission being obtained?

YES	NO	IF NO, PLEASE EXPLAIN WHY
		Not applicable

3.13 If the study involves audio taping interviews, you must allow the participant access to the transcript, if they so wish. This must be included in the Informed Consent Form and Information Leaflet (if these forms are being used). Will the participant be given access to a transcript of the audio tape interview?

YES	NO	N/A	IF NO, PLEASE EXPLAIN WHY
Yes			

References

National Consent Advisory Group (2019) *National Consent Policy V.1.3* Dublin: Health Services Executive.

Department of Children and Youth Affairs (2012) *Guidance for developing ethical research projects involving children*. Dublin: Government Publications

Department of Children and Youth Affairs (2017) *Children First: National Guidance for the Protection and Welfare of Children* Dublin: Government Publications.

Data Protection Act (2018) Available at Data Protection Act:

<http://www.irishstatutebook.ie/eli/2018/act/7/enacted/en/print.html> Last Accessed on 2nd September 2019.

4 - RISK, BENEFIT AND HARM

4.1 Are there ethical issues or problems which may arise with the proposed study, and what steps will be taken to address these?

A risk assessment has been carried out and found that the risks to the participants of taking part in this research are minimal and pose no serious risk or harm to them. This risk assessment includes an assessment of the data protection implications of the research (see Appendix 4).

4.2 What is the potential for an adverse outcome (for example, illness, pain, discomfort, distress, inconvenience) for research participants? NOTE: for the protection of both the investigator and the participant, this list must be comprehensive and must also appear in full in the participant information leaflet.

Risks to the participants associated with this study have been identified in a risk assessment and include: inconvenience, loss of personal data, psychological distress and missing out on healthcare treatment. Proposed mitigating measures have been included in the risk assessment (see Appendix 4).

4.3 If there is potential for an adverse outcome, please indicate what steps you will take in the case of an adverse outcome/results for participants.

** Please note that any substantive adverse events must be reported to the Faculty Research Ethics Committee via ethicscommittee@tcd.ie

There is no potential for an adverse outcome for the participant as a result of taking part in this research study.



4.4 Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?

If Yes, give details of procedures in place to deal with these issues

An Interview Guide has been developed to guide the researcher when collecting data for this study (see Appendix 1). The Interview Guide will be used in all of the interviews to promote consistency with questioning and hence the topics discussed during the interviews.

Psychological distress has been identified as a risk, although a low risk, to the participants as a result of taking part in this study and proposed mitigating measures outlined in the following statement which is included in the Risk Assessment:

If a child, adolescent or parent becomes distressed during an interview, they will be cared for in a sensitive manner and supported through their distress. They will be given an opportunity to end the interview early and withdraw from the study. They will be informed that the Clinical Nurse Manager or his/her deputy and the Nurse caring for the child will be informed. Before leaving the child, adolescent or parent, any necessary support will be put in place.

4.5 If participants are to undergo a clinical assessment, what is the nature and extent of this assessment?

Participants will not undergo a clinical assessment.

4.6 If applicable will there be ongoing clinical supervision of the participants by a duly insured clinical practitioner during the study?

Not applicable

4.7 Will the research participant's General Practitioner be informed that they are taking part in the study?

YES	NO	NOT APPLICABLE
	No	

4.8 Will permission be sought from the research participants to disclose information (for example, information about adverse outcomes) to their GP?

YES	NO	NOT APPLICABLE
		Not applicable

4.9 What is the potential for benefit for research participants?

There is no direct benefit identified for the individual participants as a result of participating in this research study. However, future hospitalised children and their parents/guardians will benefit following implementation of the findings from this research.

The new knowledge generated from this research will benefit Children's Health Ireland in terms of the outcomes that consistent and effective implementation of a child- and family-centred approach to care will bring to hospitalised children and their parents/guardians.

4.10 Are there elements of genetic testing involved in the proposed project? If Yes please explain.

No



SECTION 5 - FUNDING & PAYMENT

- 5.1 Outline sources of funding for the study if applicable and how you will manage any possible conflict between the funders of the study and the aims and results of the study if applicable?

This PhD study has been funded by the National Children's Hospital Foundation, based at Tallaght Hospital.

- 5.2 Will payment be made to research participants?

YES	NONE OTHER THAN MINIMAL EXPENSES TO COVER TRAVEL COSTS ETC	NO
		No

- 5.3 If you answered YES to question 5.2, please specify for what purpose the payment will be made and the amount per participant.

SECTION 6 – ETHICAL APPROVAL FROM OTHER COMMITTEES

Ethical approval from the Faculty Research Ethics Committee, if granted, does not supersede any requirements that outside bodies may have that similar applications be made to local ethical approval bodies in advance of the study commencing.

- 6.1 Has ethical approval been sought from any other organisation(s) in which the study will take place?

YES (If you answer YES go to question 6.2)
 NO (If you answer NO go to question 6.3)
 N/A (If N/A please explain why below)

- 6.2 If you have answered YES to question 6.1, where has approval been sought from and has ethical approval been given?

CHI at Crumlin			
YES	Awaiting Reply	NO	IF NO, PLEASE EXPLAIN WHY
Yes			Pending minor amendments (See Appendix 2)

- 6.3 If you have answered NO to question 6.1, is it your intention to seek ethical approval from the organisation(s) in which the study will take place?

YES	NO	IF NO, PLEASE EXPLAIN WHY

SECTION 7 - DECLARATION OF APPROVAL AND SIGNATURES

LEAD INVESTIGATOR

The lead investigator must provide all data below and sign:

- 7.1 If applicable please state briefly what preparatory work you will need to undertake to become competent in your chosen method of data collection (e.g. training in the use of a standardised schedule/test, clinical procedures, or practice in conducting an interview)

Not applicable



LEAD INVESTIGATOR DECLARATION:

- 7.2 I confirm that the information provided in this protocol is correct, that I am not aware of any other ethical issue not addressed within this form and that I understand the obligations to and the rights of participants (particularly concerning their safety and welfare, the obligation to provide information sufficient to give informed consent, the obligation to respect confidentiality and all the obligations as set out in the **Declaration of Helsinki** (appendix attached) governing the conduct of research involving human participants) and/or other relevant guidelines (please refer to your Head of Department/School)
- I undertake to provide an annual report **within twelve months of the date of approval** to the Faculty Research Ethics Group with details of the number of participants who have been recruited, the number who have completed the study and details of any adverse effects. Any serious adverse effects will be reported immediately to the Faculty Research Ethics Group, and, if involving medication this will also be reported to the Irish Medicines Board.

NAME: (BLOCK CAPITALS)	Siobhán O'Connor		
STAFF / STUDENT I.D. No.	17323700		
SCHOOL / DEPARTMENT:	School of Nursing & Midwifery		
COURSE OF STUDY: (if appropriate)	PhD (Nursing)	YEAR	2017
SIGNATURE:	<i>Siobhán O'Connor</i>	DATE:	6/09/2019

PLEASE NOTE THAT IF THERE IS MORE THEN ONE APPLICANT, ALL APPLICANTS MUST SIGN THE APPLICATION FORM.

NAME: (BLOCK CAPITALS)			
STAFF / STUDENT I.D. No.			
SCHOOL / DEPARTMENT:			
COURSE OF STUDY: (if appropriate)		YEAR	
SIGNATURE:		DATE:	

NAME: (BLOCK CAPITALS)			
STAFF / STUDENT I.D. No.			
SCHOOL / DEPARTMENT:			
COURSE OF STUDY: (if appropriate)		YEAR	
SIGNATURE:		DATE:	



RESEARCH SUPERVISOR

Student applicants are required to have their Research Supervisor complete this section.

Name of Supervisor: Prof Imelda Coyne _____
 (BLOCK CAPITALS)

Position: Professor of Children’s Nursing & Co-Director of Trinity Research in Childhood Centre, Trinity College Dublin, Ireland _____

State the educational value of this research:

This research will inform children’s nurses in Ireland and beyond of the needs of children, adolescents and their parents while in hospital. There is a lack of attention to cultural and societal changes in the existing literature. Data for this research will be gathered from children, adolescents and parents from diverse social and cultural backgrounds, adding to our understanding of the degree to which families from multi-cultural backgrounds and with diverse social status wish to be involved in the care of their child in hospital. It will also provide evidence to support the role children/adolescents wish to play in their own care in hospital.

As the student’s supervisor, I accept responsibility for the ethical conduct of this project:

Signature of the Supervisor: Imelda Coyne. _____

Date: 05/09/2019 _____

Office Use Only:

<i>Reference Number</i>	
<i>Faculty Research Ethics Committee Meeting Date</i>	
<i>Approved</i>	
<i>To be resubmitted</i>	
<i>Date</i>	



Appendix 1 – Interview Guide

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Interview guide

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participants
2. Introductions
3. Thanking the participant for agreeing to participate
4. Explain what will happen and how long approximately the interview will take
5. Inform the participants when audiotaping will commence
6. The interviewer will take brief notes during the interview
7. Confirm that consent/assent has been obtained and that the participants are still satisfied to participate.
8. Thank the participant for his/her time
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words what their experiences and expectations of family-centred care has been for them while in hospital.

Interview questions for children and adolescents will include:

- What has been your experience of your Mum's/Dad's involvement in your care while you were in hospital?
- What has been your experience of the nurses' role in your care while you were in hospital?
- What has been your experience of your involvement in your own care while you were in hospital?
- What care do you expect your Mum/Dad to be allowed to do while you are in hospital?
- What care do you expect the nurses to do while you are in hospital?
- What care, if any, do you think you should be allowed to do for yourself while you are in hospital?
- Have you any other comments to add

Interview questions for parents will include:

- What has been your experience of your involvement in your child's care while in hospital?
- What has been your experience of the nurses' role in your child's care while in hospital?
- How involved do you think your child should be allowed to be in his/her own care while in hospital?
- What care, if any, do you expect that you should be allowed to do while your child is in hospital?
- What care do you expect the nurses to do while your child is in hospital?
- Have you any other comments to add

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.



Appendix 2 – Response from Ethics (Medical Research) Committee Office, CHI at Crumlin



Sláinte Leanaí Éireann (SLE) ag Cromghlinn, D12 N512, Éire
Children's Health Ireland (CHI) at Crumlin, D12 N512, Ireland
T + 353 (0) 1 409 6100 | F + 353 (0) 1 455 8873 | www.alehc.ie
Cosc ar úsáid d'áidís leighis | Not for prescription purposes

ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE

Tel: + 353 (0)1 409 6307/6243

Ms Siobhan O'Connor
School of Nursing and Midwifery - TCD
6th Floor,
Institute of Population Health
Russell Building
Tallaght Cross
Dublin 24

23rd August 2019

REC Reference: GEN/747/19

Care for hospitalised children and adolescents – The child's, adolescent's and parent's experience of involvement in care while in hospital – A grounded theory study

Dear Ms O'Connor

The Ethics (Medical Research) Committee meeting that took place on, 16th July 2019, reviewed and approved the above Study provided the following is adhered to:

- That the Investigators provide more information in relation to the process in place if a parent becomes distressed during the participation in the Study and who would engage to manage that event e.g. the Ward Manager.
- That in the 'Title of the Study' make it clear that the study is involved with only one discipline in the care of the patient i.e. 'nurse based'.
- That the Consent/Participant Information Leaflets should state the rights of the participants under GDPR legislation.
- That the Investigators check with Trinity College Dublin that the University is the Data Controller.
- That In Section E2.11 of the Application Form the data is pseudo-anonymised and not anonymised as stated.

The Committee would like to thank you for being present at the meeting and for speaking to this item.

Yours sincerely

Claire Rice
Secretary
Ethics (Medical Research) Committee



Appendix 3 – Participant Information Leaflets and Consent/Assent Forms

Information Leaflet and Assent/Consent Form for Children aged 9-12 years

Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience and expectation of involvement in care while in hospital.

Parent's Name: _____ (Mother / Father)
Child's Name: _____ Age: _____ years: _____ months
Contact email address: _____

Participant Information Leaflet for Children

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. At the moment I am working on a research project in the School of Nursing and Midwifery at Trinity College Dublin.

Background and purpose of the study

We know from research carried out in Ireland and abroad that nurses and others working with children in hospital believe that including the child's parents in the care of the child in hospital is the best way to care for children, adolescents and their families while in hospital. We call this family-centred care. Family-centred care occurs when:

- parents are helped to take part in their child's care in hospital
- parents and children feel they are included in giving care with the nurses and doctors
- the nurses and doctors tell the family what is happening and
- the whole family are included.

My research will look at how children and their parents feel about being involved in their care while in hospital. It will also explain the child's and parents' involvement in their care while in hospital. Information for this research will be collected by interviewing children and adolescents in hospital and their parents. The findings will help nurses understand how best to care for children, adolescents and their parents in hospital.

What happens if I take part in the study?

Taking part in this study is completely of your own free will. Before agreeing to take part I will discuss any queries you may have with you and your Mum or Dad. If you agree to take part in the study, you and your Mum or Dad will need to sign a form, called an Assent/Consent Form. I will also need to ask you some questions about being in hospital. This discussion will happen in the hospital with your Mum or Dad present. I will have to record the discussion, but it should last no longer than 1 hour. Once the discussion is over, I will go back to work and write out what you said. I will ask you and your Mum or Dad to read it to make sure that it is correct and that you actually said what I have written down.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study, I will fully understand your wish. Your decision not to take part will not affect your care in any way.

Can I change my mind during the interview?

Yes, you can pull out of the study if you change your mind at any stage during the interview. Changing your mind and pulling out of the study will not affect your care in any way.

Your personal information

Only your full name, age (in years and months) and your Mum's or Dad's personal email address will be collected. This information will be recorded in a way that only I will be able to work out, we call this coding. I will be the only person who will be allowed to read this information. It will always be kept safely either in a locked press in my office or on a computer in Trinity College. Only I will have a key to the locked press and be able to log onto the computer to read this information. Once the research project is finished all paper copies of your personal information will be cut up and thrown into a waste bin. We call this confidential rubbish and use bins that are especially made for rubbish like this. All electronic information about you will be deleted once the project is finished. At the end of the research I will have to write reports. Some of these reports may be



printed in professional magazines. I will make sure that no personal information about you will be included in any report. I will not give any of your personal information to anybody else.
 I expect that this research will be finished by the end of 2020.

Child Assent

I confirm that I have read and understand the Participant Information Leaflet for Children for the above research study.	
I confirm that I understand what is expected of me by taking part in this research study.	
I confirm that I have been given the opportunity to ask questions and get clarifications	
I confirm that I have had any questions clarified to my satisfaction	
I confirm that I have had enough time to think about whether I want to take part in this research study	
I understand that taking part in this study is voluntary and that I can pull out at any time, if I choose	
I confirm that I am know what personal information will be collected about me for this study	
I confirm that I understand how the personal information collected about me for this study will be used and stored.	
I confirm that I understand how and when the personal information collected about me for this study will be thrown away	
I understand that the findings from this study may be published in professional journals and/or presented at professional conferences, and that my identity will not be recognised in any way in these publications/presentations.	

Signature of Child: _____

Parent Consent

I confirm that I have read the Participant Information Leaflet for Children and I am happy that my son/daughter understands what is involved in taking part in this study.	
I confirm that I understand that my son's/daughter's participation is voluntary and he/she can withdraw from the study at any time, if he/she chooses, without any repercussions.	

Signature of Parent: _____

Signature of Principal Investigator: _____

Date: _____

<p>Data controller: School of Nursing & Midwifery, TCD</p> <p>Data Processor: Ms Siobhán O'Connor Email: conns49@tcd.ie</p> <p>Data Protection Officer Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2. Email: dataprotection@tcd.ie</p> <p>Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge a complaint with the Data Protection Commissioner.</p>
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Information Leaflet and Assent/Consent Form for Adolescents aged 13-16 years

Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience and expectation of involvement in care while in hospital.

Parent's Name: _____ (Mother / Father)
Adolescent's Name: _____ Age: _____ years: _____ months
Contact email address: _____

Participant Information Leaflet for Adolescents

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. I am currently doing research as part of a PhD in the School of Nursing and Midwifery at Trinity College Dublin.

Background and purpose of the study

We know from research carried out in Ireland and abroad that nurses and others working in children's healthcare services believe that family-centred care is the best way to care for children, adolescents and their families while in hospital. Family-centred care occurs when:

- parents are supported to take part in their child's care in hospital
- parents and children are included as partners in the care with the nurses and doctors
- the nurses and doctors keep the family up-to-date of progress as it happens and
- the whole family are included in care.

My research will examine children's/adolescents' experiences and expectations of being involved in their own care while in hospital. It will also look at the involvement their parents have in their child's/ adolescent's care in hospital. Information for this research will be collected by interviewing children and adolescents in hospital and their parents. The findings will develop new knowledge to help nurses understand how best to care for children, adolescents and their parents in hospital.

What happens if I take part in the study?

Taking part in this study is completely of your own free will. Before agreeing to take part I will discuss any queries you may have with you and your Mum or Dad. If you agree to take part in the study you and your Mum or Dad will need to sign an Assent/Consent Form. You will also be interviewed by me. This means that I will ask you some questions which you can answer freely to explain your experiences and expectations of care in hospital. This interview will take place in the hospital and will be recorded. It should last no longer than 1 hour. Once the interview is complete I will write out what you said and ask you to read it to make sure that it is correct and that you actually said what I have written down.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study, I will fully understand your wish. Your decision not to take part will not affect your care in any way.

Can I change my mind during the interview?

Yes, you can pull out of the study if you change your mind at any stage during the interview. Changing your mind and pulling out of the study will not affect your care in any way.

Your personal information

Only your full name, age (in years and months) and personal email address will be collected. If you do not have a personal email address, I will use your Mum's or Dad's. This information will be recorded in a way that only I will be able to work out, we call this coding. I will be the only person who will be allowed to read this information. It will be kept safely at all times either in a locked press in my office or in my profile on a password protected PC in Trinity College. Once the research project is complete all paper copies of your personal information will be cut up and disposed of in a waste bin that is specially supplied for sensitive information. All personal information about you which is saved on the PC will be deleted once the project is completed. At the end of the research I will have to write reports. Some of these reports may be printed in professional magazines. I will make sure that no personal information about you will be included in any report. I will not give any of your personal information to anybody else.



I expect that this research project will be finished by the end of 2020.

Adolescent Assent

I confirm that I have read and understand the Participant Information Leaflet for Adolescents for the above research study.	
I confirm that I understand what is expected of me by taking part in this research study.	
I confirm that I have been given the opportunity to ask questions and get clarifications	
I confirm that I have had any questions clarified to my satisfaction	
I confirm that I have had enough time to think about whether I want to take part in this research study	
I understand that taking part in this study is voluntary and that I can pull out at any time, if I choose	
I confirm that I am know what personal information will be collected about me for this study	
I confirm that I understand how the personal information collected about me for this study will be used and stored.	
I confirm that I understand how and when the personal information collected about me for this study will be thrown away	
I understand that the findings from this study may be published in professional journals and/or presented at professional conferences, and that my identity will not be recognised in any way in these publications/presentations.	

Signature of Adolescent: _____

Parent Consent

I confirm that I have read the Participant Information Leaflet for Adolescents and I am happy that my son/daughter understands what is involved in taking part in this study.	
I confirm that I understand that my son's/daughter's participation is voluntary and he/she can withdraw from the study at any time, if he/she chooses, without any repercussions.	

Signature of Parent: _____

Signature of Principal Investigator: _____

Date: _____

Data controller:

School of Nursing & Midwifery, TCD

Data Processor:

Ms Siobhán O'Connor Email: conns49@tcd.ie

Data Protection Officer

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2. Email: dataprotection@tcd.ie

Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge



Information Leaflet and Consent Form for Parents

Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience and expectation of involvement in care while in

Parent's Name: _____ (Mother / Father)
Parent of: _____ Age: _____ years _____ months
Contact email address: _____

Participant Information Leaflet for Parents

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. I am currently doing research as part of a PhD in the School of Nursing and Midwifery at Trinity College Dublin.

Background and purpose of the study

We know from research carried out in Ireland and elsewhere that nurses and healthcare professionals working in children's healthcare services believe that family-centred care is the preferred way to care for hospitalised children and their families while in hospital. Family-centred care occurs when:

- parents are supported to take part in their child's care in hospital
- parents and children are included as partners with the healthcare team
- the healthcare team keep the family informed of progress as it happens and
- the entire family are included in care as needed.

The aim of my research is to explore children's/adolescents' and parents' experiences and expectations of their roles while in hospital and to develop knowledge explaining the involvement of the child/adolescent and parent in care in hospital. Information for this research will be collected by interviewing hospitalised children, adolescents and their parents.

The findings will provide evidence for nursing care and benefit future hospitalised children/ adolescents and their parents. This research will support the consistent and effective implementation of a child and family-centred approach to care of hospitalised children/adolescents and their parents.

What happens if I take part in the study?

Participation in this study is entirely voluntary. Before agreeing to take part I will clarify any queries you may have. If you agree to take part in the study you will be required to sign a Consent Form and be interviewed by me. I will ask you some questions and allow you to respond freely to explain your experiences and expectations of being in hospital with your child/adolescent. This interview will take place in the hospital and will be audio-recorded. It should last no longer than 1 hour. Once the interview is complete I will transcribe it and ask you to read the transcription to confirm that it is an accurate reflection of what you said during the interview.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study, your wish will be fully respected. Be completely assured that your decision not to take part will not affect the care your child receives in any way.

Can I change my mind during the interview?

Yes, you can withdraw from the study if you change your mind at any stage during the interview. Changing your mind and withdrawing from the study will not affect your child's care in any way.

Your personal information

Only minimal personal data will be collected, to include your full name and personal email address. Your personal information will be coded and only I will have access to it. A paper copy of your consent form will be stored in a locked press in my office for the duration of the project. Only I will have the key to this press. Once the research is completed in full, your consent form and personal information will be shredded and disposed of in confidential waste. The transcription of your interview and your email address will be stored electronically on my computer in TCD, which is password protected. This means that only I will have access to the files. Once the research is completed, I will delete both the transcription of your interview and your personal email address. I will not share any of your personal information with anybody else. Reports will be written up on completion of the research. Some of these reports may be printed in professional journals. I will make sure that no personal information about you or your child will be included in any report.



I expect that this research project will be finished by the end of 2020.

Are there any risks associated with this research?

No, there are no risks associated with taking part in this research.

Further information

I will also be interviewing children and adolescents during this research project. If a child or adolescent reveals to me during an interview that they are at significant risk of harm, I am obliged to discuss this further with appropriate persons in the hospital. Before discussing the issue further I will let the child or adolescent know that I am doing so. This practice is in line with best practice and the HSE publication *Children First: National Guidance for the Protection and Welfare of Children* (2017).

This research will help to inform children’s nurses of the best way to care for children and adolescents in hospital and their parents/guardians. If you require any further information please do not hesitate to discuss it with me directly when you meet me on the ward.

Thank you for supporting this research project.

Parent Consent

I confirm that I have read and understand the Participant Information Leaflet for Parents for the above research study.	
I confirm that I understand what is expected of me by taking part in this research study.	
I confirm that I have been given the opportunity to ask questions and seek clarifications	
I confirm that I have had any questions clarified to my satisfaction	
I confirm that I have had adequate time to consider whether I want to participate in this research study	
I understand that my participation is voluntary and that I can withdraw from the study at any time, if I choose, without any repercussions.	
I confirm that I am aware of what personal data will be collected about me for this study.	
I confirm that I understand how the personal data collected about me for the purposes of this study will be processed and stored.	
I confirm that I understand how and when the personal data collected about me for this study will be disposed of.	
I understand that the findings from this study may be published in professional journals and/or presented at professional conferences, and that I will not be identifiable in any way in these publications/presentations	

Signature of Parent: _____ Date: _____

Signature of Principal Investigator: _____

Data Controller:

School of Nursing & Midwifery, TCD

Data Processor:

Ms Siobhán O’Connor Email: ocnns49@tcd.ie

Data Protection Officer:

Data Protection Officer, Secretary’s Office, Trinity College Dublin, Dublin 2. Email: dataprotection@tcd.ie

Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge a complaint with the Data Protection Commissioner.



Appendix 4 – Risk Assessment
Title of study: Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Risk Assessment

No	Risk	Impact	Proposed mitigating measure	Comment
1	Inconvenience	The time spent receiving & processing the study information & taking part in the interview process may be considered a transient inconvenience to participants.	This risk will be minimised by agreeing a time & place suitable to the child/adolescent & parent to conduct the interview.	
2	Loss of personal data	Loss of personal data may allow identifying data to become inappropriately available to the wrong persons & to be used inappropriately.	All measures will be taken to mitigate against this risk. In line with the Data Protection Act (2018) & best practice, only minimal personal data will be collected. Data to be collected include: first name & surname of the participants, age in years/months of the child & adolescent & a personal email address for each participant. Hard copies of all data, including Consent/Assent Forms, will be stored securely in a locked press, in the Principal Investigator's (PI) office which is also locked. Only the PI will have access to this locked press. Prior to storing, personal data will be coded in such a way that only the PI will recognise the data. Electronic data will be coded & stored in the PI's personal profile on a TCD desktop PC which is password protected. Only the PI will have access to this profile. Interviews will be audio recorded. Recordings will be stored securely in the same manner as the personal data. Third party transcription services will not be used when transcribing recorded interviews, they will be transcribed in full by the PI & the content of the transcriptions agreed by the individual participant by email correspondence. Interview recordings will be retained in a secure press in the PI's office until the successful completion of the PhD. Then paper records will be shredded & disposed of in a confidential waste disposal unit. Electronic data will be deleted & interview recordings will be destroyed & disposed of in a confidential waste unit. The thesis & all reports & papers resulting from this research will be written up in an anonymised fashion, any risk of identification of participants will be removed in full.	Personal data will be retained only until successful completion of the PhD, when it will be shredded & disposed of in confidential waste unit.
3	Psychological distress	It is possible that during the course of an interview either a child, an adolescent or a parent may become distressed when recounting their hospital journey.	If a child, adolescent or parent becomes distressed during an interview, they will be cared for in a sensitive manner & supported through their distress. They will be given an opportunity to end the interview early & withdraw from the study. They will be informed that the appropriate person(s) in the clinical area will be informed. Before leaving the child, adolescent or parent, any necessary support will be put in place.	The appropriate person(s) in the clinical area include the CNM & the nurse caring for the child/ adolescent. If a parent is distressed the CNM & his/her child's nurse will be informed.
4	Missing out on healthcare treatment	It is possible that during the course of an interview the child or adolescent may need healthcare intervention.	It will be made clear to the nurse in charge & to the nurse caring for the child/adolescent before the interview takes place that any healthcare assessment, intervention or treatment must take priority over the research process. If the child/ adolescent is needed for any healthcare intervention, then this will be given priority & the interview will be suspended temporarily or ceased entirely.	



Data Protection Impact Assessment (DPIA)

Template – Research

Please review the TCD *Data Protection Risk Assessment* document before undertaking a DPIA.

It is important to note that a DPIA is required as standard for research studies conducted at St. James's Hospital, Tallaght University Hospital and all clinical sites in which Trinity researchers are active.

Study Name: NURSING CARE FOR HOSPITALISED CHILDREN AND ADOLESCENTS: THE CHILD'S, ADOLESCENT'S AND PARENT'S EXPERIENCE OF INVOLVEMENT IN CARE WHILE IN HOSPITAL: A GROUNDED THEORY STUDY	Date 4th October 2019:
Owner: Ms Siobhán O'Connor	Site: Children's Health Ireland at Crumlin
Email: aconns49@tcd.ie	Phone Number: 087.9977843

Template Version Control

Reference	Date	Author	Comments
2.0	May 2019	TCD DPO	

DPIA Circulation

Name	Date	Reviewed/Consulted
PI Details Siobhán O'Connor	1 st Oct 2019	<i>Reviewed</i>
Co-I/Other Details Prof Imelda Coyne Prof Maria Brenner	4 th Oct 2019	<i>Reviewed</i>
DPO Details	[Insert Date]	<i>Reviewed/Consulted</i>

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2. DPIA - Objective

The purpose of a DPIA is to assess and demonstrate compliance with data protection legislation. The DPIA also provides evidence that the risks to individuals have been considered and sufficient measures have been taken to protect those individuals. The DPIA should assess the activity to be carried out against all the principles of data protection and determine whether the processing of personal data is both necessary and proportionate or whether changes to the process or additional controls are required.

3. Data Protection Checklist for Health Research

If your project relates to health research, then you must comply with the requirements of the [Health Research Regulations 2018](#).

You **must** carry out the following:

Obtain ethical approval for the health research by a research ethics committee.	X
Identify and document the data controller, joint controllers and data processors.	X
Ensure relevant contractual arrangements are in place.	Not applicable
Identify and document funding bodies.	X
Identify third parties with whom data will be shared even if pseudonymised.	X
Ensure all members of the research team have completed data protection training.	X
Carry out a risk assessment of the data protection implications of the research.	X
Carry out a DPIA if the research represents a high risk to individuals or involves the use of genetic data, monitoring of behaviours, large scale processing of sensitive personal data, use of the data for new purposes or the linking of datasets.	Not applicable
Ensure you only use the minimum data necessary to carry out the	X

research.	
Implement controls to ensure the integrity and accuracy of data and determine when the data has been altered, disclosed or erased and by whom.	X
Implement security measures to protect the personal data; e.g. device encryption.	X
Ensure the data is archived, anonymised or destroyed when the research is completed.	X
Ensure that participants are provided with sufficient information about the use of their personal data via Participant Information Leaflets, Consent Forms and the project website.	X
Obtain explicit consent for the processing of personal data for the health research Including the screening of individuals for research purposes.	X

4. DPIA - Instructions

You should complete all of the questions in this template and forward the completed document to the relevant data protection officer to receive feedback on any risks identified and recommendations on the actions or controls needed to address those risks.

Trinity College: dataprotection@tcd.ie

St James's Hospital: research@stjames.ie

Tallaght University Hospital: dpo@tuh.ie

It is the responsibility of the Project Supervisor to ensure the required controls are put in place and to sign off on any risks arising from the processing.

The DPIA should be updated to reflect any material changes to the processing as the project or activity progresses.

5. Study Details

.Nature of Process/ System/ Project

Describe in detail the nature of the process, system or project to be assessed.

Include:

- The **name** of the project.
- The **scope** of the processing.
- The **purpose** for the activity..

- The **frequency** of the processing..
- The **number of individuals** involved and/or affected....
- Details of the **parties and third parties** involved including other data controllers or processors.
- Details of any **systems** to be used.

Nature of Process/ System/ Project

[INSERT DETAILS HERE – MAXIMUM 300 WORDS]

The Project title: Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study.

The aim of this study is to explore children's and parents' experiences and expectations of their roles while in hospital. These aims will be achieved through the following objectives:

- To identify children's experiences and expectations of their parents' and nurses' role in their care in hospital
- To explore children's experiences of engagement and role preferences in their own care while in hospital
- To explore parents' experiences and expectations of their role and the nurses' role in their child's care in hospital
- To explore parents' perspectives of their child's role in their own care while in hospital
- To develop a theory to explain the involvement of the child and parent in care in hospital.

Qualitative data will be collected through semi-structured interviews with pre-teenage children aged 9-12 years and with adolescents aged 13-16 years. Parents of hospitalised children will also be interviewed. The experiences and expectations of hospitalisation for both cohorts of children and their parents will be explored. An Interview Guide has been developed, (see Appendix 1).

Theoretical sampling, the purposeful selection of participants will be used in this study. Theoretical sampling involves simultaneously collecting, analysing and coding data through constant comparison analysis, in order to inform what further data is needed (Coyne, 1997). This process continues until data saturation is reached, when the new raw data being collected replicates what is already identified by earlier participants (Charmaz, 2014). It is expected that 15-20 interviews with children/ adolescents and 15-20 interviews with parents will be required before data saturation occurs.

The Data Controller is TCD. Only the PI will have access to personal data. Recorded interviews will be transcribed in full by the PI. Third party transcription services will not be used.

[Further details in respect of the intended processing](#)

Does the activity involve processing data on a large scale? If so, provide detail.

No

Does the activity involve matching or combining datasets? If so, provide detail.	No
Does the activity involve data concerning vulnerable individuals or children? If so, provide detail.	Yes The first name, surname and age in years and months of children/adolescents participating in the study will be collected. A contact email address will be collected in order to seek agreement that the content of the transcription is reflective of the interview.
Does the activity involve new, or innovative uses of, technological or organisational solutions? If so, provide detail.	No
Could the activity prevent individuals from exercising a right, using a service, or fulfilling a contract? If so, provide detail.	No
Why the use of personal data is necessary for this activity?	Only minimal personal data will be collected in order to allow identification of transcribed interview data so that matching codes across data sets can be applied during data analysis.
Who will benefit from the activity?	There are no direct benefits to individual participants taking part in this study. However the benefits to future hospitalised children/adolescents and their parents/ guardians will be evident following implementation of the findings. The PI will benefit if the research is approved and a PhD is awarded. The new knowledge generated from this research will benefit CHI in terms of the outcomes that consistent and effective implementation of a child and family-centred approach to nursing care will bring to hospitalised children and their families.
Could the use of the personal data for this activity result in any harm to the individual?	No

Any other information in respect of the study which may be relevant

Additional information
[INSERT DETAILS HERE – MAXIMUM 300 WORDS]

6. Personal Data

List the types of personal data that will be **collected, used, accessed or shared** for the purpose of this activity.

Data Collected	Justification	Processing Activity
<i>EXAMPLE: Participant names</i>	<i>Identification, so that we can apply matching codes across longitudinal data sets.</i>	<i>Excel database, situated in 'X' Drive on 'X' desktop computer at 'X' site.</i>
<i>EXAMPLE: Written consent</i>	<i>Legal basis for processing.</i>	<i>Paper forms, stored in locked filing cabinet at 'X' site. Access restricted to [detail] only.</i>
Completed written consent/ assent forms.	Legal basis for participation in health research	Hard copies of consent/assent forms will be stored securely in a locked press, in the PI's office on the 6 th Floor, Institute of Population Health, Russell Building, Tallaght Cross, D24. This office is also locked. Only the PI will have access to this locked press. Hard copies of consent/assent forms will be shredded and disposed of in a confidential waste disposal unit upon successful completion of the PhD.
Participant names	To allow identification of transcribed interview data so that matching codes across data sets can be applied during data analysis.	Prior to storing, personal data will be coded in such a way that only the PI will recognise the data. Electronic data will be coded & stored in the PI's personal profile on the C-Drive on a TCD desktop PC at PI's office on the 6 th Floor, Institute of Population Health, Russell Building, Tallaght Cross, D24. This PC is password protected. Only the PI will have access to this profile. Electronic data will be deleted upon successful completion of the PhD.

Child and adolescent age in years and months	To allow data to be analysed within pre-defined age groups, identifying the experiences and expectations of children and adolescents of their involvement in care while in hospital.	This data will be transcribed from the consent/assent forms to a Microsoft excel document and coded in such a way that only the PI will recognise. This coded data will be stored electronically in the PI's personal profile on the C-Drive on a TCD desktop PC at PI's office on the 6 th Floor, Institute of Population Health, Russell Building, Tallaght Cross, D24. This PC is password protected. Only the PI will have access to this profile. Electronic data will be deleted upon successful completion of the PhD.
Email address of participants	To allow communication with the participant following transcription of the interview data. The participant will be asked to confirm the content of the transcription by email correspondence.	Interviews will be audio recorded. Recordings will be stored securely in the same manner as the hard copies of the consent/assent forms. Third party transcription services will not be used when transcribing recorded interviews, they will be transcribed in full by the PI and the content of the transcriptions agreed by the individual participant by email correspondence. Electronic data will be deleted upon successful completion of the PhD.
Audio recordings of interviews	To allow for transcription and analysis of raw data for research purposes	
Transcriptions of interviews	To allow for analysis of raw data for research purposes	
Code keys	Codes will be developed to pseudo-anonymise the personal data of the participants.	Numbers and letters in code format will be used to record the participants' names and interview numbers, (eg. Adolescent Interview1 14yrs & 5mths; Parent (of 9yrs & 4mths child) Interview6). Only the PI will hold the key to this code.

7. Transparency of Processing

How will you notify participants about the data processing that will be carried out using their personal data? Provide details and **attach copies** of the Consent Form(s) and Participant Information Leaflet(s).

Transparency of processing

[INSERT DETAILS HERE]

8. Data Security – Storage and Sharing

Describe in detail the technical and organisational security measures which will be taken to protect personal data including but not limited to; access controls, data sharing restrictions, encryption, pseudonymisation, anonymisation etc.

Data security – storage and sharing

[INSERT DETAILS HERE]

9. Data Minimisation

Have you ensured that you will only collect the minimum data that you need or that is necessary for the activity? Provide details.

Data minimisation

[INSERT DETAILS HERE]

10. Lawful Basis – Ordinary Personal Data

If processing 'Ordinary' personal data then you must satisfy at least one of the lawful bases as set out under [Article 6 GDPR](#):

Consent	
Performance of a contract	
Legal obligation	
Public interest or exercise of official authority	
Vital interests of data subjects	
Legitimate interests	

If using *Consent*, then describe the consent process and attach supporting documentation.

11. Lawful Basis – Special Category Data (Sensitive Personal Data)

Sensitive personal data is defined as:

- Processing of personal data revealing
 - racial origin
 - ethnic origin
 - political opinions
 - religious beliefs
 - philosophical beliefs
 - trade-union membership
- Processing of genetic data for the purpose of uniquely identifying a natural person
- Processing of biometric data for the purpose of uniquely identifying a natural person
- Data concerning health
- Data concerning a natural person's sex life
- Data concerning a natural person's sexual orientation

If processing sensitive personal data then, in addition to the Article 6 lawful basis, you must also satisfy one of the conditions as set out under [Article 9 GDPR](#):

Explicit Consent	
Employment / DSP rights	

Vital Interests of the data subject or another person	
Carried out (internally) by a not-for-profit organisation	
Information that has been already made public by data subject	
Necessary for the establishment, exercise or defence of legal claims	
Necessary for substantial public interest	
Necessary for the provision of medical care/ administration	
Necessary for reasons of public interest in the area of public health	
Archiving purposes in the public interest/ Scientific or Historical Research purposes/ Statistical purposes	

If using *Explicit Consent*, then describe the consent process and attach supporting documentation.

12. Health Research Regulations - Explicit Consent required for Health Research

In addition to satisfying Articles 6 & 9 GDPR requirements you must also obtain explicit consent for processing personal data for health research purposes. This mandatory requirement is set out under Regulation 3(1)(e) of the [2018 Health Research Regulations](#).

Describe how you will ensure that explicit consent is obtained for processing personal data for health research purposes. **Attach supporting documents**, including Consent Forms and Participant Information Leaflets.

If you intend to seek a Public Interest Waiver from the Health Research Consent Declaration Committee (HRCDC) please review the *Pre-submission Checklist* which is available to download from the HRCDC [website](#) before proceeding further. If you require further assistance please contact the TCD Data Protection Unit at dataprotection@tcd.ie or St James's DPO at research@stjames.ie.

Heath Research Regulations, Consent, Participant Information Leaflets
[INSERT DETAILS HERE]

13. High-Risk Processing

Does the research involve any of the following:

- evaluating or predicting outcomes in individuals;
- decision making by automated means e.g. using algorithms;
- monitoring the behaviours of individuals;

- the surveillance of individuals, use of location or the use of biometric technology such as facial recognition.

If so, provide details and describe the impact to the individuals.

High risk processing
[INSERT DETAILS HERE]

14. Internal Data Sharing

Will the data be shared internally? i.e. with departments or business units within the organisation? If so, provide details on the data sharing including information on the necessity for the processing, the format of the data that is to be shared, with whom the data will be shared and confirmation of the security measures in place to protect the data in transit.

Internal data sharing
[INSERT DETAILS HERE]

15. Third Parties

Will the data be shared with third parties including IT service providers, Cloud-based solutions, sub-contractors etc.? If so, provide details including information on the contractual arrangements in place and confirm what due diligence has been carried out.

Third parties
[INSERT DETAILS HERE]

16. International Data Transfers

Will the data be transferred or stored outside the EEA at any point or placed with Cloud providers that store data outside the EEA? Provide details. If you are transferring personal data outside the EEA have you ensured that suitable conditions for transferring the data are in place? Provide details or state if unsure. These include:

- Adequate jurisdiction
- US Privacy Shield

- Standard Contract Clauses
- Binding Corporate Rules
- Authorisation from the Data Protection Commission

International data transfers

[INSERT DETAILS HERE]

17. Data Retention

How long will the data be retained for and why? Provide details.

Data retention

[INSERT DETAILS HERE]

18. Data Subject Rights

What plans are in place for responding to a request from an individual in relation to their data protection rights?

These include:

- right of access;
- right to rectification;
- right to erasure;
- right to object to processing based on legitimate or public interest;
- right to data portability;
- right to object to profiling or making decisions about individuals by automated means.

Data subjects rights

[INSERT DETAILS HERE]

19. Training

What guidance and training will be provided to individuals involved in this project or activity to enable them to understand their data protection responsibilities? Provide details.

Training
[INSERT DETAILS HERE]

20. Processing Risks - Examples

See Table below. Describe the source of risk and nature of potential impact on individuals. Include associated Compliance and Corporate risks as necessary.

Examples of privacy risks that might be applicable:

Risks to individuals

- Hacking of computers where project data is stored.
- The context in which information is used or disclosed can change over time, leading to it being used for different purposes without people's knowledge.
- New surveillance methods may be an unjustified intrusion on their privacy.
- Measures taken against individuals as a result of collecting information about them might be seen as intrusive.
- The sharing and merging of datasets can allow organisations to collect a much wider set of information than individuals might expect.
- Identifiers might be collected and linked which prevent people from using a service anonymously.
- Vulnerable people may be particularly concerned about the risks of identification or the disclosure of information.
- Collecting information and linking identifiers might mean that an organisation is no longer using information which is safely anonymised.
- Information which is collected and stored unnecessarily, or is not properly managed so that duplicate records are created, presents a greater security risk.
- If a retention period is not established information might be used for longer than necessary.

Compliance risks

- Non-compliance with the common law duty of confidentiality
- Non-compliance with the Data Protection Acts 2018/ General Data Protection Regulation (GDPR), Privacy and Electronic Communications Regulations (PECR)/ e-Privacy Regulation.

Associated organisation/corporate risks

- Non-compliance with the data protection or other legislation can lead to sanctions, fines and reputational damage.
- Problems which are only identified after the project has launched are more likely to require expensive fixes.
- The use of biometric information or potentially intrusive tracking technologies may cause increased concern and cause people to avoid engaging with the organisation.
- Public distrust about how information is used can damage an organisation's reputation and lead to loss of business.
- Data losses which damage individuals could lead to claims for compensation.

Different projects carry different risks and these should be considered. The above examples are a guide, not an exhaustive list.

21. Processing Risks - Table

Describe the source of risk and nature of potential impact on individuals. Include associated Compliance and Corporate risks as necessary.

Risk detail	Risk rating (High, medium, low)	Solutions/Mitigating Actions	Effect	Outcome	Measure approved
<i>Hacking into computers where project data is stored.</i>	<i>Low</i>	<i>All computers storing data are password protected. The external hard drive and remotely accessible computer are also encrypted and locked in an office (on Trinity's campus). Access is restricted to designated staff only.</i>	<i>Reduced</i>	<i>Low</i>	<i>Yes/No</i>

22. Disclaimer

This material contained in this guidance contains general information and guidance only. Please note that this guidance does not constitute legal advice and is provided for general purposes only. Neither is it intended to provide a comprehensive or detailed statement of the law.

No liability whatsoever is accepted by Trinity College Dublin, the University of Dublin for any action taken in reliance on the information contained in this guidance. You should not act or refrain from acting, on the basis of any information provided in this guidance but rather you should always seek specific legal or other professional advice. Any and all information is subject to change without notice.



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Siobhán O'Connor
School of Nursing & Midwifery
Trinity College Dublin
Institute Of Population Health,
Russell Centre, Tallaght Cross West
Tallaght,
Dublin 24 DH74

25th November 2019

Ref: 191010

Title of Study: Nursing care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Dear Siobhán,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in October 2019. We are pleased to inform you that the above project has ethical approval.

We would advise you to seek review and comments on your DPIA, PIL and Consent forms from the DPO prior to study commencement. The revised PIL/Consent should be logged back with this ethics committee, not for review just for noting and filing.

Yours sincerely,

Prof. Jacintha O'Sullivan
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Tionscnamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Appendix 15 Participant Information Leaflets

Care for hospitalised children and adolescents: a research study examining the hospitalised child's, adolescent's and parent's experience of involvement in care while in hospital.

Participant Information Leaflet for children

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. At the moment I am working on a research project in the School of Nursing and Midwifery at Trinity College Dublin. The research is looking at the how children and their parents feel about being involved in their care while in hospital.

Reason for the study

We already know from research carried out in Ireland and abroad that nurses and others working with children in hospital believe that including the child's parents in the care of the child in hospital is the best way to care for children and adolescents in hospital and their families. We call this family-centred care. Family-centred care occurs when:

- parents are helped to take part in their child's care in hospital
- parents and children feel they are included in giving care with the nurses and doctors
- the nurses and doctors tell the family what is happening and
- the whole family are included.

This research will look at how children and their parent feel about being involved in their care while in hospital. It will also explain the child's and parent's involvement in care while in hospital. Information for this research will be collected by interviewing children in hospital and their parents.

The findings from this research will help to tell nurses how best to care for children and their parents in hospital. It will also help future children in hospital and their parents.

What happens if I take part in the study?

Taking part in this study is completely of your own free will. Before agreeing to take part I will discuss any queries you may have with you and your Mum or Dad. If you agree to take part in the study, you and your Mum or Dad will need to sign a form, called a Consent Form I will also need to ask you some questions about being in hospital and listen to what you have to say. I hope that you will have lots to say about being in hospital. This discussion will happen in the hospital with your Mum or Dad present. I will have to record the discussion, but it should last no longer than 1 hour. Once the discussion is over, I will go back to work and write out what you said. I will ask you and your Mum or Dad to read it to make sure that it is correct and that you actually said what I have written down.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study, I will fully understand your wish. Your decision not to take part will not affect your care in any way.

Can I change my mind during the interview?

Yes, you can pull out of the study if you change your mind at any stage during the interview. Changing your mind and pulling out of the study will not affect your care in any way.

Your personal information

Only your full name, age (in years and months) and Mum or Dad's personal email address will be collected. This information will be recorded in a way that only I will be able to work out, we call this coding. I will be the only person who will be allowed to read this information. It will be kept safely at all times either in a locked press in my office or on a PC in Trinity College. Only I will have a key to the locked press and be able to log onto the computer to read this information. All paper copies of your personal information will be cut up and thrown into a waste bin once the research project is finished. We call this confidential rubbish and use bins that are especially made for rubbish like this. All electronic information about you will be deleted once the project is finished. At the end of the research I will have to write reports about what I found. Some of these reports may be printed in a professional magazine. I will make sure that no personal information about you will be included in any report. I will not give any of your personal information to anybody else. I expect that this research will be finished by the end of 2020.

Are there any risks associated with this research?

No, there are not risks associated with taking part in this research.

Further information

This research will help to inform children's nurses of the best way to care for children and adolescents in hospital and their parents/guardians. If you require any further information please do not hesitate to discuss it with me directly when you meet me on the ward.

Thank you for supporting this research project.

Data controller:

Ms Siobhán O'Connor

PhD student, School of Nursing & Midwifery, TCD

E-mail: oconns49@tcd.ie

Data Protection Officer

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland

Email: dataprotection@tcd.ie

Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge a complaint with the Data Protection Commissioner.

Care for hospitalised children and adolescents: a research study examining the hospitalised child's, adolescent's and parent's experience of involvement in care while in hospital.

Participant Information Leaflet for Adolescents

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. I am currently doing a piece of research as part of a PhD in the School of Nursing and Midwifery at Trinity College Dublin. The research is looking at the experiences and expectations of children/adolescents and their parents being involved in care while in hospital.

Background and purpose of the study

We already know from research carried out in Ireland and abroad that nurses and others working in children's healthcare services believe that family-centred care is the best way to care for children, adolescents and their families in hospital. Family-centred care occurs when:

- parents are supported to take part in their child's care in hospital
- parents and children are included as partners in the care with the nurses and doctors
- the nurses and doctors keep the family up-to-date of progress as it happens and
- the whole family are included in care.

This research will examine children's/adolescents' and parents' experiences and expectations of how they should be cared for while in hospital. It will also explain the child's/adolescent's and parent's involvement in care in hospital. Information for this research will be collected by interviewing children and adolescents in hospital and their parents.

The findings from this research will help to tell nurses how best to care for children, adolescents and their parents in hospital. It will also help future hospitalised children/adolescents and their parents.

What happens if I take part in the study?

Taking part in this study is completely of your own free will. Before agreeing to take part I will discuss any queries you may have with you and your Mum or Dad. If you agree to take part in the study you and your Mum or Dad will need to sign a Consent Form. You will also need to be interviewed by me. This means that I will ask you some questions and allow you to answer freely to explain your experiences and expectations of being in hospital. This interview will be recorded and will take place in the hospital. It should last no longer than 1 hour. Once the interview is complete I will write out what you said and ask you to read it to make sure that it is correct and that you actually said what I have written down.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study, I will fully understand your wish. Your decision not to take part will not affect your care in any way.

Can I change my mind during the interview?

Yes, you can pull out of the study if you change your mind at any stage during the interview. Changing your mind and pulling out of the study will not affect your care in any way.

Your personal information

Only your full name, age (in years and months) and personal email address will be collected. If you do not have a personal email address, I will use your Mum's or Dad's. This information will be recorded in a way that only I will be able to work out, we call this coding. I will be the only person who will be allowed to read this information. It will be kept safely at all times either in a locked press in my office or in my profile on a password protected PC in Trinity College. All paper copies of your personal information will be cut up and disposed of in a waste bin that is specially supplied for sensitive information once the research project is complete. All electronic information about you will be deleted once the project is completed. At the end of the research I will have to write a report about what I found. I will make sure that no personal information about you will be included in any report. I will not give any of your personal information to anybody else. I expect that this research project will be finished by the end of 2020.

Are there any risks associated with this research?

No, there are not risks associated with taking part in this research.

Further information

This research will help to inform children's nurses of the best way to care for children and adolescents in hospital and their parents/guardians. If you require any further information please do not hesitate to discuss it with me directly when you meet me on the ward.

Thank you for supporting this research project.

Data controller:

Ms Siobhán O'Connor

PhD student, School of Nursing & Midwifery, TCD

E-mail: aconns49@tcd.ie

Data Protection Officer

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland

Email: dataprotection@tcd.ie

Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge a complaint with the Data Protection Commissioner.

Care for hospitalised children and adolescents: a research study examining the hospitalised child's, adolescent's and parent's experience of involvement in care while in hospital.

Participant Information Leaflet for Parents

Introduction

My name is Siobhán O'Connor. I am a children's nurse normally based at Children's Health Ireland at Tallaght Hospital. I am currently doing a piece of research as part of a PhD in the School of Nursing and Midwifery at Trinity College Dublin. The research focuses on the experiences and expectations of involvement in care of hospitalised children/adolescents and their parents while in hospital.

Background and purpose of the study

We know from research carried out in Ireland and elsewhere that nurses and healthcare professionals working in children's services believe that family-centred care is the preferred way to care for hospitalised children and their families. Family-centred care occurs when:

- parents are supported to take part in their child's care in hospital
- parents and children are included as partners with the healthcare team
- the healthcare team keep the family informed of progress as it is happening and
- the entire family are included in care as needed.

The aim of this research is to explore children's/adolescents' and parents' experiences and expectations of their roles while in hospital and to develop knowledge explaining the involvement of the child/adolescent and parent in care in hospital. Information for this research will be collected by interviewing hospitalised children, adolescents and their parents.

The findings from this research project will provide evidence for nursing care and benefit future hospitalised children/adolescents and their parents. This research will support the consistent and effective implementation of a child- and family-centred approach to care of hospitalised children/ adolescents and their parents.

What happens if I take part in the study?

Participation in this study is entirely voluntary. Before agreeing to take part I will discuss any queries you may have. If you agree to take part in the study you will be required to sign a Consent Form and be interviewed by the researcher. I will ask you some questions and allow you to respond freely to explain your experiences and expectations of being in hospital. This interview will be audio-recorded and will take place in the hospital and should last no longer than 1 hour. Once the interview is complete I will transcribe it and ask you to read it to confirm that it is an accurate reflection of what you said at the interview.

What will happen if I decide not to take part in the study?

If you decide not to take part in the study your wish will be fully respected. Be completely assured that your decision not to take part will not affect the care your child receives in any way.

Can I change my mind during the interview?

Yes, you can withdraw from the study at any time if you change your mind during the interview.

How will my personal information be protected?

Only minimal personal data will be collected, to include your full name and personal email address. Your personal information will be coded and only the researcher will have access to it. A paper copy of your consent form will be stored in a locked press in my office for the duration of the project. Only I will have the key to this press. Once the research is completed in full, your consent form and personal information will be shredded and disposed of in confidential waste. The transcription of your interview and your email address will be stored electronically on my computer in Trinity College Dublin, which is password protected. This means that only I will have access to the files. Once the research is complete in full, I will delete both the transcription of your interview and your personal email address. The personal information of all those who take part in this research will be anonymised in any reports produced. I will not share any of your personal information with anybody else. Expected completion date for this research project is end of 2020.

Are there any risks associated with this research?

No, there are not risks associated with taking part in this research.

Further information

I will also be interviewing children and adolescents during this research project. If a child or adolescent reveals to me during an interview that they are at significant risk of harm, I am obliged to discuss this further with appropriate persons in the hospital. Before discussing the issue further I will let the child or adolescent know that I am doing so. This practice is in line with best practice and the HSE publication *Children First: National Guidance for the Protection and Welfare of Children* (2017).

This research will help to inform children's nurses of the best way to care for children and adolescents in hospital and their parents/guardians. If you require any further information please do not hesitate to discuss it with me directly when you meet me on the ward.

Thank you for supporting this research project.

Data controller:

Ms Siobhán O'Connor

PhD student, School of Nursing & Midwifery, TCD

E-mail: aconns49@tcd.ie

Data Protection Officer

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland

Email: dataprotection@tcd.ie

Under data protection legislation you have the right to request access to your personal data and a copy of it. You have the right to have any inaccurate information corrected or deleted. You have the right to lodge a complaint with

Appendix 16 Assent / Consent Forms

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a research study Assent Form for Child aged 9-12 years

Parent Name: _____ (Mother / Father)
Child's Name: _____ Age: _____ years _____ months
Contact email address: _____

Consent/Assent Form

I confirm that I have read and understand the Information Leaflet for Children for the above research study with my parent.

I confirm that I understand what is expected of me by taking part in this research study.

I confirm that I have been allowed to ask questions.

I confirm that I have had any questions answered to my satisfaction.

I confirm that I have had enough time to think about whether I want to take part in this research study.

I understand that taking part in this research study is my own choice and that I can pull out at any time, if I choose.

I confirm that I know what personal information will be collected about me for this study.

I confirm that I understand how the personal information collected about me for this study will be used and stored.

I confirm that I understand how and when the personal information collected about me for this study will be thrown away.

I understand that the findings from this study may be published in professional magazines and/or presented at professional meetings, and that I will not be able to be recognised in any way in these publications/presentations.

Signature of Child: _____

I confirm that I have read the Participant Information Leaflet for Children with my son/daughter and I am happy that my he/she understands what is involved in taking part in this research study.

I confirm that I understand my son's/daughter's participation is voluntary and that he/she can withdraw from the study at any time, if he/she chooses, without any repercussions.

Signature of Parent: _____

Signature of Principal Investigator: _____

Date: _____

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a research study
Assent Form for Adolescent aged 13-16 years

Parent's Name: _____ (Mother / Father)
Adolescent's Name: _____ Age: ____ years: ____ months
Contact email address: _____

Consent/Assent Form

I confirm that I have read and understand the Participant Information Leaflet for Adolescents for the above research study.

I confirm that I understand what is expected of me by taking part in this research study.

I confirm that I have been given the opportunity to ask questions and get clarifications.

I confirm that I have had any questions clarified to my satisfaction.

I confirm that I have had enough time to think about whether I want to take part in this research study.

I understand that taking part in this study is voluntary and that I can pull out at any time, if I choose.

I confirm that I am know what personal information will be collected about me for this study.

I confirm that I understand how the personal information collected about me for this Study will be used and stored.

I confirm that I understand how and when the personal information collected about me for this study will be thrown away.

I understand that the findings from this study may be published in professional journals and/or presented at professional conferences, and that my identity will not be recognised in any way in these publications/presentations.

Signature of Adolescent: _____

I confirm that I have read the Participant Information Leaflet for Adolescents and I am happy that my son/daughter understands what is involved in taking part in this research study.

I confirm that I understand that my son's/daughter's participation is voluntary and he/she can withdraw from the study at any time, if he/she chooses, without any repercussions.

Signature of Parent: _____

Signature of Principal Investigator: _____

Date: _____

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a research study

Parent's Name: _____ (Mother / Father)
Parent of: _____ Age: _____ years _____ months
Contact email address: _____

Consent Form

I confirm that I have read and understand the Participant Information Leaflet for Parents for the above research study.

I confirm that I understand what is expected of me by participating in this research study.

I confirm that I have been given the opportunity to ask questions and seek clarifications.

I confirm that I have had any questions clarified to my satisfaction.

I confirm that I have had adequate time to consider whether I want to participate in this research study.

I understand that my participation is voluntary and that I can withdraw from the study at any time, if I choose, without any repercussions.

I confirm that I am aware of what personal data that will be collected about me for this study.

I confirm that I understand how the personal data collected about me for the purposes of this study will be processed and stored.

I confirm that I understand how and when the personal data collected about me for the purposes of this study will be disposed of.

I understand that the findings from this study may be published in academic journals and/or presented at professional conferences, and that I will not be identifiable in any way in these publications/presentations.

Signature of Parent: _____

Signature of Principal Investigator: _____

Date: _____

Appendix 17 Interview Guide (Version 1)

Title of study: Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Interview guide

1. Locate a quiet suitable place and time to conduct the interview. This space and time should be suitable for the participants
2. Introductions, to allow the participants, especially the younger ones, to relax and establish a rapport with the researcher before the interview proper begins. This may involve playing games or talking about the participant's interests and hobbies to promote the establishment of a rapport and develop the conversation. This practice has been shown to lessen participants' anxieties, and promote more detailed discussion (Coyne *et al*, 2009).
3. Thank the participants for agreeing to participate and for his/her time
4. Explain what will happen and how long approximately the interview will take
5. Inform the participants when audiotaping will commence
6. Explain that the interviewer will take brief notes during the interview
7. Confirm that consent/assent has been obtained and that the participants are still satisfied to participate.
8. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words what their experiences and expectations of their involvement in care has been for them while in hospital.
9. It is important also to inform the participants that there is no right or wrong answers, that this is not a test.

Interview questions for children and adolescents will include:

- What has been your experience of your Mum's/Dad's involvement in your care while you were in hospital?
- What has been your experience of the nurses' role in your care while you were in hospital?
- What has been your experience of your involvement in your own care while you were in hospital?
- What care do you expect your Mum/Dad to be allowed to do while you are in hospital?
- What care do you expect the nurses to do while you are in hospital?
- What care, if any, do you think you should be allowed to do for yourself while you are in hospital?
- Have you any other comments to add

Interview questions for parents will include:

- What has been your experience of your involvement in your child's care while in hospital?
- What has been your experience of the nurses' role in your child's care while in hospital?
- How involved do you think your child should be allowed to be in his/her own care while in hospital?
- What care, if any, do you expect that you should be allowed to do while your child is in hospital?
- What care do you expect the nurses to do while your child is in hospital?
- Have you any other comments to add

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.
- In the event of a child, adolescent or parent becoming unwell or distressed during an interview, the interview will be ceased and the participant cared for appropriately. The CNM of the clinical area will be informed.
- The researcher will always adhere to infection prevention and control measures as they are applied within the clinical area. Permission from the CNM will always be sought prior to approaching a child or parent.

This interview guide will be piloted in the first three child/adolescent interviews and the first three parent interviews. The data from these pilot interviews will be analysed and used in the research. Following the first three interviews of both cohorts the interview guide will be reviewed and amended if necessary.

Reference

Coyne, I., Hayes, E. and Gallagher, P. (2009) Research with hospitalized children: Ethical, methodological and organizational challenges. *Childhood* **16**(3): 413-429.

Appendix 18 Revised Interview guides

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Child Interview guide (Version 2 – April 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the child separate from the parent. There is evidence that the child may be less participatory when a parent is present, allowing the parent to do the talking for him/her (Gardner and Randall, 2012). He/she may look to the parent for approval of their response.
3. Confirm that full and voluntary consent/assent has been obtained and that the child is still satisfied to participate.
4. Thank the child for agreeing to participate.
5. Introductions, begin with warm-up questions to put the child at ease. (siblings/favourite movie/ sports interests/hobbies/music/pets/ share something about myself with the participant eg. my daughter, my dog or my hobbies)
6. Explain what will happen and how long approximately the interview will take
7. Inform the child when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for children will include:

- a) Can we begin by you telling me a little bit about what being in hospital has been like for you?
 - Have your parents been allowed to stay with you whenever they wanted to?
 - What kind of things are there in the hospital that make it easier for your Mum/Dad to stay beside you?
 - Is there anything else that you can think of which would make it easier for your Mum/ Dad when staying with you in hospital?
 - What has your Mum/Dad been allowed to do for you while you are here?
 - Would you say they have been helped & encouraged to do things for you in hospital?
 - In what way?
- b) What kind of things have the nurses being doing for you while you are in hospital?
 - What do you mean by that?
 - Can you explain what that was like a bit more?
 - How did that make you feel?
 - Is there anything the nurses have been doing that you would prefer your Mum/Dad to do?
 - Is there anything your Mum/Dad have done that you would prefer the nurses to do?
- c) What have you been allowed to do for yourself while you are in hospital?
 - How much have you been allowed to take part in looking after yourself in hospital?
 - How did that feel for you?

- Can you describe for me what you were able to do or to say that was important to you in looking after yourself while in hospital?
 - Was there anything you were not allowed/able to do or say that you would have wanted to do or say?
- d) What would you like your Mum/Dad to be allowed to do for you while you are in hospital?
- Is there anything they were not allowed to do (that the nurses did instead) and that you would have preferred your Mum/Dad to do for you?
 - How did that make you feel?
- e) What kind of things would you like the nurses to do for you while you are in hospital?
- Can you describe things that the nurses did that really helped you to look after yourself in hospital?
 - Was there anything the nurses did that made it difficult for you to care for yourself in the way you wanted to?
- f) What do you think you should be allowed to do for yourself while you are in hospital?
- How would you compare the way you look after yourself at home with how you are allowed to look after yourself in hospital?
- g) Is there something else you would like to add about being in hospital?
- Is there anything else that the nurses could have done to make it easier for you to take care of yourself in hospital?
 - Is there anything else that could be in place to make it easier for you Mum/Dad to stay with you in hospital?

Thank the child for his/her time, reassure the child that his/her parent will return as planned, if he/she has not already returned. Ensure the adolescent is comfortable and contented before leaving his/her bedside.

The following is a list of core principles that will be adhered to throughout each interview:

- Information between participants will never be shared.
- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the assent/consent process.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Adolescent Interview guide – Version 2 (April 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the adolescent separate from the parent. There is evidence that the adolescent, especially those in the younger age range, may be less participatory when a parent is present, allowing the parent to do the talking for him/her (Gardner and Randall, 2012). He/she may look to the parent for approval of their response. It is expected that the adolescent may discuss their experiences more freely in the absence of the parent.
3. Confirm that full and voluntary consent/assent has been obtained and that the adolescent is still satisfied to participate.
4. Thank the adolescent for agreeing to participate.
5. Introductions, begin with warm-up questions to put the child at ease. (favourite movie/sports interests/hobbies/music/pets. Share something personal about myself with the participant (eg, my daughter, my pet, my hobbies) to aid in the development of rapport.)
6. Explain what will happen and how long approximately the interview will take
7. Inform the adolescent when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for adolescents will include:

- a) Can we begin by you telling me a little bit about what being in hospital has been like for you?
 - Have your parents been allowed to stay with you freely, whenever they wanted to?
 - What kind of things are there in the hospital that make it easier for your Mum/Dad to stay beside you in hospital?
 - Is there anything else that you can think of which would make it easier for your Mum/ Dad when staying with you in hospital?
 - What has your Mum/Dad been allowed to do for you while you are here?
 - Would you say they have been helped & encouraged to do things for you in hospital?
 - In what way?
- b) What kind of things have the nurses been doing for you while you are in hospital?
 - What do you mean by that?
 - Can you explain what that was like a bit more?
 - Is there anything the nurses have been doing that you would prefer your Mum/Dad to do?
 - Is there anything your Mum/Dad have done that you would prefer the nurses to do?
 - How did that make you feel?
- c) What have you been allowed to do for yourself while you are in hospital?
 - How much have you been allowed to take part in looking after yourself in hospital?

- How did that feel for you?
 - Can you describe what you were able to do or to say that was important to you in looking after yourself while in hospital?
 - Was there anything you were not allowed/able to do or say that you would have wanted to do or say?
- d) What would you like your Mum/Dad to be allowed to do for you while you are in hospital?
- Is there anything they were not allowed to do (that the nurses did instead) and that you would have preferred your Mum/Dad to do for you?
 - How did that make you feel?
- f) What kind of things would you like the nurses to do for you while you are in hospital?
- Can you describe things that the nurses did that really helped you to look after yourself in hospital?
 - Was there anything the nurses did that made it difficult for you to care for yourself in the way you wanted to?
- g) What do you think you should be allowed to do for yourself while you are in hospital?
- How would you compare the way you look after yourself at home with how you are allowed to look after yourself in hospital?
- h) Is there something else you would like to add about being in hospital?
- Is there something else that the nurses could have done to make it easier for you to take care of yourself in hospital?
 - Is there something else that could be in place to make it easier for you Mum/Dad to stay with you in hospital?

Thank the adolescent for his/her time, reassure the adolescent that his/her parent will return as planned, if he/she has not already returned. Ensure the adolescent is comfortable and contented before leaving his/her bedside.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Parent Interview guide – Version 2 (April 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the parent separate from the child/adolescent, in an effort not to prompt or contaminate the child's data with that of the parent, or vice versa. (Gardner and Randall, 2012)
3. Confirm that full and voluntary consent has been obtained and that the parent is still satisfied to participate.
4. Thank the parent for agreeing to participate.
5. Introductions, begin with warm-up questions to put the parent at ease (other children/topical national or international events eg six nations rugby or a recent appearance on the Late Late Show)
6. Explain what will happen and how long approximately the interview will take
7. Inform the parent when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for parents will include:

- a) As a parent you are used to taking care of your child's/adolescent's needs in a certain way, making sure he/she is well looked after at home, yet in hospital parents often say that so much of that changes. Perhaps we can begin by you telling me what it has been like for you while your child is in hospital?
- What has been your experience of your involvement in your child's care while in hospital?
 - How much has your involvement in your child's care been discussed with you?
 - How much have you been allowed/encouraged to do in taking care of your child while in hospital?
 - How much are parents allowed to visit their children?
 - What facilities exist to make your presence and participation possible?
 - How much do you believe the parent should be included in the child's health care & decision-making?
 - What supports are there to help you (& your child) make informed healthcare decisions?
 - Is there anything you were unable/not allowed to do that you would have wanted to do?
 - Can you describe for me what you were able/allowed to do or to say that was important to you in caring for your child in hospital?
 - Is there anything you were unable to do or say that you would have wanted to do/say?
- b) What have the nurses been doing for your child/adolescent while in hospital?
- Can you explain that further?
 - How does that make you feel?
 - Is there anything the nurses have been doing that you would prefer as the Mum/Dad to do?
 - Is there anything that you have been doing as the Mum/Dad that you would prefer the nurses to do?

- c) How involved do you think your child/adolescent should be allowed to be in carrying out his/ her own care while in hospital?
- Can you describe for me what your child was able/allowed to do or to say that was important to him/her in caring for himself/herself in hospital?
 - Was there anything he was not allowed to do or say that he would have wanted to?
 - How much discussion occurred around your child's involvement in care took place?
- d) What care activities, if any, do you expect that you should be allowed to do while your child is in hospital?
- How would you compare the way you are able to look after your child in hospital with how you are used to looking after your child at home?
- e) What care do you expect the nurses to do while your child is in hospital?
- Can you describe things that the nurses did that really helped you to care for your child in hospital in the way you wanted to?
 - Can you describe things that the nurses may have done that made it difficult for you to care for your child in hospital in the way you wanted to?
 - Can you describe what the nurses did that made it easier for you to stay with your child in hospital?
- f) Is there something else you would like to add relevant to the topic?
- Is there something else that the nurses could have done to support you in taking care of your child in hospital?

Thank the parent for his/her time. Ensure the parent is at ease before leaving his/her side.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Child Interview guide – Version 3 (September 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the child separate from the parent. There is evidence that the child may be less participatory when a parent is present, allowing the parent to do the talking for him/her (Gardner and Randall, 2012). He/she may look to the parent for approval of their response.
3. Confirm that full and voluntary consent/assent has been obtained and that the child is still satisfied to participate.
4. Thank the child for agreeing to participate.
5. Introductions, begin with warm-up questions to put the child at ease. (siblings/favourite movie/ sports interests/hobbies/music/pets/ share something about myself with the participant eg. my daughter, my dog or my hobbies)
6. Explain what will happen and how long approximately the interview will take
7. Inform the child when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for children will include:

- a) Can we begin by you telling me a little bit about what it has been like to be in hospital?
 - Has your Mum or Dad been allowed to stay with you whenever she/he wanted to?
 - What kind of things are there in the hospital that make it easier for your Mum or Dad to stay beside you?
 - Is there anything else that you can think of which would make it easier for your Mum or Dad when staying with you in hospital?
 - What arrangements are there for your Mum or Dad to eat while they are in hospital with you?
 - What has your Mum or Dad been allowed to do for you while you are here?
 - Would you say your Mum or Dad has been helped and encouraged to do things for you in hospital?
 - In what way?
- b) What kind of things do you think the nurses should do for you while you are in hospital?
 - What do you mean by that?
 - Can you explain that a little bit more?
 - How did that make you feel?
 - Is there anything the nurses have been doing that you would prefer your Mum/Dad to do?
 - Is there anything your Mum or Dad have done that you would prefer the nurses to do?
- c) What kind of things have you been allowed to do for yourself while you are in hospital?
 - How much have you been allowed to do for yourself in hospital?
 - How did that feel for you?

- Can you describe what you were able to do or say that was important to you in looking after yourself while in hospital?
 - Was there anything you were not allowed/able to do or say that you would have wanted to do or say?
- d) What kind of things do you think your Mum or Dad should do for you while you are in hospital?
- Is there anything they were not allowed to do (that the nurses did instead) and that you would have preferred your Mum/Dad to do for you?
 - How did that make you feel?
- e) What kind of things do you think the nurses should do for you while you are in hospital?
- Can you describe things that the nurses did that really helped you to look after yourself in hospital?
 - Was there anything the nurses did that made it difficult for you to care for yourself in the way you wanted to?
- f) What kind of things do you think you should be allowed to do for yourself while you are in hospital?
- How is looking after yourself at home different to looking after yourself in hospital?
- g) If you had a magic wand and could change just one thing about what it's like to be in hospital, what would you change?
- h) What advice would you give to another child the same age as you who is coming into this hospital next week?
- i) Is there something else you would like to add about being in hospital?
- Is there something else that the nurses could have done to make it easier for you to take care of yourself in hospital?
 - Is there something else that could be in place to make it easier for you Mum or Dad to stay with you in hospital?

Thank the child for his/her time, reassure the child that his/her parent will return as planned, if he/she has not already returned. Ensure the adolescent is comfortable and contented before leaving his/her bedside.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Adolescent Interview guide – Version 3 (September 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the adolescent separate from the parent. There is evidence that the adolescent, especially those in the younger age range, may be less participatory when a parent is present, allowing the parent to do the talking for him/her (Gardner and Randall, 2012). He/she may look to the parent for approval of their response. It is expected that the adolescent may discuss their experiences more freely in the absence of the parent.
3. Confirm that full and voluntary consent/assent has been obtained and that the adolescent is still satisfied to participate.
4. Thank the adolescent for agreeing to participate.
5. Introductions, begin with warm-up questions to put the child at ease. (favourite movie/sports interests/hobbies/music/pets. Share something personal about myself with the participant (eg, my daughter, my pet, my hobbies) to aid in the development of rapport.)
6. Explain what will happen and how long approximately the interview will take
7. Inform the adolescent when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for adolescents will include:

- a) Can we begin by you telling me a little bit about what it has been like to be in hospital?
 - Has your Mum or Dad been allowed to stay with you, whenever she/he wanted to?
 - What kind of things are there in the hospital that make it easier for your Mum or Dad to stay with you?
 - Is there anything else that you can think of that would make it easier for your Mum or Dad when staying with you in hospital?
 - What arrangements are there for you and your Mum or Dad to eat while they are in hospital with you?
 - What has your Mum or Dad been allowed to do for you while you are here?
 - Would you say your Mum or Dad has been helped and encouraged to do things for you in hospital?
 - In what way?
- b) What kind of things do you think the nurses should do for you while you are in hospital?
 - What do you mean by that?
 - Can you explain that a little bit more?
 - How did that make you feel?
 - Is there anything the nurses have been doing that you would prefer your Mum or Dad to do?
 - Is there anything your Mum or Dad have done that you would prefer the nurses to do?
- c) What kind of things have you been allowed to do for yourself while you are in hospital?

- How much have you been allowed to do for yourself in hospital?
 - How did that feel for you?
 - Can you describe what you were able to do or to say that was important to you in looking after yourself while in hospital?
 - Was there anything you were not allowed/able to do or say that you would have wanted to do or say?
- d) What kind of things do you think your Mum or Dad should do for you while you are in hospital?
- Is there anything they were not allowed to do (that the nurses did instead) and that you would have preferred your Mum or Dad to do for you?
 - How did that make you feel?
- e) What kind of things do you think the nurses should do for you while you are in hospital?
- Can you describe things that the nurses did that really helped you to look after yourself in hospital?
 - Was there anything the nurses did that made it difficult for you to care for yourself in the way you wanted to?
- f) What kind of things do you think you should do for yourself while you are in hospital?
- How is looking after yourself at home different to looking after yourself in hospital?
- g) If you had a magic wand and could change just one thing about what it's like to be in hospital, what would you change?
- h) What advice would you give to another adolescent the same age as you who is coming into this hospital next week?
- i) Is there something else you would like to add about being in hospital?
- Is there something else that the nurses could have done to make it easier for you to take care of yourself in hospital?
 - Is there something else that could be in place to make it easier for you Mum or Dad to stay with you in hospital?

Thank the adolescent for his/her time, reassure the adolescent that his/her parent will return as planned, if he/she has not already returned. Ensure the adolescent is comfortable and contented before leaving his/her bedside.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Parent Interview guide – Version 3 (September 2020)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the parent separate from the child/adolescent, in an effort not to prompt or contaminate the child's data with that of the parent, or vice versa. (Gardner and Randall, 2012)
3. Confirm that full and voluntary consent has been obtained and that the parent is still satisfied to participate.
4. Thank the parent for agreeing to participate.
5. Introductions, begin with warm-up questions to put the parent at ease (other children/topical national or international events eg six nations rugby or a recent appearance on the Late Late Show)
6. Explain what will happen and how long approximately the interview will take
7. Inform the parent when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

Interview questions for parents will include:

As a parent you are used to taking care of your child's/adolescent's needs in a certain way, making sure he/she is well looked after at home, yet in hospital parents often say that so much of that changes. Perhaps we can begin by you telling me what it has been like for you while your son/daughter is in hospital?

- What has been your experience of your involvement in your son's/daughter's care while in hospital?
- How much have the nurses discussed (negotiated) with you what you can do and what is best left for the nurses to do for your son/daughter while you are in hospital with your son/daughter?
- How much have you been encouraged to do in taking care of your child while in hospital?
- How much are parents allowed to visit/stay with their children while in hospital?
- What facilities exist to make your presence and participation more do-able?
- How much do you believe the parent should be included in their son's/daughter's health care & decision-making?
- What supports are there to help you (and your son/daughter) make informed healthcare decisions?
- Is there anything you were unable to do that you would have wanted to do?
- Can you describe for me what you were able to do or to say that was important to you in caring for your son/daughter in hospital?
- Is there anything you were unable to do or say that you would have wanted to do or say?

What have the nurses been doing for your son/daughter while in hospital?

- Can you explain that further?
- How does that make you feel?
- Is there anything the nurses have been doing that you would prefer as the Mum/Dad to do?
- Is there anything that you have been doing as the Mum/Dad that you would prefer the nurses to do?

How involved do you think your son/daughter should be in carrying out his/her own care while in hospital?

- Can you describe for me what your son/daughter was able to do or to say that was important to him/her in caring for himself/herself in hospital?
- Was there anything he/she was not able/encouraged to do or say that he/she would have wanted to or say?
- How much discussion with the nurses occurred around your son's/daughter's involvement in their own care took place?

What care activities, if any, do you expect that you should be able/encouraged to do while your son/daughter is in hospital?

- How would you compare the way you are able to look after your son/daughter in hospital with how you are used to looking after him/her at home?

What care do you expect the nurses to do while your son/daughter is in hospital?

- Can you describe things that the nurses did that really helped you to care for your son/daughter in hospital in the way you wanted to?
- Can you describe things that the nurses may have done that made it difficult for you to care for your son/daughter in hospital in the way you wanted to?
- Can you describe what the nurses did that made it easier for you to stay with your son/daughter in hospital?

If you had a magic wand and could change something about staying with your son/daughter in hospital, what one thing would you change about being in hospital with your child?

What advice would you give to another parent coming into this hospital to stay with their son/daughter next week?

Is there something else you would like to add relevant to the topic?

- Is there something else that the nurses could have done to support you in taking care of your child in hospital?

Thank the parent for his/her time. Ensure the parent is at ease before leaving his/her side.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Adolescent/child interview guide – Version 4 (June 2021)

1. Locate a quiet suitable place to conduct the interview. This space should be suitable for the participant.
2. Aim to interview the adolescent separate from the parent. There is evidence that the adolescent, especially those in the younger age range, may be less participatory when a parent is present, allowing the parent to do the talking for him/her (Gardner and Randall, 2012). He/she may look to the parent for approval of their response. It is expected that the adolescent may discuss their experiences more freely in the absence of the parent.
3. Confirm that full and voluntary consent/assent has been obtained and that the adolescent is still satisfied to participate.
4. Thank the adolescent for agreeing to participate.
5. Introductions, begin with warm-up questions to put the child at ease. (favourite movie/sports interests/hobbies/music/pets. Share something personal about myself with the participant (eg, my daughter, my pet, my hobbies) to aid in the development of rapport.)
6. Explain what will happen and how long approximately the interview will take
7. Inform the adolescent when audio recording will commence
8. The interviewer may take brief notes during the interview
9. The interview will be semi-structured, it will be guided by planned open-ended questions. It is important that the interview plan will be flexible to allow the participants to articulate in their own words their experiences & expectations of involvement in care while in hospital.

The following is a list of core principles that will be adhered to throughout each interview:

- Respect for persons - Respect the autonomy, decision-making and dignity of participants.
- Minimising any possible risks (physically or psychologically).
- Confidentiality and anonymity of the participants will be reassured.
- Information between participants will never be shared.
- Procedures are in place to protect the personal data of participants. This has been explained to all participants during the consent/assent process.

I have already interviewed children and adolescents about how they look after themselves in hospital and what their parents do for them while they are in hospital. They have been saying that doing their own personal care, like washing/showering, going to the toilet on their own when they can, is important to them. In this interview I would like to talk more about this.

- 1. Can we begin by you telling me a little bit about what it has been like for you to be in hospital?**
 - Has your Mum or Dad been allowed to stay with you, whenever she/he wanted to?
 - How have your Mum or Dad been involved in planning your care with the nursing staff while you are here?
- 2. Tell me about how you have been involved in planning your own care with the nursing staff?**
 - Did the nurses include you in planning your own care while in hospital?

- What have you been doing for yourself while you have been in hospital?
- How did you feel about that? - doing those things for yourself?
- What kind of things do you think you should be doing for yourself while you are in hospital?
- How involved have you been in decisions/discussions about your own healthcare while you are in hospital?

Some children/adolescents have said that they prefer their parents did NOT do “the medical stuff”, like checking temperature and blood pressure, medications, checking drips and cannulae, cleaning wounds etc. Some have said they prefer the nurses to do these things because it is their job and they know how to do these things.

3. What kind of things would you like your Mum or Dad to do for you while she/he is in hospital with you?

- How does having your Mum or Dad in hospital with you help you?
- How does that make you feel?

4 What kind of things have the nurses been doing for you while you are in hospital?

- What kind of things do you think the nurses should be doing for you while you are in hospital?
- Who do you think should do the “medical stuff” for you while you are in hospital?
- What do you mean by “medical stuff”?
- How do you feel about the nurses
 - Is that about trusting the nurses because they are qualified and know what they are doing?
- What do you think is the nurses’ job?
- Can you explain that a little bit more?

5. If you had a magic wand and could change just one thing about what it’s like to be in hospital, what would you change?

6. What advice would you give to another child the same age as you who is coming into this hospital next week?

7. Is there something else you would like to add about being in hospital?

- Is there something else that the nurses could have done to make it easier for you to take care of yourself in hospital?
- Is there something else that could be in place to make it easier for you Mum or Dad child/to stay with you in hospital?

Thank the adolescent for his/her time, reassure him/her that his/her parent will return shortly, if not already returned. Ensure the adolescent is comfortable & contented before leaving the bedside.

- Procedures are in place to protect the personal data of participants. /assent process.

Care for hospitalised children and adolescents: the child's, adolescent's and parent's experience of involvement in care while in hospital: a grounded theory study

Parent Interview Guide – Version 4 (June 2021)

I have already interviewed parents about their roles are when they are in hospital with their child. They have been telling me that they believe their role is to be a reassuring presence for their child and to help him/her with personal/intimate care. Some of them have said they prefer to leave the medical treatment to “the experts” ie the nurses. In this interview I would like to specifically explore these issues further.

1. Can we begin by you telling me what it has been like for you while your son/daughter is in hospital?

- What has been your experience of your involvement in your child's care in hospital?
- Tell me how you see your role while you are in hospital with your son/daughter?
- What have you been doing for your son/daughter while you have been here?
- How do you think your presence has helped a) your son/daughter, b) you and your family and c) the nursing staff?

Some parents have said that what they do for their child is often “left to chance”, they are left to their own devices. Their involvement is not discussed formally with them and their child.

2. How much have the nurses discussed with you what you can do and what the nurses will do for your son/daughter while he/she is in hospital?

- Tell me about how you and the nurses discussed and agreed your role while your son/daughter is in hospital.
- How did you find out what you can or cannot do?
- How have you been involved in planning your son's/daughter's care with the nurses?
- What has been the most difficult thing about being in hospital with your child?
- What could make your stay in hospital with your son/daughter easier?

3. What have the nurses being doing for your son/daughter while in hospital?

- Is there something the nurses have been doing that you would prefer to do for your child?
- Is there something that you have been doing that you would prefer the nurses to do?

4. How involved do you think your child should be in carrying out his own care in hospital?

- Did the nurses include your child in planning of his/her own care while in hospital?
- How involved has your child been in his/her own healthcare decisions while in hospital?
- How much discussion with the nurses occurred around your son's/daughter's involvement in his/her own care?

5. If you had a magic wand and could change something about staying with your son/daughter in hospital, what one thing would you change about being in hospital with your child?

6. What advice would you give to another parent coming into this hospital to stay with their son/daughter next week?

- 7. Is there something else you would like to add relevant to the topic?

Appendix 19 Memo – Reflections following Round One of data gathering – 2nd February 2020

As I reflect following the first round of interviews while listening to the recordings and reading the transcripts, I can't help wondering about my communication skills and interview style. I have been nursing for more than 30 years and have always considered myself to be a good communicator. After 30 years one would expect that I have honed, even perfected, my communication skills. To my surprise I was nervous and not at all at ease, with either the children/adolescents or the parents I interviewed in Round 1. I failed to acknowledge that I am a novice at research interviews, I expected that my extensive experience would have stood to me. Not that it didn't, it did, but there are other skills/techniques that need to be developed to improve the data gleaned from the interviews.

On reading over the interview transcripts and listening to the recordings again, I am somewhat disappointed with my interviewing style. My line of questioning doesn't appear to be focused, especially my use of probing questions to follow leads. If I want to probe cues and follow leads as they arise during the interview, my line of questioning will need to be much more focused. By developing this skill the data gleaned from the interviews will be enhanced.

In preparing for Round 2 of data gathering I need to prepare a solid Interview Guide for each group of participants with consistent prompts which will guide me as the interview progresses. Version 1 of the Interview Guide was a single guide for all three cohorts: children, adolescents and parents. It was broad and unstructured, I did not want to constrain the research interview with an overly structured Guide. I viewed it as structuring what should be a semi-structured interview. Charmaz (2014) comments that a well-structured Interview Guide is important as a support tool for beginning researchers.

I also need to be mindful of what individual participants bring with them to the interview. Their personal backgrounds and life experiences, their experiences of being sick or of being in hospital, will all have an impact on how they respond. I must always be open to the alternative viewpoints of the participants, all of which are valid and legitimate. I must also be open to surprising and unexpected findings which may arise during data analysis. After all that's the whole purpose of my research - to explore children's and parents' experiences and expectations of their roles in hospital. Asking well thought-out, focused questions and listening attentively to the answers will open up a whole other perspective to me. I have a responsibility to the participants to hear their stories and interpret their experiences accurately, so that the research can contribute to a better understanding of what it is like to be an in-patient in a children's hospital in Dublin or to be the parent staying with that child in hospital.

Appendix 20 Memo – Coding concerns - 24th Feb 2020

“Nurses knowing exactly what they're doing” “Nurses doing the clinical care”

Adolescent: *“Em, I like that the nurses are doing that cos I know they know exactly what they're doing everything like that, ... like measure my temperature, my antibiotics and everything like that and just make sure my oxygen is OK.”*

It appears that this adolescent prefers that the nurses are doing the clinical care because they know what they are doing. This adolescent explains that *“As much as I love that my Mom takes care of me, I like that they [the nurses] are taking care of me too.”*

Do I need to explore further adolescents' desire to have the nurses doing the clinical care and they themselves (or maybe their parent?) doing the intimate personal care? Some questions coming to mind might include:

- .Is there anything the nurses have been doing that you would prefer your Mum/Dad to do?
- .Is there anything your Mum/Dad have done that you would prefer the nurses to do?
- .How much have you been allowed to take part in looking after yourself in hospital?
- .How did that feel for you?
- .Is there anything they were not allowed to do (that the nurses did instead) and that you would have preferred your Mum/Dad to do for you?
- .Was there anything the nurses did that made it difficult for you to care for yourself in the way you wanted to?

These are just preliminary reflections on initial coding of the data so far (first round of data gathering). I will continue to code freely and create as many codes as I can, I don't want to miss anything that could turn out to be important. I can revisit these initial codes again to check if the new data in the next round supports these codes. I will also continue to write memos which will hopefully become more analytic as the analysis progresses. I will also discuss these issues at my next academic supervision meeting.

Appendix 21 Most frequently occurring initial codes for children and adolescents

Initial code	Number of participants who mentioned this	Number of times referred to by participants	Example
Parents staying	20	39	"I think it's really important that they [<i>my parents</i>] are here 'cos it's like emotional support like." (Adolescent interview 4) "It [<i>having my parents here</i>] helps 'cos if you're here on your own it'd be a bit boring." (Child interview 8)
What parents do	18	72	"I just have company" (Adolescent interview 6) "They [<i>my parents</i>] would snuggle me" (Child interview 6)
Doing my own intimate personal care	17	39	"I'd prefer to go to the toilet and do my bath on my own." (Child interview 2) "Using the bathroom definitely myself" (Adolescent interview 11).
Doing for myself	17	52	"They'd [<i>the nurses</i>] just make sure I'm OK when I'm doing it [<i>my own physio</i>], and they'd [<i>the nurses</i>] encourage me." (Adolescent interview 7)
What nurses do	17	77	"Well they [<i>the nurses</i>] are giving me medication" (Child interview 8)
Being allowed to do for myself	15	70	"The bathroom, I really want to be allowed to go to the toilet." (Adolescent interview 1)
Parents helping me	12	23	I don't think I'd be able to do a lot [<i>if my Mum was not here</i>] because normally if I need something, like Mum would ask." (Child interview 7)
Facilities for parents	12	41	"There's the chairs that can turn into beds, so they [<i>my parents</i>] can stay overnight and be comfy." (Child interview 5)
Parents keeping me company	11	20	"I think just to have someone to talk to and to have someone from home here." Adolescent interview 13)
Being in hospital is a good experience	11	22	"Well it was much more calming than you'd think it might be." (Adolescent interview 5)
Making decisions	10	20	"It was me who got to say will I have that [<i>the pre-med</i>] or will I not. And you know it is nice, it is good." (Adolescent interview 4)
Not being allowed to do for myself	10	30	"I'd like to be allowed to walk around to the shops and stuff, 'cos the room is a bit small." (Child interview 4)
Asking questions	10	25	"They [<i>the nurses</i>] always ask if I have any questions." (Adolescent interview 14)

Appendix 22 Codebook of initial codes from parents' data

Codes\\Phase 1 Initial coding\\Initial codes Parents

Name	Description	Files	References
Asking nurses	"I wouldn't feel bad at all about going out to ask a nurse what should I do here." (Parent Interview 14)	4	12
Assuming roles	"I suppose we kind of fall into what we see and what our place is, without having to discuss it with the nurse. It's unsaid ..." (Parent Interview 17)	1	1
Being a companion	"I'm sort of a companion as much as anything else I suppose is my role." (Parent Interview 16)	3	4
Being an advocate for your child	"As parents we have to advocate as strongly as possible for our child" (Parent Interview 23)	2	12
Being at home is difficult	"I found it quite difficult being away, but even though my wife was here." (Parent Interview 14)	2	2
It's easier at home	"When we go home it'll be an awful lot easier. I can hook her up [<i>to her infusion</i>] at 10 at night and she won't have to come off until maybe 12 the following day." (Parent Interview 9)	1	4
Being hands-on	"Just to do a little bit of low impact physio, so that element was hands on." (Parent Interview 22)	3	5
Being her or his Mam	"To basically be her Mam" (Parent Interview 19)	1	1
Being hopeful	"I'd be hopeful [<i>of her daughter gaining more independence</i>] given that how it had gone on to this point, that that would be the case going forward." (Parent Interview 16)	1	1
Being in a small space	"SMW have got the chair beds provided. But with that the rooms are quite small, so you're compromised because you have to allow [space for] the nursing staff to come in and monitor your son during the night." (Parent Interview 13)	3	5
Being in hospital is arduous	"Just be prepared, that it's [<i>being in hospital</i>] arduous." (Parent Interview 17)	1	3
Being in hospital is challenging	"We'll say it's [being in hospital] challenging in different ways." (Parent Interview 23)	1	1
Being in hospital is difficult	It's difficult on the family, really difficult. The long stay is difficult,	1	2

Name	Description	Files	References
Being in hospital is emotional	"Your emotions go in to overdrive right" (Parent Interview 14)	3	3
Being in hospital is exhausting	Tiring, exhausting." (Parent Interview 9)	3	6
Being in hospital is expensive	the canteen is really expensive." (Parent Interview 10)	6	18
Being in hospital is frustrating	"I think a lot of the bureaucracy behind everything can lead to a lot of frustration for parents." (Parent Interview 16)	3	5
Being in hospital is scary	"It's a scary place." (Parent Interview 15)	2	6
Being in hospital is stressful	"I guess it is hard because you're trying to not break down in front of him because some of the procedures that he goes through and some of the treatment that he goes through, it's difficult to watch, it really is ..." (Parent Interview 13)	7	15
Being in hospital is harder than home	"So it hurts every single time she pricks her finger, so the experience in hospital is just worse." (Parent Interview 6)	1	2
Being in the right place	"I just felt we were in competent hands." (Parent interview 17)	2	6
Being more in control	"Now that we've had it [<i>the diabetes</i>] for 6 years with him, I feel that I was able to give more input this time." (Parent Interview 8)	2	3
Being out of their comfort zone	"They're [<i>children in hospital</i>] out of their comfort zone (Parent Interview 14)	1	1
Being professional	"Obviously they had to rule that [Covid-19] out. Em, that was handled really professionally." Parent Interview 10)	1	1
Being pushed over the edge	if you're hungry or you're tired it can push you over the edge. (Parent Interview 16)	1	1
Being treated like an adolescent	"He didn't feel like he was being treated I'd say like a small baby, you know that he was being treated like a bigger boy." (Parent Interview 1)	1	2
Being unsure	"They're [<i>parents</i>] not sure whether to ask or to not ask whether to approach the desk, whether to you know those types of things." (Parent Interview 15)	1	1
Being with child	"You'd sit here hungry quicker than put your child sitting here on her own, 'cos L is not very	11	33

Name	Description	Files	References
	confident being on her own." (Parent Interview 4)		
Blended care	"It was kinda blended as in obviously I still do certain things for L here, but they [<i>the nurses</i>] have done the majority of things." (Parents Interview 10)	2	2
Bonding time	"We've had nice 'together time', just the two of us (Parent Interview 15)	1	3
Caring is stressful	"It [<i>caring for J</i>] has been quite stressful over the last 8 years." (Parent Interview 13).	1	1
Child being anxious	"S has Asperger's so anxiety and worry and "what ifs" the unknown really have a huge impact upon her." (Parent Interview 11)	8	11
Child doing personal care	"He should be promoted independently to to do now his intimate care." (Parent Interview 13)	3	4
Children being through so much	"I just know that he has been through so much but he has been phenomenal through it all." (Parent Interview 13)	3	6
Children doing own personal care	"In terms of her own personal care as well as her [<i>care</i>] plan she needs to be involved in that because it's her body." (Parent interview 23)	4	5
Children eating	"If she wants any food that's my job." (Parent interview 19)	2	2
Continuity of care	"You know it's [<i>my presence here</i>] the continuity of care." (Parent interview 17)	1	1
Doing when I go home	"I'm not going to change dressings, well not now I will when I go home." (Parent interview 17)	1	1
Easier for the child	"I know I have a lot of experience 24/7 with this one patient so I know how to inject her without her even waking up." (Parent Interview 6)	2	2
Facilities for children	"S would be able to walk down and get the food herself, maybe meet other kids and you know that would be nice." (Parent Interview 15)	7	23
Facilities for parents	"Something very simple like food, because at the weekends you are limited to what you can get here." (Parent Interview 4)	20	127
	"I have to go home to have a shower." (Parent Interview 8)		
	"Now there is a toilet available to me, however there isn't wash/shower facilities." (Parent		

Name	Description	Files	References
	Interview 11)		
Falling between the cracks	“Sometimes things fall through the cracks. We were waiting for dermatology so we thought they were coming, but it turns out there was a miscommunication and it didn't happen.” (Parent Interview 16)	1	2
Falling into place	So it [my involvement in care] just fell into place (Parent interview 24)	1	1
Feeding children	“Sometimes she wouldn't feel well when there'd be food around and if you're not on the ball then she'd be hungry later on, and there'd be nothing for her to eat.” (Parent Interview 16)	3	11
Feeling safe	“At a time of huge uncertainty when you don't want to go to hospital, we felt very safe actually ironically, in the place you really don't want to be, it felt the opposite.” (Parent Interview 10)	4	8
Finding out for yourself	“Sometimes you're kind of having to go and find them out yourself.” (Parent Interview 16)	1	1
Getting home	“It's to get out [<i>home</i>] of the hospital as well. That's the main thing.” (Parent Interview 9)	1	1
Giving 100% attention	“When you [<i>the parent</i>] are minding a child in hospital it's 100% attention to the child.” (Parent Interview 14)	1	2
Giving parents choice	“I think parents should really be given the choice of doing it.” (Parent Interview 9)	3	3
Going outside	“He wanted to go outside a couple of times but he was just confined to the ward because they needed him to be careful not be where you could knock off something.” (Parent Interview 13)	2	2
Having to be on the ball	“Sometimes to she wouldn't feel well when there'd be food around and if you're not on the ball then she'd be hungry later on then, and there'd be nothing there for her.” (Parent Interview 16)	1	1
Helping nurses	“I think they [<i>the nurses</i>] are actually happy that there's a parent here and involved, I think it helps their job a lot makes it a lot easier for them.” (Parent Interview 7)	7	16
Hospital being a lonely place	“There's nobody looking after the parents. You phone a friend, yeah it can be a lonely place, it can be a very lonely place, because you've a huge amount of worry” (Parent Interview 14)	1	2

Name	Description	Files	References
Hospital being a positive experience	"From the time we came in our experience has been very good, it's all been a positive experience under the circumstances so far." (Parent Interview 2)	9	21
Hospital being a strange place	"It was strange, it was odd." (Parent interview 22)	1	1
I'm his voice	"I had to be his voice, when he was too sick to talk to the nurses." (Parent interview 24)	1	2
Involving child in care	<p>"When they [<i>children</i>] are sick they're not making rational decisions, so I'd have mixed feelings on how involved they should be. I think it's very much down to child and maybe the appropriate clinician to be able to read that. I don't think a one size fits all." (Parent Interview 1)</p> <p>"Yeah she knows what's going on, she knows what's happening and for that reason that's why she's so content." (Parent Interview 4)</p> <p>"I think if a child is old enough to understand and they're old enough to know what's going on, we're trying to involve J as much as we can, he's 13 [<i>years old</i>]." (Parent Interview 12)</p> <p>"He should be promoted independently to to do now his intimate care." (Parent Interview 13)</p>	23	119
Involving parents in care	<p>"They [<i>the nurses and doctors</i>] have always asked if that's OK with me, they've given two [<i>treatment</i>] options, but it's not really up to me because she's 15 [<i>years old</i>], it's what's best for her not me. I've always found that they'll look at me and they'll say 'Well Mammy how do you feel about that?' ... so it's good and I'm pleased about that. (Parent Interview 3)</p> <p>"The nurses always include me and the doctors always include me look for my opinion, look for what symptoms I found at home, there hasn't been a time where they didn't include me in it [<i>C's care</i>]." (Parent Interview 7)</p> <p>"I think parents should be completely involved. I mean it is your child at the end of the day, you know your child better than anybody." (Parent Interview 10)</p>	22	140
Jodie's "dodie"	"I'm her "dodie" that she knows she's not on her own up here." (Parent interview 18)	2	3
Keeping the place tidy	"I like to get the room ship shape." (Parent interview 17)	1	2

Name	Description	Files	References
Knowing from experience	"We have been in hospital a number of times, so I suppose we've kind of come accustomed to how the day might transpire" (Parent Interview 14)	4	10
Knowing staff by name	"I've had a great reaction with the staff, I know most of the staff by name." (Parent Interview 7)	1	1
Knowing your child best	"You know the limits to what your son or daughter can do and I think that's very important because you know your child best." (Parent Interview 7)	2	8
Lack of privacy	there's lots of activity, so I suppose it's uncomfortable and it doesn't allow for privacy." (Parent interview 22)	1	1
Lacking sleep	"It's very hard to sleep when you're right beside him, and people [<i>nurses and doctors</i>] coming and going and it's just, yes the wards are busy." (Parent Interview 13)	4	13
Left to chance	"You know I just think everything is left to chance, and I suppose some parents know what they are about and maybe some don't." (Parent Interview 15)	2	4
Limited visiting due to Covid	"Because of the Covid [<i>pandemic</i>] restrictions at the moment it's only one person allowed in the hospital per child at the moment." (Parent Interview 14)	10	21
Listening to children	"She knows what she likes and doesn't like and what would upset her or worry her or scare her, so I think its absolutely important that she voices her opinions." (Parent Interview 10)	7	8
Listening to parents	"If we have any questions to ask or if we know little things that could help the nurses about J, we inform then and they [<i>the nurses</i>] just take it all on board." (Parent Interview 13)	6	19
Looking after yourself	"Look after yourself and then you'll be able to look after your child better." (Parent interview 24)	1	1
Making sure she's safe	"We have to keep her safe at the same time." (Parent interview 23)	1	3
Making sure they are fed	"It's just kind of making sure she's fed." (Parent interview 16)	3	11
Managing expectations	"I know the priority is the patient but at the end of the day a lot of parents are staying for long spells as well." (Parent Interview 2)	8	14

Name	Description	Files	References
	"This is a hospital and you know, accept what you get, you get very good care, and you know what it's not a hotel and they [<i>the nurses and doctors</i>] are busy saving children's lives." (Parents Interview 15)		
Miscommunication	"If the communication overall between all the different departments were tidied up, it would probably free up people in terms of being able to actually operate more efficiently." (Parent Interview 16)	1	3
Not doing the big things	"I'm quite happy to sit back and let them [<i>the nurses</i>] do the big stuff." (Parent interview 16)	1	2
Not feeling overshadowed	"I didn't kinda feel overshadowed by the nurses this time." (Parent Interview 8)	1	1
Not getting in their way	"But just to not get in the way."	2	7
Not involving child in care planning	"So with her age in mind at the moment [<i>child is 9 years and 10months</i>] I do think it's OK for her not to have a lot of involvement in the decision-making and that sort of thing in the hospital." (Parent Interview 6)	6	14
Not involving parents	"Sometimes the amounts [<i>dose of insulin</i>] that they would inject I don't really agree with, but because I'm here and she's basically in their care I just go with it and I'll just do it." (Parent Interview 6)	6	17
Not knowing what to expect	"Maybe just a little bit at the outset of what they [<i>the nurses</i>] expected of parents and what they didn't." (Parents Interview 15)	2	2
Not much going on for the children in hospital	"I just think if there was a little more recreation for them [<i>children in hospital</i>] just to keep them stimulated." (Parent Interview 8)	6	13
Nurses advocating for families	"They [<i>the nurses</i>] are, when I'm not here or that they are dealing with the team, that they are her voice, you know." (Parent Interview 15)	6	13
Nurses are helpful	"They [<i>the nurses</i>] are a big help for me, so this is very great, it works well for me." (Parent interview 20)	1	7
Nurses being approachable	"They've been ... everyone has been very approachable." (Parent Interview 15)	3	5

Name	Description	Files	References
Nurses being gentle	"And they [the nurses] were so gentle with the way they spoke to her." (Parent interview 18)	3	6
Nurses being friendly	I suppose if someone's demeanour is, is ... kinda closed off you're not going to approach those people and ask, so we've been lucky with everyone that we've seen, they're all very, very good and friendly." (Parent Interview 11)	9	26
Nurses being great	"Gosh you know I've been overwhelmed really by how good everybody is." (Parent Interview 1) "Every nurse that she's been delegated to is amazing, ... they've been brilliant, they really have." (Parent Interview 3) "They have been fabulous, I couldn't fault anything at all, you know they've been great." (Parent Interview 5)	20	69
Nurses being patient	"They [the nurses] are extremely tolerant." (Parent interview 17)	2	3
Nurses being professional	"Em, that was handled really professionally." (Parent interview 10)	1	1
Nurses being re-assuring	"So they [the nurses] put my mind at ease, very much so." (Parent interview 18)	4	12
Nurses caring	"They [<i>the nurses</i>] have been very on the ball and checking in with him that he doesn't need anything and even though he's had no pain they'll always ask every time they're checking his obs if he's having or had any pain." (Parent Interview 2) "There's never been a case where I'm like 'Where have they been, they haven't been checking her or they haven't been'. I have to say they're on top of it, there's nothing that I feel they should be doing and they're not." (Parent Interview 6)	20	59
Nurses caring for parents	"They're [<i>the nurses</i>] always asking me if I'm OK, do I need anything. They do make sure that I'm OK as well." (Parent Interview 3) "I was on my own for two hours [while L was in theatre], and one of the nurses came in with tea and a sandwich and a cake, like above and beyond, so things like that." (Parent Interview 10)	11	35
Nurses communicating with	Before they change her [<i>position or nappy</i>], they are always telling her what they are going to	6	25

Name	Description	Files	References
children	do." (Parent interview 20)		
Nurses communicating with parents	"That wasn't communicated to me, so I've been let to do a lot, but no one told me to do it or not to do it." (Parent Interview 15)	11	43
Nurses co-ordinating	"They [<i>the nurses</i>] have to be the goalkeeper maybe, keeping everything co-ordinated and minded, making sure that everybody knows what everybody else is supposed to be doing." (Parent Interview 16)	2	2
Nurses doing	"They're [<i>the nurses</i>] checking his blood pressure, they're listing what he has to eat, they're doing his carb [<i>carbohydrate</i>] counting, making sure he understands the carb counting and how to do the corrections." (Parent Interview 8)	17	71
	"I'm expecting the nursing and medical staff to make the decisions and administer care." (Parent Interview 14)		
Nurses doing everything medical	"Really mainly doing medical stuff, the likes of her drips and so on and giving medication." (Parent Interview 11)	11	34
Nurses explaining and teaching	"He's made aware of what's happening I think that's important as well I know some children mightn't want to know all the details but C is the type who likes to be told what's happening." (Parent Interview 2)	19	76
	"They can see that A understands what they're talking about. Once they're happy that he understands what's going on and I understand what's going on, everybody's job is done." (Parent Interview 8)		
	"We were well informed about everything they [<i>the nurses</i>] were doing, S was quite happy and quite at ease with that care. They've kept us well informed as to what they're doing, we're fully informed as to why things are being done." (Parent Interview 11)		
Nurses introducing themselves	"We were made very welcome. I mean when the nurse or anyone new comes in they introduce themselves, both to Alex and myself." (Parent Interview 5)	3	5
Nurses job to look after patients	"I feel their [<i>the nurses</i>] job is to look after the patients, and Mommy and Daddy should look after themselves." (Parent Interview 14)	2	4

Name	Description	Files	References
Nurses know best	"At the end of the day the nurses and doctors still know best in the hospital so there is a balance." (Parent Interview 7)	1	1
Nurses leaving it to parents	"They [<i>the nurses</i>] know you are around they're tending to leave stuff to you." (Parent Interview 15)	4	10
Nurses not communicating with parents	"It hasn't been really clarified exactly what my role is, although I haven't asked." (Parent interview 19)	5	14
Nurses not knowing	"He has a loop, a heart monitor in his chest, none of the nurses down here have ever seen one before, they don't even know what it actually does. I'm explaining it to them." (Parent Interview 12)	3	7
Nurses understanding	"The nursing staff it's all fine because they sort of understand." (Parent interview 23)	1	2
Nursing support at home	"I feel like, they're there now at the end of the phone if I need them when I go home." (Parent Interview 15)	3	3
Open environment	"The atmosphere is very open here, we're encouraged to ask questions." (Parent Interview 14)	1	2
Other children being sicker	"You don't really shout too loud, 'cos you know that next door there might be a sicker kid." (Parent Interview 15)	1	1
Parent not doing intimate care	"I [Dad] probably wouldn't introduce a bedpan here because I would prefer not to, to be frank." (Parent interview 22)	2	3
Parent staying	"We are encouraged to be with the child at all times, as a parent you want to be with your child." (Parent Interview 14)	15	39
	"I've been trapped, I'm a prisoner, I can't leave!! There's nobody to swap out with me, I'm the only one ... they [<i>the nurses</i>] kind of encourage you to stay, they don't really tell you why." (Parent Interview 16)		
Parental comfort	"I've had two hours sleep last night, because we could only get in here [<i>to this room</i>] at 5 in the morning. ... At half seven people started coming in to check her, so I had to put the bed	18	55

Name	Description	Files	References
	back up because the room is too small, nobody could get in to check her.” (Parent Interview 6)		
	“The [<i>sleeping</i>] mats on the floor, they’re not very comfortable. They are great and you’re so delighted to get them on the first or second night. But by the end of the week you do ... like my back is killing me, my shoulders are killing me.” (Parent Interview 10)		
	“It’s not exactly the Ritz, so it’s more kind of hostel sort of standard accommodation.” (Parent Interview 16)		
Parents asking questions	“If there was anything we weren’t sure about we’d just ask them [<i>the nurses</i>] then.” (Parent interview 21)	6	33
Parents being allowed to	“Em, well there’s nothing I haven’t been allowed to do bar obviously his medical treatment and administering his medication and everything like that.” (Parent Interview 2)	6	16
	“I appreciate that they give me the grace you know we can inject her ourselves or prick her fingers so it just makes it a little bit more do-able. ... So as a parent I think we are allowed to be quite involved in what’s happening.” (Parent Interview 6)		
Parents being anxious	“When we had the scoliosis operation the rods came away from the spine. I thought it was what I had done. ... So I’m very happy to sit back and watch rather than do some of the care.” (Parent Interview 4)	12	26
	“It’s a tough thing to go through, to stay calm and stay sane with very little to no sleep and obviously you’re worried as well.” (Parent Interview 6)		
Parents being company for their child	“They [<i>the nurses</i>] don’t have to worry about her being on her own all the time, when I’m here.” (Parent interview 19)	4	6
Parents being compliant	“In hospital we sort of submit care [<i>of our child</i>] to the team.” (Parent Interview 6)	1	4
Parents being experts	“It’s very important to keep the parents included because they know their child best.” (Parent Interview 7)	5	12
Parents being fed	“They [<i>the Healthcare Assistants</i>] make sure that the parents eat and drink.” (Parent Interview 13)	7	18

Name	Description	Files	References
Parents being grateful	<p>"We've had times where I was sleeping on the bed with O, which is fine, I'm just grateful to be with her. ... I'm very grateful even if I did not get a bed today." (Parent Interview 6)</p> <p>"So facilities wise it's a bit lacking actually, but we'll make do." (Parent Interview 14)</p>	11	29
Parents being incidental	"I was incidental to the whole thing." (Parent interview 22)	1	2
Parents being labeled	"You get labelled as being the annoying or cranky parent." (parent interview 23)	1	2
Parents being unsure	"Not sure whether to ask or to not ask whether to approach the desk." (Parent interview 15)	1	1
Parents doing	<p>"That's is a job I feel that I should have to do, they [<i>the nurses</i>] should be looking after more of the expertise [<i>the sicker children</i>] and I should be doing that [<i>personal day-to-day care</i>], and I want to do that." (Parent Interview 1)</p> <p>"I'm really here to support L in a [<i>personal</i>] caring capacity." (Parent Interview 10)</p> <p>"I can go make him a slice of toast or I make him a cup of tea, every day we have a cup of tea." (Parent Interview 12)</p> <p>"Whether it's to put pressure on to get the doctors if there's a period of time without some communication. ... The parents do the emotional bit, and the medical and nursing staff do the technical, medical bit."(Parent Interview 14)</p>	19	114
Parents eating	"You have to go out and buy food." (Parent Interview 12)	9	26
Parents feeling responsible	"I would prefer [<i>to do the TPN myself</i>], because I know that I'd be doing it right. ... mistakes won't be happening. ... I don't want no line infection, I don't want to be sitting in here another two weeks." (Parent Interview 9)	9	25
Parents feeling useless	I just rub his back, you feel useless, very, very useless." (Parent interview 24)	1	1
Parents fending for themselves	"They [the hospital authorities, including the nurses] expect you to fend for yourself in hospital, you know we don't get your breakfast lunch or dinner, as parents we have to go and buy them." (Parent Interview 9)	1	2
Parents helping their child	"I get him a drink, you know "Where's my crutches?" "Where's my frame?"" (Parent interview	8	38

Name	Description	Files	References
	17)		
Parents input in supplies	“Now they have the needles here [those this parent sourced in the community], I love that they were open just for my involvement, you know, so I can give a little bit of input.” (Parent Interview 6)	1	1
Parents keeping child occupied	“Keeping her distracted, and keep her interested in different things.” (Parent interview 23)	1	5
Parents knowing	“I'm more confident with his care this time 'cos I know so much more.” (Parent Interview 8)	6	13
Parents needing help	“You as a parent will need help as well as the child.” (Parent Interview 14)	1	1
Parents' needs	“Your needs are little. Your need is to make your child better.” (Parent Interview 14)	3	7
Parents not being allowed to	I can't draw the insulin myself. ... I find it quite hilarious that I'm not allowed to do that myself, I'm handed it [<i>the insulin</i>] to inject. So injecting her 24/7 at home [<i>counts for nothing</i>].” (Parent Interview 6)	2	3
Parents not knowing the medical stuff	“Oh yeah, temperature and stuff, I'd be happy to let someone else do it for him, because they're tracking that, and I would be afraid I'd do something that wasn't right.” (Parent Interview 1) “I'm not a [<i>healthcare</i>] professional, you know so I kinda depend on them [the nurses]. They're stepping in to look after the medical end of it.” (Parent Interview 3) “I'm not overly confident with myself, but I will do it [<i>wound dressing</i>] if I have to do it when we're going home I'll do it and I know I can phone if I have a problem.” (Parent Interview 4)	18	45
Parents not knowing what to do	“Em, well I wasn't told really or given any guidelines about what I needed to do or didn't need to do.” (Parent interview 2)	7	17
Parents providing reassurance	“They [children in hospital] need that little clutch of their parent to support them.” (Parent Interview 14) “it's more comfortable for her and reassuring that's she's not really on her own.” (Parent Interview 4)	11	34

Name	Description	Files	References
Parents providing support	"So just for support and for security." (Parent interview 19)	8	39
Parents representing their child	"To be a champion for your child." (Parent Interview 16)	4	10
Parents sharing information with family	"I'm the link between hospital and family at home." (Parent interview 22)	5	13
Parents trusting nurses	"I can step back knowing that he's in capable hands of nurses." (Parent Interview 13)	7	9
Parents watching over	"I would just prefer to be here to see what's happening." (Parent Interview 9)	2	7
People being busy	"I'm here all day and the fact is they [<i>the nurses</i>] have other things to do, I can manage the bedpan." (Parent Interview 4) "I think there's 21 patients in the ward, I was looking at the board to pass the time, there are days when there are 2 or 3 nurses on they will have 7 patients each or more." (Parent Interview 7) "The nurses can get on with other stuff that's important while a parent looks after the needs that are not medical needs." (Parent Interview 15)	13	22
Planning care with family	"No we never really sat down and discussed it in black and white but it was an implied that I was happy to do it [<i>helping participant's daughter to use the bedpan</i>] and they were happy to let me do it." (Parent Interview 4) "There was absolutely no guidance as to what I should do or should not do, it just evolved in the manner it did." (Parent Interview 14)	10	43
Promoting independence	"I tell S [<i>participant's daughter</i>] you need to say when something's hurting you, when you're hungry, em, you need to shout 'cos in fact they listen to children here more than they sometimes listen to parents, and rightly so." (Parent Interview 15)	5	14
Relationship evolving	"It just becomes that kind of evolving relationship." (Parent interview 17)	1	1
Renovating to care	L [<i>participant's daughter</i>] has to go back on TPN, she has to get home, and work needs to be done to the house you know before she comes home." (Parent Interview 9)	1	1

Name	Description	Files	References
Roles can be confusing	"Sometimes you're afraid that maybe you're stepping on their [<i>the nurses</i>] toes or maybe you're doing a little bit too much." (Parent Interview 6)	3	3
Sharing responsibility with family	"We're a family unit dealing with a family issue." (Parent interview 22)	3	5
Speaking directly to child	"I like the way people [healthcare staff] speak directly to him." (Parent interview 17)	1	2
Support from specialist nurse	"She [<i>the Clinical Nurse Specialist</i>] is absolutely the top one on my list, she's been fantastic." (Parent Interview 9)	1	1
Supporting parents at home	"I've had the support of the girls, the nurses on the Diabetic team, and they're fantastic, they are only a phone call away if you're at home, and then they phone you back within a couple of hours, they're fantastic team they have in place." (Parent Interview 8)	1	1
Supporting parents in hospital	"The support that we got was mostly from the nursing staff." (Parent Interview 10)	5	5
The days are long	"It's a long auld day, it's a long night." (Parent interview 17)	1	3
Trusting parents	"They had trust in me and I had trust in them, which was good, it was a brave way to do it." (Parent Interview 9)	2	2
Trying not to break down	"I guess it is hard because you're, you're trying to not break down in front of him because some of the procedures that he goes through and some of the treatment that he goes through, it's difficult to watch [<i>participant is emotional</i>], it really is ..." (Parent Interview 13)	1	1
Trying not to overstep	"You're trying your best not to overstep an imaginary mark." (Parent interview 23)	1	2
Trying to look after him	"You're trying to look after him to the best of your ability, but you know like he's in the hands of the nursing staff." (Parent Interview 13)	1	1
Varies from ward to ward	"It very much seems to vary from ward to ward in terms of how much they need you to be involved." (Parent Interview 16)	1	1
Voicing concerns	"We both got equal opportunity to voice any concerns, they gave us so much time." (Parent Interview 10)	1	1
Wanting my child to be com	"I just want my child to be comfortable and not scared or feel alone." (Parent interview 17)	5	11

Name	Description	Files	References
Watching over treatment	"It's basically watching over the treatment." (Parent Interview 9)	1	1
Well handled	"It [<i>parental involvement</i>] has all been kind of well handled, really well handled." (Parent Interview 10)	1	1
What's coming next	"I'm always listening, to the care plan, so I know what's coming next." (Parent interview 17)	1	1
Working as a team	"I feel part of that team." (Parent interview 20)	2	4
Working on hospital time	"We have to do the [<i>TPN</i>] training say at 8 in the morning then back training at 2pm." (Parent Interview 9)	1	1

Appendix 23 Memo - Jodie's dodie!! - 22nd July 2021

What does this Mum mean when she describes her role in hospital with her adolescent daughter as being “Jodi's dodie”? She goes on to say that she is “a kind of a support network” for her daughter while she is in hospital. That her daughter is content once she knows her Mum is around: “I feel she is much more at ease when I am around.”

According to Wikipedia “a dodie” is another name for a pacifier, which is used to soothe a baby in distress. The word “pacifier” is more associated with the American culture. In our culture we frequently use the terms “soother”, “dodie” or “dummy”. The baby gets comfort from a soother (typically a rubber, plastic or silicone nipple-shaped substitute given to a baby to suck) by sucking it. Some parents choose not to use soothers for their infants and toddlers for various reasons such as: because it is thought that they can contribute to nipple confusion in very young infants which can interrupt breastfeeding, or because they can cause dental malformation in toddlers, or because the toddler has simply discarded it. I'm not sure of the evidence base for any of this information but it is widely discussed among the general population. These infants and toddlers often use what we refer to in Ireland as a “comforter”, which they cling to. The term “comfort blanket” or “comforter” is often used to describe something a small child clings to for comfort when they are frightened or distressed in unfamiliar surroundings, often a favourite blanket or soft toy.

Some children have described being out of their “comfort zone”, without actually using that exact phrase. Many children have said that hospital is a “scary place” when they first come in. Especially if they are alone. Even older children/adolescents described being afraid in hospital and being too shy to ask questions of the nurses and doctors. Many parents mentioned that they are a source of “comfort and support” and/or “reassurance” to their child in hospital. Despite almost every participant saying that the nurses are friendly, approachable, smiley, fun and chatty, when a child is in hospital it appears he/she is not comfortable, not at ease or simply not able to articulate the questions they need to ask of the nurses. It seems children in hospital depend on their parents being present to ask the right questions and to explain their health history to the healthcare teams. Their parents also provide clarification on treatment, treatment options, medications and care interventions if the child does not clearly understand what the nurses and doctors have said. Is the parents' presence in hospital with their sick child a comfort blanket, a comforter or a security blanket for the child who is scared?

Is this the light bulb moment I've been waiting for?

Appendix 24 Coding strategy

Focused codes (parents' data) and their associated initial codes

Focused code	Associated initial codes	
Keeping my child company	Being a companion	Being in hospital is scary
	Being with child	Bonding time
	Children being anxious	It's easier for the child
	Going outside	Hospital being a lonely place
	Jodie's dodie	Parent staying
	Not much going on for children in hospital	Parents being company for their child
	Parents keeping their child occupied	Parents providing support for their child
Advocating for my child	Parents providing reassurance for their child	
	Asking nurses	Being an advocate for your child
	Being at home is difficult	Being in the right place
	Being more in control	Feeling safe
	Having to be on the ball	I'm his voice
	Listening to children	Listening to parents
	Voicing concerns	Making sure she's safe
Parents responsibilities evolving	Parents representing their child	Parents asking questions
	Assuming roles	Being hands-on
	Being in hospital is exhausting	Children eating
	Falling between the cracks	Falling into place
	Finding out for yourself	Giving parents choice
	Involving parents in care	Knowing from experience
	Knowing your child best	Left to chance
	Miscommunication	Not doing the big things
	Not getting in their way	Parent not doing intimate care
	Not involving parents in care planning	Parents being allowed to ...
	Nurses not communicating with parents	Parents doing
	Parents feeling responsible	Parents helping their child
	Parents not knowing the medical stuff	Parents not knowing what to do
	Parents sharing information with family	Parents watching over
	Planning care with family	Trusting parents
	Trying not to overstep	Trying to look after him
	Varies from ward to ward	Watching the nurses
Wanting my child to be comfortable	Watching over treatment	
What's coming next		
Parents helping nurses	Helping nurses	Keeping the place tidy
	Making sure they are fed	Nurses leaving it to parents
	Parents being experts	Working as a team
Parents making do with	Parents being experts	Working as a team
	Being in a small space	Being in hospital is expensive
	Being in hospital is frustrating	Being pushed over the edge
	Facilities for children	Facilities for parents
	It's a relay	Lack of privacy
	Lacking sleep	Limited visiting due to Covid
	Managing expectations	Not knowing what to expect
	Other children being sicker	Parental comfort
Parents being compliant	Parents being grateful	
Parents eating		

Appendix 25 Memo - Focused coding – 30th Nov 2020

“There was no discussion, there was no guidance to the parents, it just happened naturally. ... It [parents' involvement in care] was something that just seemed to happen and evolve naturally.” (Parent 14 - of female child with a chronic condition).

A lack of formal discussion to plan the child's/adolescent's care with his/her parent is emerging as a common issue for parents, as described very clearly by Parent 14 above. When I reviewed the transcripts of earlier parent interviews I note that others have been less explicit but have referred to this issue also. The following excerpts support this observation:

“Em, well I wasn't told really or given any guidelines about what I needed to do or didn't need to do. We haven't ever been given guidelines or told what we can or can't do.” (Parent 2 – of male child with an acute condition)

“No we never really sat down and discussed it [parents' role] in black and white but it was implied that I was happy to do it and they were happy to let me do it.” (Parent 4 – of female adolescent with chronic condition).

“I haven't had very much involvement at all in discussions about his care really.” (Parent 12 - of male adolescent with a chronic condition).

“No they didn't really discuss it [care plan]. Maybe just a little bit [of advice from the nurses] at the outset of what they expected of parents and what they didn't.” (Parent 15 – of female child with a chronic condition) and

“I haven't really had a conversation with anybody about how much to do or not to do with her or what to do for her or not. So there hasn't really been any kind of conversation at all in terms of what should be or shouldn't do done.” (Parent 16 – of female adolescent with a chronic condition).

The above quotes demonstrate that there appears to be a lack of formal planning and negotiation with parents as to what they want to do and what they would prefer not to do when their child is in hospital. Does this lack of negotiation occur because planning care with parents and their child is time consuming and requires nurses to have strong communication and negotiation skills ?. One parent said it (her role) was not discussed rather it was implied....I wonder what she meant by that. How is it implied – are parents just left to get on with it? How do parents find out what they can and cannot do / are any afraid of stepping on nurses toes (territory) if they do some care that they are not supposed to do? Do they watch other parents or do they learn over time? Is it the same for parents of children with an acute or chronic condition? Perhaps I should check and

interview a parent of a child with a chronic condition and then a parent of a child admitted for the care of an acute illness.

This issue certainly needs to be explored further with more focused questions. Suggested focused questions to explore this issue further:

1. How have you been involved in planning your son's/daughter's care with the nurses while in hospital?
2. Tell me about how you and the nurses have discussed and decided your role and responsibilities with regard to the care of your child while in hospital?

Appendix 26 Coding frameworks

Table 1 The coding framework that led to a major category for children and adolescents “Keeping me company/Providing emotional support for me”

Initial codes			
Having someone to talk to	Parent being with me	Parent providing emotional support	Parent keeping me safe
Parent keeping me company	Parent staying	Parent's presence being reassuring	Parent making me comfortable
Focused codes			
Keeping me company		Providing reassurance	
Major category / concern			
Parent being my companion / Providing emotional support for me			

Table 2 The coding framework that led to a category for children and adolescents “Parents helping me/Parents advocating for me”

Initial codes			
Parents helping me with personal care	Parents getting me food and drinks	Parents asking questions	Parents taking care of me
Parents keeping me safe	Parents making me comfortable	Parents doing the medical stuff	Parents checking up on me
Focused codes			
Parents being there to help me		Parents speaking to nurses and doctors	
Major category / concern			
Parents helping me / Parents advocating for me			

Table 3 The coding framework that led to a major category for children and adolescents “Taking care of myself/Doing my own personal care”

Initial codes			
Asking questions	Being careful	Doing my own personal and intimate care	Doing my own medical stuff
Entertaining myself / Keeping myself busy	Getting better	Resting and sleeping	Keeping myself calm
Focused codes			
Looking after myself		Personal cares	
Major category / concern			
Taking care of myself / Doing my own personal care			

Table 4 Coding framework that led to a major category for parents “Keeping my child company - Being their comforter or comfort blanket”

Initial codes				
Being a companion	Parents keeping their child occupied	Being with my child	Children are anxious	Being in hospital is scary
Not much going on for children	Parents being company	Hospital is a lonely place	Parents providing support	Parents providing reassurance
Focused codes				
Keeping them company		Providing reassurance		
Major category / concern				
Keeping my child company – Being their comforter or comfort blanket				

Table 5 The coding framework that led to a major category for parents “Advocating for my child”

Initial Codes					
Asking nurses	Like trying to walk a tight rope	Having to be on the ball	Listening to parents	I'm his voice	Being an advocate for my child
Parents asking questions	Not stepping on their toes	Making sure she's safe	Listening to children	Voicing concerns	Parents representing their child
Focused codes					
Seeking information			Being their voice		
Major category / concern					
Advocating for my child					

Table 6 The coding framework that led to a major category for parents “Limited negotiation with nurses about the role of the parent”

Initial codes						
Assuming roles	Parents feeling responsible	Finding out for yourself	Knowing from experience	Not knowing what's coming next	Not getting in their way	Nurses not communicating with parents
Falling between the cracks	Parents watching nurses	Falling into place	Trying to look after him	Left to chance	Trying not to overstep	Parents not knowing
Focused codes						
Roles and responsibilities evolving				Not knowing what to do		
Major category / concern						
Lack of formal negotiation with nurses about the role of parents						

**Table 7 The coding framework that led to a major category for parents
“Parents helping the nurses”**

Initial codes			
Parents helping the nurses	Parents making sure they are fed	Nurses leaving it to parents	Parents being the experts
Parents keeping the place tidy	Parents being experts – knowing their own child best	Working as a team	Nurses being busy
Focused codes			
Nurses having a busy workload		Parental presence being necessary	
Major category / concern			
Parents helping the nurses			

Table 8 The coding framework that led to a major category “Parents “making do with” inadequate facilities”

Initial codes				
Lack of privacy	Other children being sicker	Being in a small space	Being in hospital is frustrating	I'm here for my child not for me
Lacking sleep	Being in hospital is expensive	Parents being grateful	Parents being compliant	It's not a hotel
Focused codes				
Making do with challenges			Not complaining	
Major category / concern				
Parents making do with inadequate facilities				