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**Real voices: A participatory  
action research study to explore  
the support provided to children  
visiting adult patients in hospital.**

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**Thesis submitted for the degree  
of Doctor of Philosophy**

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**Keele University**

## Acknowledgments

***“...I have seen that in any great undertaking it is not enough***

***For a man to depend simply upon himself”***

*(Lone Man (Isna la-wica) late 19<sup>th</sup> century, Teton Sioux*

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***This thesis is dedicated to John and Hamish Jervis***

## Abstract

**Background:** There is evidence that a supportive and open approach to children visiting adult relatives in hospitals has positive benefits for the children, patient, families and healthcare staff. Despite this, many children (<17 years) are still restricted from visiting.

**Aim:** To identify and critically explore the issues around children visiting adult relatives in hospital and ways to improve visiting opportunities.

**Method:** A Participatory Action Research (PAR) design was chosen, as it both identifies challenges and change opportunities through collaboration with participants. Two informal consultation focus groups with children were held prior to the study. These confirmed issues relating to children visiting adult relatives which informed the research with nursing staff in a large teaching hospital. Three PAR cycles were conducted during the study using a series of focus groups. Adult and children's registered nurses, and local college students participated.

**Findings:** Findings showed that there was variation and inconsistency in visiting practice across all areas of the hospital. A number of reasons for the exclusion or restriction of children, such as presumed hospital policy, were offered by staff. Staff identified a need for specific education and resources, and a number of remedial actions were implemented. Multidisciplinary focus groups provided the opportunity for active learning through knowledge transferability, and encouraged individual nurses to challenge their own assumptions. The college students reported that they did not feel welcome in hospitals and were often ignored. They identified that being acknowledged by nursing staff would give them confidence and help ensure they felt included.

**Conclusion:** Nurses' lack of knowledge of hospital policies and excessive concern about protection of the child, deter nurses from relaxed visiting for children which in

turn leads to children feeling excluded and anxious. Adult nurses need to challenge their own and other peoples' assumptions and values in relation to family centred care and child visitation to hospitals. A structured holistic approach needs to be established and implemented in all clinical areas. Multidisciplinary working and learning opportunities should be encouraged.

**Keywords:** Participatory Action Research, child visitation, hospital visiting

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## Glossary of terms

**Advanced Nurse Practitioner (ANP)** “Advanced Nurse Practitioners are educated at Masters Level in clinical practice and have been assessed as competent in practice using their expert clinical knowledge and skills. They have the freedom and authority to act, making autonomous decisions in the assessment, diagnosis and treatment of patients” (Royal College of Nursing (RCN), 2018, p.4).

**Center for Disease Control (CDC)** The leading national public health institute of the United States of America (USA). Its main goal is to protect public health and safety through the control and prevention of disease, injury, and disability in the USA and internationally.

**Child/Children** Anyone under the age of 18 years as per the UN Convention on the Rights of the Child (United Nations (UN) General Assembly, 1989).

**Hospital visitors** Family or friends visiting a hospitalised patient.

**Medicines for Children Research Network (MCRN)** Established in England in 2005 and is part of the National Institute for Health Research (NIHR). The aim was to improve children’s health through the provision of safer medicines. The MCRN supports publicly and industry sponsored research at all points from initial ideas to study delivery in NHS sites in England and links to research networks in Wales, Scotland and Northern Ireland (Rose, Hoff, Beresford and Tansey, 2013).

**Medicines for Children Research Network Young Persons Advisory Group (YPAG)** Established in 2006. At the time of this research there were groups in Liverpool, London, Nottingham, Birmingham and Bristol. Members are young people aged less than 18 years who support research activities involving children and young people. They promote awareness to the public, support researchers in the design and delivery of studies, and collaborate with national governing bodies (Rose et al, 2013).

**National Health Service Health Research Authority (NHS HRA)** Established as an executive non-departmental public body sponsored by the Department of Health in 2015. The core purpose of the HRA is to protect and promote the interests of patients and the public in health and social care research. This is achieved by ethics review and approval for health research and the provision of independent recommendations on the processing of identifiable patient information.

**Nosocomophobia** The extreme fear of hospitals. Derived from the Greek word 'nosos' which stands for diseases and the Latin word 'comes' meaning consequences or companion. Nosokomein is also the Greek word for hospital.

**Quality Nurses (QN)** Senior clinical nurses based on each ward and department whose role includes responsibility for the management of the clinical area on a shift basis, participation in innovation and evidence based nursing practice and being a professional role model encouraging and empowering other staff to develop both personally and professionally.

**Senior Nursing Team (SNT)** The senior nursing management team consisting of the Chief Nurse, Director of Nursing Education and Workforce, Director of Nursing Quality and Safety, Senior Nurse Education & Workforce, Deputy Director of Nursing Quality and Safety.



## Abbreviations

ANP	Advanced Nurse Practitioner
AR	Action Research
BACCN	British Association of Critical Care Nurses
BSc	Bachelor of Science
CDC	Center for Disease Control
CNS	Clinical Nurse Specialist
CF	Cystic Fibrosis
CPR	Cardiopulmonary Resuscitation
FG	Focus Group
GF	Group Facilitator
GMC	General Medical Council
ICU	Intensive Care Unit
ID	Infectious Diseases
MAU	Medical Assessment Unit
MCRN	Medicines for Children Research Network
MDT	Multidisciplinary Team
MSc	Master of Science
NHS	National Health Service
NHS HRA	National Health Service Health Research Authority
P	Participant
P-AN	Participant - Adult Nurse
P-CN	Participant – Children’s Nurse
P-CS	Participant – College Student
P-CT	Participant – College Tutor
PAR	Participatory Action Research
QN	Quality Nurse
RCN	Royal College of Nursing

R&D	Research and Development
SNT	Senior Nurse Team
UK	United Kingdom
USA	United States of America
YPAG	Young Persons Advisory Group

# Chapter 1

## Introduction

**“Adult efforts to protect children often leave them confused and alone with their fears and fantasies, which may be much worse than the reality. Children always notice when something important is happening in their family: they are aware of adult anxieties, observe body language and practical changes, and often overhear adult conversations”**

**(Monroe and Oliviere, 2009, p.13).**

### Background and rationale

This thesis is a critical account of a Participatory Action Research (PAR) study which aimed to explore and improve the support provided to children and young people who visit ill adult relatives in a large teaching hospital in the United Kingdom (UK). It is a research study inspired by the children and young people encountered in clinical practice who were experiencing a difficult time in their lives. It has been a challenging and interesting journey which started with reflections upon some unexpected experiences in clinical practice. To place the study into context this chapter will firstly introduce the historical perspective of relatives visiting hospitalized patients. This will be followed by a description of my personal journey in clinical practice and the associated reflections. It details encounters with the children and young people visiting relatives whose stories led to the research proposal and my subsequent enrollment as a PhD student. Finally, the thesis overview is provided to guide the reader through the thesis chapters.

This thesis is written using the active voice. Traditionally, the active voice has been discouraged, but in current Action Research (AR) the “use of ‘I’ is expected (McNiff, 2017, p.111). This PAR study evolved (and was based) in this practitioner’s clinical practice. The researcher’s positionality and reflections are integral to the study. The use of the active voice and ‘I’ can therefore be justified as opposed to using ‘the researcher’ or ‘the author’ which “tends to sound distant and uninvolved” (Bloomberg and Volpe, 2016, p.69). The use of ‘I’ within the thesis is used to reflect upon my own positionality, learning, and contribution, as part of the collective group of participants and is important in demonstrating ethical practice and the trustworthiness of the research.

### **Hospital visiting in the UK – Historical perspectives**

Traditionally, visitors have been categorised as not only family and friends, but also public visitors who had no direct involvement with the hospital or patients; house visitors who were associated with the hospitals management and governance; and official visitors who would carry out inspections (Mooney and Reinartz, 2009). Much of the historical records pertain to the latter three groups. This perhaps reflects the prolonged challenges in obtaining a balance between the needs of the organisation and patient’s families. For the purposes of this thesis the term ‘visitors’ will refer to family and friends and this is the group that will be discussed in the remainder of this section.

The issue of visitation rights to hospitals has a long history with visits to patients, or inmates as they were called in the past, by relatives and friends over the years being either “prohibited, discouraged, policed or positively welcomed” (Mooney and Reinartz,

2009, p.9). The changing position and importance attributed to the family by healthcare professionals and hospital management through time is reflected in the limited reference to them in documents and books. The terms 'family' and 'relative' do not appear in the indexes or contents lists of books about the history of hospitals, such as those by the authors Rosenberg (1987) and Granshaw and Porter (1989).

Modern healthcare purports to support patient and public engagement (NHS England Public Participation Team, 2017). Concepts, such as open visiting, family presence during procedures (Clark and Guzzetta, 2017), family witnessed resuscitation (Hansen and Strawser, 1992; Meyers et al, 2000), person (patient) centred care (Morgan and Yoder, 2012) and family centred care (Mitchell, Chaboyer, Burmeister and Foster, 2009) make it easy to imagine that all visitors are welcome in all hospital wards and departments. Yet there is evidence in the literature that children are excluded or restricted from visiting (Alonso-Ovies and La Calle, 2017; Knutsson, Enskär and Golsäter, 2017). Memoirs such as that by Kirk (2016) highlights that when visiting a seriously ill adult relative even the modern healthcare system does not allow for true holistic and family centred care, and often results in increasing an already stressful situation:

“After I’d packed Mums bag, I went downstairs to see the girls before I headed straight back to the hospital. As I entered the kitchen, I realised with a jolt that I couldn’t bring Ruby with me. She wasn’t allowed on the ward. No children were. The shock of what this was going to mean prickled my skin with tiny needles of realisation. As time went on, the choices I had to make would build and build until I felt I was being stabbed over and over and over by the knives of guilt.” (Kirk, 2016, p.56).

Historical evidence suggests that families moved from the position of care providers in the home to almost complete outsiders as the new institutional culture of hospitals developed (Mooney and Reinartz, 2009; Rosenberg, 1987). In the 1800's visiting by friends and family was restricted, often to only two short time slots in a week. At Birmingham General, hospital visitors were restricted to two per patient on Tuesday and Friday between 2pm and 4pm. Relatives travelling a distance were also allowed in on Thursdays and Sundays, although medical staff complained about this (Reinartz, 2009). In other institutions visitors were encouraged by the Matron as they brought in clean linens (Lindsay, 2009) and other goods such as tea, sugar and alcohol (Reinartz, 2009). At some voluntary hospitals visitors would be permitted overnight so that night nurses were not required (Reinartz, 2009) and in the Jenny Lind Hospital for Sick Children, Norwich, relatives were also encouraged to help with care to reduce staff workload and running costs (Lindsay, 2009).

By the 1880's knowledge about the causes of disease resulted in stricter visiting rules and visiting times. An association between the introduction of infection to the hospital from visitors from outside was more widely understood. The development of isolation hospitals in the mid 1860's saw an increase in the sequestration of infectious people and by World War One there were more than 750 isolation hospitals containing almost 32 000 beds (Mooney, 2009). In many cases, including when the patient was a child, visitors were only allowed in when the patient was thought to be 'so dangerously ill' that they were close to death (Mooney, 2009). Even in these cases visiting rules were strict and restricted. Visitors were sometimes required to wear special clothing, to sit at a distance "to avoid touching the patient, or exposing themselves to the breath or to the emanations from the skin" (Mooney, 2009, p.162). In the absence of protective clothing visitors were required to remove their clothing for fumigation and take a wash

or bath (Mooney, 2009). Reducing visitors at this time was also seen as a way of reducing noise and cleaning expenses (Reinarz, 2009).

Restrictions not only applied to adult patients, but also to children. There is little evidence of parents in the archived records from Great Ormond Street between 1852 and 1879, which was the first and most influential children's hospital in the UK. Parents were not required to sign visiting books, not asked their opinions about the hospital or the child's treatment and from 1858 visiting was strictly controlled (Tanner, 2009). Similarly, the first policy for visiting the Jenny Lind Hospital for Sick Children established in 1854 stated that parents were allowed to visit only on Mondays, Wednesdays and Saturdays between 2pm and 4pm (Lindsay, 2009). Regular parental contact was not considered important to a child's medical or psychological wellbeing, with parental presence on wards "seen as a danger to the effective treatment and care of the in-patient children" (Lindsay, 2009, p.120).

As with adult patients relatives visiting children patients provided care and resources such as clean linens. Visiting was also seen as an opportunity to provide parental education. Initially children were accepted visitors, but by 1900 the formal visiting times had been reduced to two days in the week. In March 1902, it was decided that to reduce the risk of smallpox visitors were to be banned from infected areas and children visitors were banned completely. In 1904, visiting times were again reduced and no visitors were allowed on the wards. It is thought that infection risks were the initial basis for such rigid restrictions. By 1918 visitors were recorded as causing problems due to behaviours such as trampling the flower beds, and in 1924 visiting was declared to be a problem for both hospital staff and patients.

The limited access for parents to visit their children could be withdrawn at any time and without reason (Lindsay, 2009). At Great Ormond Street Hospital from 1880 visiting was restricted to the mother on Thursday afternoons and fathers on a Sunday with the only exception to this rule until the early 1960's being when a child was thought to be dying (Tanner, 2009).

There was no parity in relation to family visitors across different populations. Non-paying patients in some institutions were not allowed visitors whereas the paying patients were (Rosenberg, 1987). In one oral testimony of a nurse who worked at the London Fever Hospital as late as the 1930's there was no visiting at all except in the private wards (Mooney, 2009).

By the interwar period there was a growing appreciation of hospital patients psychological needs. Visiting practices became more relaxed in the 20th century (Reinarz, 2009), although rules and restrictions continued. Additional visiting days were often added, such as at the Birmingham Women's Hospital where in 1918 visiting was increased to three times a week for two hours daily (Reinarz, 2009). By the 1940's new theories in psychology and new medical treatments to treat infections saw the meeting of children's emotional needs increasing and slowly visiting opportunities were increased (Lindsay, 2009). A shortage of nurses was also predicted, and care provided by mothers was again seen as a way of alleviating this (Lindsay, 2009). As the fear of infection diminished with the increasing knowledge and availability of medical treatments daily visiting was slowly introduced into hospitals which admitted children. However, a survey of 1300 hospitals which admitted children in the 1950's recorded 150 hospitals which still did not allow any visiting and only 300 allowing daily parental visits (Lindsay, 2009).



Restrictions in visiting often resulted in family and friends being required to check the daily list of dangerously ill patients kept at the hospital lodge or printed in newspaper bulletins. An appearance on the list made the patient eligible for visitors (Mooney, 2009). Following the opening of the Edinburgh isolation hospital a system of categorisation was developed to inform families whether visiting was permitted. Patients were ascribed a number on admission which was known to the family and newspaper bulletins printed each patient number classified into one of four categories according to the patient's condition:

Dangerously ill, friends requested to come out

Seriously ill – no immediate danger

Ill, making satisfactory progress

Not quite so well, no cause for anxiety

These notifications would provide an indication of the condition of the patient and also alert the family to when visiting would be allowed because the patient was dangerously ill (Mooney, 2009, p.165).

Newspaper notification of patient conditions was also found in the West Midlands. In the 20<sup>th</sup> Century 'The Staffordshire Sentinel' newspaper listed the daily condition of patients according to numbers, listing those who could receive visitors as they were dangerously ill (Figure 1.1, p.25). It is noted in this excerpt from The Staffordshire Sentinel of April 23, 1912 (Figure 1.1, p.25) that visiting was only allowed on Thursdays between 2pm and 4pm, and on Sundays between 2pm and 3.30pm, unless in the case of critical illness. There are also instructions that children under fourteen years of age are not allowed to visit without special permission. The concept that there was a hospital policy restricting visiting to the hospital on the basis of age

appeared consistently through this PAR study and this historical base may underpin some of the modern-day themes discussed in Chapter 5.

Scotland, and Ireland, by a further decline in Dr. Ewing delivered in which he dealt with in the present social

**UARY.**

iced of the Rev. Frederic rs a master at Harrow nence; and the Rev. well-known Evangelical

**JOHN GOODWIN.**

**firm of Flint Millers**

the death of Mr. John se, Longsdon, sole pro- dler's business, known dwin and Son, carried Lichfield-street, Hanley. n, who passed away at Sunday morning, was un- stall, in 1839. He is- ness when he was 20- most successfully come- se death of his father e father of the late Mr. r. George Goodwin, of rcknall, and he estab- Westwood Mills in 1846. ears, the late Mr. John- prior of the Consall gave up the tenancy He was a keen busi- his progress was due duty and the general himself by his methods r. He received little

Photo by Gover, Hanley.

**NORTH STAFFS. INFIRMARY.**

**Condition of Patients To-day.**

N.S. INFIRMARY, Tuesday.

The following patients are in a dangerous condition and may be visited by relatives at any time:—

None.

The following patients are seriously but not dangerously ill. Their condition at 10.50 this morning was stated to be as follows:—

IMPROVING.—1027—1040—1127—1081—1076—1048—1008—1132—1138—1186—1120—1090—1098—1113.

SAME STATE.—1125—1145—1037—1164—1088.

NOT SO WELL.—1077.

The remainder of the patients in the Infirmary are going on very well.

Visiting, except in cases of critical illness, is only allowed on Thursdays (2 p.m. to 4 p.m.) and on Sundays (2 p.m. to 3.30 p.m.).

Children under 14 years of age will not be allowed to visit, except after a special request from the patient and the sanction of the Secretary and House Governor.

Two visitors will be allowed, as a general rule, to each patient on any one visiting day, but if the first two visitors give up their tickets at 3 p.m. to the porter in attendance and leave the building, two more visitors (and two more only) will be permitted to visit the patient.

SIR W. LEVER'S HEIR ENGAGED.

Figure 1.1 The Staffordshire Sentinel April 23, 1912

There has continued slow but steady improvements over the past 58 years in allowing parents to visit at any time during a child's hospital admission as recommended in 'The Welfare of Children in Hospital', commonly referred to as the Platt Report (Ministry of Health, 1959). This Parliamentary Committee headed by Sir Harry Platt was set up in 1956 "to make a special study of the arrangements made in hospitals for the welfare of ill children – as distinct from the medical and nursing treatment – and to make suggestions which could be passed on to hospital authorities" (Ministry of Health,

1959, p.1). Occurring at a time when the established practices of nursing and medicine for children were being challenged by the developments in psychological research of Bowlby, Spence and Robertson, the Platt Report was considered timely and instrumental in changing the healthcare profession's attitudes and relationships with parents in the UK (Davies, 2010). One of the fifty-five main recommendations was that "parents should be allowed to visit whenever they can and to help as much as possible with the care of the child" (Ministry of Health, 1959, p.38). There was not an immediate change in clinical practice in response to this recommendation from the Platt Report. However, over the following three decades unrestricted visiting for parents has become the norm in the UK (Davies, 2010). Further developments have resulted in children visiting their siblings in paediatric wards and departments becoming accepted practice since the 1980's (Goodall, 1982; Johnson, 1994a, Knutsson and Bergbom, 2007a).

The strict rules surrounding visiting to both adult and child patients found in historical records are in stark contrast to the initiatives implemented to improve the patient and family experience of hospital admissions over the past 40 years. Open visiting by family and friends is widely accepted in many ICU's (Clark and Guzzetta, 2017), relatives have been facilitated to be present during resuscitation (Hanson and Strawser, 1992) and feedback from family as well as patients is encouraged by many UK hospitals. Experience from clinical practice in adult patient areas however, seemed to demonstrate that these improvements only applied to adult visitors.

## **Rationale - My personal journey**

The initial rationale for this study arose from unexpected personal and professional experiences which highlighted that healthcare professionals often encounter situations they feel ill prepared for. The researcher previously worked as an Advanced Nurse Practitioner (ANP) in a large teaching hospital in the UK. This role primarily included responsibility for the initial clinical assessment and management of adult medical patients and as a lead member of the cardiac arrest team. Ensuring that quality care was provided on the wards through education and support of both nursing and medical staff, and the development of policies and procedures were essential components of this role.

Training for the role of ANP required completion of an MSc in Advanced Clinical Practice. This incorporated core modules and an elective module where the student could choose a subject that was most relevant to their individual clinical practice and developmental needs. At this time, I was working on an Infectious Diseases (ID) ward as part of the medical team, where many of the patients were under the age of 45 years. The ward team also cared for patients with Cystic Fibrosis, all of whom were aged under 25 years of age. Cystic Fibrosis is an autosomal recessive inherited disorder affecting more than 10 400 people in the UK (Cystic Fibrosis Trust, 2017). The main symptoms relate to the respiratory and digestive systems and patients will often have been using hospital services since birth or a very young age. The patients cared for on the ID ward were all very experienced in dealing with healthcare professionals and would often tell us what they thought their best treatment options were. I became very interested in transition from child to adult services whilst on this ward as it seemed apparent that this was a time of great stress and anxiety for both the patients and their families.

The experience of caring for patients with CF on the ID ward resulted in a decision to complete a child health module for my elective entitled 'Children; Critical Perspectives'. The plan was to use this module assignment to explore the subject of transition from child to adult services. This was to both improve my knowledge and skills and to help improve the quality of care on the ID ward for this patient group. However, two clinical incidents occurred which changed the path of this elective module work and ultimately resulted in this study. Without these incidents, the interest in how healthcare professionals deal with children visiting adult patients may not have developed. Reflecting upon the incidents, the discussions that followed, the subsequent study and the potential impact of the study for the future feels like an epic story. There were lots of instances and challenges with the potential for discarding or forgetting the associated knowledge and experience.

“I expect they had lots of chances, like us, of turning back,  
only they didn't. And if they had, we shouldn't know,  
because they'd have been forgotten...

I wonder what sort of a tale we've fallen into?”

(Tolkien, 1995, p.695).

In keeping with the quotation by Tolkien, there were many times when this research could have been aborted, including from the onset. Without both my own personal reflections and those from members of the clinical teams, the exploration of what we knew (and didn't know) would not have commenced.

The first incident happened at the beginning of the MSc elective module and it challenged my own personal perspectives and clinical practice. The result was the

questioning of many assumptions that I held about what good clinical practice was. This included elements that I had co-authored with a colleague in a book chapter about dealing with sudden death in acute medical areas, specifically the section on creating a child friendly environment (Read and Jervis, 2003, 2012).

Whilst working a shift in the acute medical admissions unit (MAU) a female patient arrived accompanied by her two young children. An older sibling arrived almost immediately. The patient was critically unwell and required urgent intubation and ventilation. The older sibling, who was under 20 years of age, did not know what to do with the two younger children, and did not know how to explain what was happening. The medical staff were also reluctant to talk to the children, explaining that they did not know how to explain such a serious condition. As a team, we knew we had to explain the situation to the younger children. They had travelled to the hospital with their mother in the ambulance and seen her deteriorate rapidly.

I was the person willing to explain to them what was happening, with the older sibling helping to provide some support. The explanation was simple but honest, about what we thought was wrong, what we needed to do, and what the equipment was. They wanted to see their mother and they were accompanied into the cubical together with the older sibling. They all sat with their mother and talked to her until she went for urgent investigations. They were obviously very upset, but asked questions and seemed more settled knowing what was happening.

Whilst their mother was undergoing investigations, other older siblings arrived and they all remained together in the dayroom where the doctors told the family the results.

Sadly, the results showed a catastrophic medical condition for which there was no treatment available. Palliation was the only option and she was likely to die within a few hours. All the family were upset, but at this point the two youngest children wanted to go and sit with their mother again. The older siblings decided that this would be too stressful for them and that they should be taken home. The teenager at this point became extremely upset and aggressive towards the others. There was shouting that they had no right to tell them what to do, in addition to screaming and shouting that they needed to go in to their mother.

The healthcare team felt the need to advocate for the children at this time. It was explained to the older siblings that the children had been sitting with their mother on and off since admission and they had sat with her after she had been intubated and ventilated. It was further explained that to forcibly remove them at this point would be detrimental to their ability to cope with the impending bereavement. After these discussions they all agreed to let the children stay at the hospital and have full access to their mother. The children spent much of the time with the ANP's on the MAU and then on the ward that the mother was transferred to.

Although this is an extremely unusual case, it raised my awareness of the family unit, particularly when children were present. I started to notice that there were often children wanting to visit acutely ill or dying patients at the hospital. On reflection, I wondered whether there were more children wanting to visit or I had just not taken notice of them before. Although most of the patients were grandparents there were occasions where the patient was an older sibling, aunt, uncle or parent. The role of the ANP provided the opportunity to observe the interaction that occurred between

relatives and the healthcare staff particularly when patients were acutely unwell or dying.

Not long after the case detailed above I attended an emergency call where the patient had suffered a cardiac arrest just as the family had arrived on the ward for visiting time. Cardiopulmonary resuscitation (CPR) was unsuccessful, and the family was understandably upset. The patient's wife and adult child wished to go to the patient before all CPR efforts were stopped. The teenage grandchild was devastated and alternated between crying and shouting, blaming the entire ward nurses for his deterioration, screaming that they were all useless. The parent said to me 'you will have to deal with this, I can't at the moment'. I sat with the grandchild whilst the parent and grandmother sat with the patient. During this time we discussed how close they were and how devastated she felt. Although continuing to alternate between sorrow and anger, significant anger was directed at the ward nursing staff. This was due to a lack of understanding of what had happened, and this anger escalated as the nursing staff continued to avoid her.

These experiences caused me to change my elective module topic to study childhood bereavement rather than transition services. Whilst researching the literature and watching staff in clinical practice, I recognized that the teams were often doing the opposite of what was required by the children. A review of my contribution to the book chapters (Read and Jervis, 2003, 2012) was also performed to assess what strategies had been included as 'child friendly'. Critical analysis of the literature which is presented Chapter 2 demonstrated a complex and sensitive subject matter. Research showed clear benefits to supporting children visitation to patients in hospital and



significant distress related to restrictions. However, significant barriers remained in clinical practice internationally, in addition to the local barriers experienced.

The incidents described are just two amongst many when I noted that healthcare staff appeared to ignore children and young people who were visiting. Situations involving children appeared particularly stressful to both healthcare staff and adult relatives. At times, children had been restricted from visiting their relative due to concerns about them coping or causing an increased infection risk. These situations caused considerable discussion within the teams I worked with as many nursing and medical staff were concerned that they had either very limited (or no) knowledge and experience of dealing with children either during a bereavement or when their relative was ill but likely to survive. We also identified that there was no guidance within the hospital policy or procedures regarding children visiting the adult acute medical environment, who may be experiencing an extremely stressful situation due to the acute illness of their family member. Several nursing staff were interested in how this situation could be addressed to improve the quality of care provided and two important questions were raised during informal discussions with staff at the time:

1. How could staff be better prepared to deal with child visitors in the future?
2. Was it feasible for staff to change current practice and improve the experiences in their clinical areas for children visitors and their families?

These questions together with the personal experiences described began to raise the fundamental issues in my clinical practice that would inform my future research study and research aim, in addition to underpinning changes in my own clinical and teaching practice.

## **Research aims and objectives**

The aim of this study related directly to the questions raised in discussion with the healthcare staff at the hospital where the research was conducted:

- To identify and critically explore the issues surrounding children visiting adult relatives on any ward in one large teaching hospital in England.

The primary objectives were to;

- Enhance understanding into how staff could be better prepared to deal with children who visit acutely ill adult patients on the wards
- Explore the feasibility for staff to change current practice and improve the experience of child visitors and their families
- Contribute to enhancing the knowledge and skills of staff in dealing with child visitors and their families
- Inform future education, policy and procedure within the NHS to improve the quality of service provided to children and young people when visiting hospitals.

## **Thesis overview**

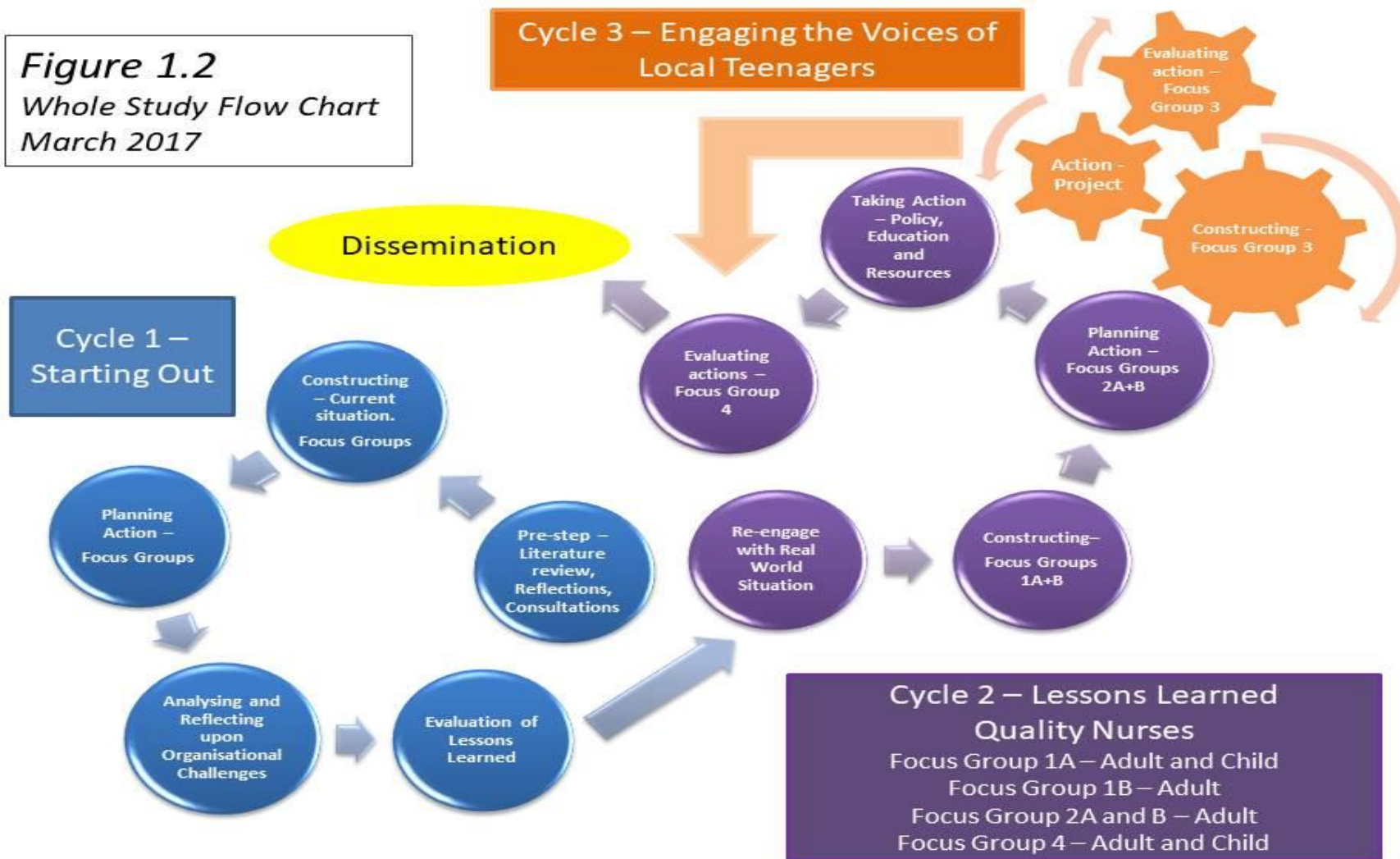
This chapter has provided the background and context to the research. The rationale for the research is described including personal reflections from clinical practice which underpin the aims and objectives. Chapter 2 will present the findings of the literature review. The search strategy is detailed and relevant themes and concepts are

explored, from the perspectives of parents and guardians, children, and healthcare professionals. Contemporary practices to facilitate children visiting adult patients are described, as are identified policies and procedures. Finally any themes that have implications for this study are identified.

Chapter 3 will discuss the research methodology. The rationale, strengths and limitations of the chosen methodology will be explored. The ontological position, epistemological perspectives and social purpose underpinning the research will be presented. Prior to commencing the research in the Pre-step phase, consultation focus groups took place with children and young people. The outcomes of these and their influence upon the research design will be discussed in this chapter. The planned methods for recruitment, data collection and data analysis will be presented. There were three research cycles during this study (Figure 1.2, p.35) and full details of each cycle will be presented in individual chapters.

Chapter 4 will present the first cycle of the study. It includes participant engagement, researcher positionality and the challenges encountered which were associated with local political and healthcare pressures. Chapter 5 describes Cycle 2 of the study. Further analysis of the research process and exploration of the experiences in the healthcare environment are then presented. This includes critical appraisal of the challenges and barriers encountered, particularly issues of participant recruitment and retention, degrees of importance placed upon the subject, conflicting priorities within the hospital and researcher positionality.

**Figure 1.2**  
 Whole Study Flow Chart  
 March 2017



Chapter 6 details Cycle 3 of the study. This cycle represented a cycle within Cycle 2 (Figure 1.2, p.35) as it evolved from one of the planned actions. Cycle 3 involved working with young people at a local college. This provided an insight into the lived experiences of children and young people, along with an opportunity to explore their opinions on what support healthcare staff should aim to provide. This cycle gave a voice to the very group that the study was aiming to improve support for at the hospital.

Chapter 7 provides a discussion of the findings of the evaluation phase of Cycle 2. This evaluation phase followed on from the planned actions which included Cycle 3. An evaluation of the whole study will then be presented, including the strengths and limitations of the PAR approach, researcher positionality and the impact of the study. Chapter 8 concludes with the new knowledge gained and recommendations for clinical practice, nurse education and future research.

## **Summary**

This chapter has provided the background and rationale to this PhD study. The historical context to hospital visiting by relatives and friends has been detailed along with reflections from clinical practice incidents. The thesis overview has been provided with details of each chapter. The following chapter will now present the literature review.

## **Chapter 2**

### **Literature review**

#### **Introduction**

The aim of this chapter is to provide a context for the PhD study by locating it within the previous body of knowledge through the process of a comprehensive literature review. It begins by introducing and describing the aims of the review, the search strategy and the key themes found. Finally, the gaps in the evidence base which form the foundation of this research project will be emphasised.

#### **Aim of the review**

The literature review aimed to systematically identify and appraise the evidence available to ascertain what was already known about children visiting adult patients in hospital settings. It was expected that the search undertaken for the review could yield at least six possible datasets:

1. Policies and procedures relating to children and young people visiting adult patients
2. Reasons for excluding or restricting children and young visiting adult patients
3. Perspectives and experiences of healthcare professionals
4. Perspectives and experiences of parents and/or guardians/custodians

5. Perspectives and experiences of children and young people
6. Strategies to facilitate children and young people visiting adult patients

A comprehensive and systematic search of the current literature and evidence base was the first stage of the study. A systematic review of the literature is defined as “the rigorous search, selection, appraisal, synthesis and summary of the findings of primary research in order to answer a specific question” (Parahoo, 2006, p.134). In healthcare, systematic reviews are viewed as an integral component of evidence based practice (Parahoo, 2006; Petrie and Sabin, 2005) and are used to answer specific questions relating to clinical practice, policy or methodologies (Parahoo, 2006, p.135).

Systematic reviews have many advantages, including the reduction and refinement of large quantities of information (Petrie and Sabin, 2005), for which impartial summaries of evidence can be presented (Davies and Crombie, 2001). They are efficient as they are quicker and less costly than performing a new study, results can often be generalised to wider populations than from single studies, and they can prevent the performance of unnecessary studies (Petrie and Sabin, 2005). The latter is particularly relevant in this case; as demonstrated in Chapter 1, the questions and issues associated with relatives and friends visiting patients in hospital has an extensive history. It was important to identify whether significant research studies had already been performed which could inform this study.

Some types of literature review are criticised for not providing information to demonstrate rigour in the search or review process (Parahoo, 2006). Although the literature review presented is not a full systematic review, the approach used was

based upon The Cochrane Collaboration (Higgins and Green, 2011) in order to provide detailed information of each step. The aim of this was to provide adequate information for the reader to be able to judge the rigour of the review process and be able to draw conclusions on the credibility of the conclusions drawn (Parahoo, 2006).

### **Criteria for considering literature for this review**

The rigorous search and identification of the relevant literature was based upon clearly defined inclusion and exclusion criteria. Papers were included if they related to children visiting ill adult patients in general (medical or surgical) hospitals from any of the three following participant groups;

1. Children and young people who have experience of visiting adult relatives in hospital.
2. Parents, guardians or custodians who have experience of children and young people visiting or not visiting adult relatives in hospital.
3. Hospital staff of any grade.

Papers were excluded if they related to adult visitors or children visiting other healthcare environments, such as child health, maternity departments, and mental health units.

A culturally progressive approach (Onwuegbuzie and Frels, 2016) aimed to reduce bias in the literature review, by placing no restrictions on language or publication status. In this way emphasis was given on finding evidence to represent “all cultures,



racess, ethnic backgrounds, languages, classes, religions, and other diversity attributes” (Onwuegbozie and Frels, 2016, p.36). Multilingual medical and nursing colleagues and friends agreed to assist in the translation of any foreign literature identified, in the following languages; Arabic, Dutch, French, German, Japanese, Norwegian, Polish, Spanish, Swedish and Asian dialects. There were no date restrictions placed.

## **Search strategy**

For any rigorous and systematic literature review to be credible the reviewer needs to make every effort to locate all relevant studies, including unpublished (grey) trials (Parahoo, 2006). This also helps to reduce publication bias in the completed review (Higgins and Green, 2011). Therefore, for the purposes of this review every effort was made to locate all relevant literature using the following sources as recommended in The Cochrane Handbook (Higgins and Green, 2011).

The following electronic databases were searched:

- **Cochrane Library** – (ISSN 1465-1858). A collection of databases that contain different types of high-quality, independent evidence to inform healthcare decision-making. The Cochrane Library is owned by Cochrane and published by Wiley.
- **MEDLINE** (1950 to date) - Created by the U.S. National Library of Medicine (NLM) this is a major healthcare database containing citations and abstracts for biomedical and health journals covering a wide range of subjects.

- **CINAHL** (1982 to date) - The Cumulative Index to Nursing and Allied Health Literature. Database of references to journal articles in nursing and allied healthcare professions. Literature covers a wide range of topics including nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines.
- **AMED** (1985 to date) - Allied and Complementary Medicine Database. Database of references to journal articles in alternatives and complementary medicine and therapies. Subjects Include complementary medicine, occupational therapy, palliative care, physiotherapy, podiatry, rehabilitation and speech and language.
- **PsycINFO** (1967 to date) Database of references to journal articles focussing on psychology, psychiatry and mental health. Produced by the American Psychological Association.
- **Web of Science** (1970 to date) - A multidisciplinary database covering science, social sciences and arts and humanities. The Web of Science Core Collection contains access to the following:
  - Science Citation Index Expanded (1970-present)
  - Social Sciences Citation Index (1970-present)
  - Arts & Humanities Citation Index (1975-present)
  - Conference Proceedings Citation Index- Science (1990-present)
  - Conference Proceedings Citation Index- Social Science & Humanities (1990-present)
  - Book Citation Index– Science (2005-present)
  - Book Citation Index– Social Sciences & Humanities (2005-present)
  - Other databases within Web of Science include: Biosis Citation Index, Biosis Previews, Data Citation Index and MEDLINE.

- **Google Scholar** - freely accessible internet search engine that indexes scholarly literature from a wide range of disciplines and publishing formats.

The searches were carried out using both index (Medical Subject Headings or MeSH) and free text terms. This method was used as it is considered that using this combination will maximise the sensitivity of a search. The database search strategy subject headings and keywords are shown below in Table 2.1 (p42).

1	Child or children
2	Adolescence or Adolescent
3	Paediatric or pediatric
4	Young people or young adult
5	Adolescence or teenager
6	All above as OR
7	Visitors to patients or visitors
8	Hospital visiting or hospital visit
9	Visiting relatives
10	All above as OR
11	6 AND 10

*Table 2.1 Electronic database search terms*

Standard reference books on nursing procedures and the history of hospitals/ hospital visiting were searched for information about policies or procedures relating to children visiting adult patients. No journals were hand searched as all relevant publications

were available on electronic databases or direct from publishers. An attempt was made to identify any relevant conference proceedings using the online database and by personal communication. References quoted in included and excluded studies were reviewed for information on other research or cases and for additional citations.

As the study proposal had originated within local clinical practice, the hospital's policy and procedures databases were searched in addition to the hospital Intranet and Internet sites. The Senior Nurse Team (SNT) and other healthcare colleagues were asked if they were aware of any guidelines or policies, or any papers presented at conferences. None were named that had not already been identified using the electronic database search. Members of the SNT could remember visiting restrictions relating to hospital policy historically, but were unaware of any policies or guidelines used at the hospital within the previous twenty years.

It was proposed that an attempt would be made to identify and contact the authors of any ongoing or unpublished trials identified. Attempts were made to contact authors throughout the study, particularly Knutsson (Knutsson, Samuelsson, Helström, Bergbom, 2008) in both 2011 and 2014 without success. After the publication of further work in 2017 (Knutsson, Enskär and Golsäter, 2017; Knutsson, Enskär, Andersson-Gäre and Golsäter, 2017) a further attempt to make contact was made which was successful and resulted in possible collaborative work in the future.

## **Identification, screening and eligibility of the literature**

Relevant literature was identified using the search strategy detailed (Table 2.1, page 42) and screening processes for eligibility were applied at each stage. Titles and abstracts were reviewed against the criteria detailed on page 39. Following this all potentially relevant papers were reviewed in full using the inclusion/exclusion criteria.

### **Search results**

The electronic database search initially provided 1879 records. Following screening of the titles at the electronic database stage and removal of duplicates 73 records were retained for a more detailed review. Review of the abstracts resulted in the exclusion of 15 papers and a further 24 papers were removed following full-text evaluation. There were 25 papers identified through citations in the papers reviewed from the database search and these were included in the review. No additional citations were identified through personal communication.

Full-text evaluation revealed that 59 papers met the inclusion criteria (Table 2.2, p.45). Data was extracted and documented using a standardized data extraction form (Higgins and Green, 2005) which detailed the records identification, study methodology or record type, characteristics of participants, details of any intervention, outcome measures or results and recommendations. The data extraction form is presented in Appendix 1 (p.320).



## PRISMA Flow Diagram

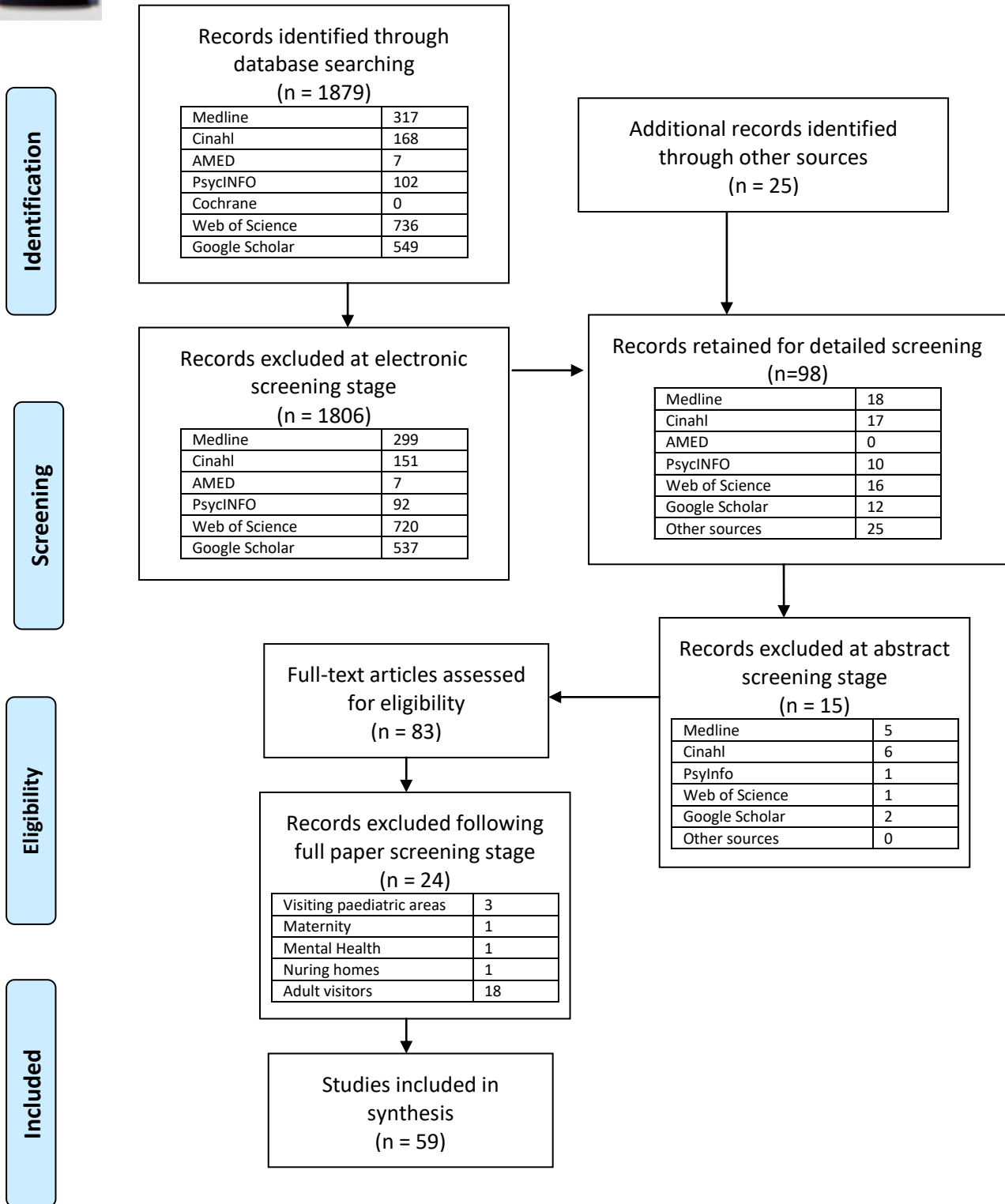


Table 2.2: PRISMA flow diagram

(Based on Moher, Liberati, Tetzlaff and Altman. The PRISMA Group, 2009)

## **Characteristics of excluded studies**

Papers excluded as they did not meet the inclusion criteria included those related to paediatric intensive care (Bonifacio and Boschma, 2008; Dokken, Parent and Ahmann, 2015; Hill, 1996; Kamerling, Lawler, Lynch and Schwartz, 2008; Maxton, 1997; Rozdilsky, 2005; Walls, 2009) and parental or sibling visiting of child patients (Caldwell, 1982; Davies, 2010; Domaison et al, 2011; Jefferies, 1973; Morgan, 1967; Poster and Betz, 1987). Those discussing children visiting maternity units (Goodman, 1982, Spear, 2009), mental health units (Carlisle, 1998; O'Brien, Anand, Brady and Gillies, 2011a, O'Brien et al, 2011b) and nursing homes (Huus and Bruun, 2014; Siddell, 1993) were also excluded.

Papers which related to adult visitors (Agård and Maindal, 2009; Agård and Lomborg, 2010; Athanasiou, Papathanassoglou, Patiraki, McCarthy and Giannakopoulou, 2014; Cox, James and Hunt, 2006; Cullen, Titler and Drahozal, 2003; Fisher et al, 2008; Green et al, 2012; Leske, 1998; Levers, 2014; Maxwell, Stuenkel and Saylor, 2007; Mendonca and Warren, 1998; Paladiuchuk, 1998; Paul and Rattray, 2008; Piechniczek-Buczek, Riordan and Volicer, 2007; Sulmasy and Rahn, 2001; Takman and Severinsson, 2005; Tin, French and Leung, 1999; Trueland, 2014; Zaforteza, Gastaldo, de Pedro, Sánchez-Cuenca and Lastra, 2004) were excluded if there was no reference to children visitors within the text.

## **Characteristics of included studies**

In total fifty-nine papers informed the literature review. Three papers were not published in English and have been translated by international colleagues. Of these two papers were based in France (Blot et al, 2007; Pinoël, 2015) and one paper was based in Austria (Granaas-Elmiger, 2000). Translation by appropriate international colleagues aided the culturally progressive approach of the review strategy by providing an opportunity to enhance understanding and meaning. The translators had an understanding of the associated cultural perspectives and linguistics underpinning the papers. This supported ethical principles in the review, such as integrity, scholarly responsibility and respecting diversity (Onwuegbuzie and Frels, 2016).

The complexity and relevance of this subject area is evidenced in the amount of literature available spanning back to the 1950's and across a number of countries (Table 2.3, p.48). Literature was found originating in Western Europe and North America. No literature was found from Eastern Europe, Asia or Australasia which related to child visitation to hospitals. There are many potential reasons for this and in some countries it may relate to differing values and cultures (Boslaugh, 2013). Child visitation may not be seen as an issue in some countries or there may be contemporary priorities which take precedent, such as conflict and political instability.



<b>UK n = 22</b>	<b>USA n = 25</b>
Bates 2010 Chaloner 1972 Child Bereavement Charity, 2011 Clarke 2000 Clarke and Harrison 2001 Dopson, 1989 Forrest, Plumb, Ziebland and Stein, 2006 Gibson et al, 2012a Gibson et al, 2012b Gilbert 1959 Goodall 1982 Johnstone, 1994 Jones, 1984 Kean, 2009 Kean 2010 Macpherson and Cooke 2003 McIvor, 1998 Moore 2006 Pengelly, 2000 Staines 2007 Vint, 2005a Vint, 2005b	Anon, 1991 Barchue 2012 Berlow, 1960 Bruck, 2011 Craft, Cohen, Titler and DeHamer, 1993 Davis, 2015 Falk, Wongsang, Dang, Comer and LoBiondo-Wood, 2012 Gremillion 1980 Hanley 2008 Hanley and Piazza 2012 Ihlenfeld 2006 Johnson, 1994a Johnson, 1994b Lewandowski, 1992 Matorin 1985 Morgan 2012 Nicholson et al, 1993 Norman 1995 Pierce 1998 Rainer, 2012 Simon, Phillips, Badalamenti, Ohlert and Krumberger, 1997 Sutter and Reid 2012 Whitis, 1994 Winch 2001
<b>Sweden n = 5</b>	<b>Canada n = 2</b>
Knutsson and Bergbom 2007a Knutsson and Bergbom 2007b Knutsson and Bergbom 2007c Knutsson, Otterberg and Bergbom 2004 Knutsson, Samuelsson, Hellstrom and Bergbom 2008	Perry and Goulet 2006 Schofield 2016
<b>France n= 2</b>	<b>Italy n = 1</b>
Blot et al, 2007 Pinoël, 2015	Anzoletti, Buja, Bortolusson and Zampieron, 2008
<b>Austria n =1</b>	<b>Belgium n = 1</b>
Granaas-Elmiger, 2000	Vandijck et al 2010
<b>Denmark n = 1</b>	
Christenson 2011	

*Table 2.3 papers by country of origin*

It is recognised that healthcare systems across the world are different. However, even within each country different systems may be operating, based on resource availability and, the needs and values of local populations (Boslaugh, 2013). Some issues and challenges were consistent internationally. Almost all countries reported that children under twelve years were often restricted from visiting. Whereas there was variation in some strategies described. Providing play rooms and play facilities in hospitals for children visiting were identified in the USA (Gremillion, 1980; Matorin, 1985), including areas where children could be left with reception staff whilst their parents visited the patient. Although these are older papers, the introduction of such measures may reflect the hospital resources and receptionist facilities in some hospitals in the USA, which has a private insurance system. Such facilities are not available in UK hospitals which has a national health service

There have been a number of research studies published since the 2000's using quantitative, qualitative and mixed method approaches. The initial quantitative research studies relating to children visiting adult patients in ICU's concentrated upon policies and procedures (Anzoletti et al, 2008; Knutsson et al, 2004; Vandijck et al, 2010; Vint, 2005, 2005b). Knutsson et al (2004) carried out a multi-centre descriptive study to survey Swedish ICU policies, guidelines and recommendations about child visitation. Similarly in the UK, Vint (2005a, 2005b) performed a postal survey to identify how many ICU's had a policy on child visitation. Knuttson and Bergbom (2007a) went on to perform a quantitative descriptive multicentre study using postal questionnaires based on their previous research exploring the reasons for restricting child visitation to ICU. This was followed up by a descriptive study questionnaire to custodians of children visited ICU (Knutsson and Bergbom, 2007b, 2007c).

A number of qualitative methodologies have been used to explore perceptions, experiences and opinions of staff, parents and young people. Craft et al (1993) used a phenomenology approach and used open ended audiotaped interviews with children of parents admitted to critical care. Knuttson et al (2008) used Gadamer's hermeneutic philosophy to analyse interviews with children who had visited a patient on ICU and Kean (2010) employed a constructivist grounded theory approach to explore families' experiences with critical illness in ICU and nurses' perceptions of families. A descriptive exploratory design gathering both quantitative and qualitative data was used by Simon et al (1997) to examine current policies and nurses' perceptions of these. Clarke's (2000) exploratory pilot study used in-depth focused interviews to examine the perceptions of nurses.

There is a lack of detail in some of the reports about the characteristics of the participating children and parents/guardians. Nicholson et al (1993) and Kean (2010) state that they included English speaking families only. This raises the question of what differences there may be in these situations for none-native speaking families and those from different cultural backgrounds.

The aim of this review was to appraise the evidence available to ascertain what was already known about children visiting adult patients in hospital settings. The synthesis of the identified literature was therefore conducted and is presented using the six datasets identified in the search strategy as relating to the research questions:

1. Policies and procedures relating to children and young people visiting adult patients
2. Reasons for excluding or restricting children and young visiting adult patients

3. Perspectives and experiences of healthcare professionals
4. Perspectives and experiences of parents and/or guardians/custodians
5. Perspectives and experiences of children and young people
6. Strategies to facilitate children and young people visiting adult patients

### **Policies and procedures relating to children and young people visiting adult patients**

Progress has been made in maternity services (Goodman, 1982; Spear, 2009), paediatric services (Davies, 2010; Dokken et al, 2015) and childhood bereavement (Adams et al, 1999; Child Bereavement UK, 2011; Cole, 2001; Macmillan Cancer Support and Winston's Wish, 2015 and 2018; Thompson and Payne, 2000). However, restrictions on children who wish to visit acutely ill adult relatives in hospital remains a controversial international issue (Anzoletti et al, 2008; Moore, 2006; Vandijck et al, 2010) with policies and guidelines not being embedded in practice.

No reference to child visitation was found in the search of local policies and procedures. There was also no evidence of any guidance relating to children visiting adult patients located on the local hospital intranet. A lack of written policy had previously been found in other UK ICU's. Vint (2005b) reported that there was a lack of written policy and information available in forty-six adult general and cardiothoracic ICU's in the UK. Knutsson et al (2004) in a survey of 72 Swedish ICU's of which 57 replied found that only one had any written policy or guideline relating to children visiting and only two actively encouraged children to visit. In a survey of the visiting policies of 110 ICU's in North East Italy Anzoletti et al (2008) reported that children

less than twelve years of age were not allowed in 78% of the units. This applied to both adult and paediatric patients, with 64% of the paediatric ICU's not allowing children to visit. One positive result was that in 85% of the ICU's nursing staff were involved in decisions relating to visiting policies. Despite this, the ICU's continued to have very restrictive visiting rules and policies which it was suggested possibly could be linked to the level of nurse training in Italy at that time where there were very few graduate nurses (Anzoletti et al, 2008).

In addition to a wide disparity in the availability of visitation policies with reference to children, adherence with those policies that were in place was also found to be variable (Anzoletti et al, 2008; Clarke, 2000; Simon et al, 1997). Simon et al (1997) conducted a descriptive exploratory study using both quantitative and qualitative data in the USA. Fourteen sets of questions were asked in this study, about current visitation practices, nurse's perceptions of the effects of their institutions policy on visitation and how nurses viewed policies that govern practice with the nurse's perceptions. Study questionnaires were distributed via the mailboxes of staff nurses working in critical care units in five area hospitals. Two-hundred and one nurses completed the questionnaire, a return rate of 33.5%. Females accounted for 90% of respondents: 65% had a BSc qualification, 17% an Associate degree in nursing, 9% a Diploma and 4% an MSc in nursing. There is no conclusive evidence documented in the paper that educational level had a significant effect upon visiting policy and practices.

Visiting policies were reported to be restrictive by 70% of respondents. However 78% of nurses were non-restrictive in their clinical practice. In relation to adherence to official visiting policy, Simon et al (1997) found that nursing judgement was reported as

the main reason given as to why an official policy was or was not followed. Nurses reported that these judgements were based upon the assessment of the patient, patient choice where able, the family situation, the patient's length of stay in ICU and cultural factors. When discussing children visiting, evaluation of the age of the child was reported as a factor in decision making and an example of when official visitation was enforced included when children were unsupervised.

Simon et al (1997) concluded that hospital and ICU visitation policies should be reviewed and revised to ensure that there are opportunities for nurses to use their clinical judgement in decision making thereby individualizing visitation to meet the needs of the patient and family. Replication studies are recommended, as it is acknowledged that limitations to the study could include researcher bias, sample bias and a lack of generalisability (Simon et al, 1997).

Within the UK, the British Association of Critical Care Nurses (BACCN), a leading organisation for critical care nursing produced a position statement on visiting practices in adult ICU's (Gibson et al, 2012b). Using nursing experts together with representatives from patient and relatives' groups' clinical practices and current literature were reviewed to develop the position statement. The stance relating to children visiting was that although facilitating child visitation to the ICU proved a positive experience for staff, the literature reviewed demonstrated that there was a deficit in the education and resources required to support staff in this area.

To summarise, visitation policies directly concerning children as the visitors to adult clinical areas were found in the literature but related only to ICU's and critical care areas. Many of the ICU's were found to have either no policy or very restrictive

policies. Often the restrictions were age limits, particularly for those aged under twelve years. Adherence to the policies which were in existence was variable, with evidence that some nurses used their own clinical judgement when deciding whether or not to allow children to visit regardless of the status of any policy.

### **Perspectives and experiences of healthcare professionals**

Gilbert's (1959) UK paper provides a valuable discussion relating to the question of allowing children to visit patients in hospital from the position of a hospital administrator. Although clearly located in its historical context, this paper does contain themes which reverberate throughout current literature, relating to the need to 'mitigate the damage' to the 'deserted' child' when the mother is admitted to hospital. Gilbert (1959) identifies four separate circumstances which should be considered from the perspectives of the patient, the child and the hospital staff. The first situation is that of the mother admitted with an infectious illness such as tuberculosis, where the mother may be absent from home for up to two years. It is advocated that arrangements should be made for the children to visit at least weekly, while taking precautions to stop any child becoming infected, such as the use of open air meetings.

The second situation identified, is that of the mother who is involved in an accident. In this instance it is advised that the mother may be suffering shock and in need of absolute quiet and freedom from worry. Again, infection control is a consideration as it is advised that the hospital must ensure that there is no introduction of infection. In these cases, it is advised that the child may be better not visiting until any bandages or disfigurement have been dealt with (Gilbert, 1959).

The third situation involves any surgical or medical care involving a short hospital stay of ten to fourteen days. It is stated that the mother and hospital staff may think the child does not need to visit in these circumstances as the mother will be home soon. However, Gilbert (1959) expands to consider the child's perspective and highlights that the child may worry that their mother has gone for good. The possibility of the child hearing stories in the school playground of mothers who have disappeared causing distress is discussed as is the likelihood that the child may not feel able to ask questions. An example is provided of a child whose mother was pregnant who began to object to going back to boarding school on a Monday morning. This resolved once the new baby was born and the child later disclosed that a school friend had told her she had read in a story book of a Mummy who died when she had a baby. The child in this case had been too afraid to talk about this story or their concerns and thereby received no comfort or reassurance from any adult (Gilbert, 1959).

The fourth situation discussed is that of confinement care. In the historical context confinement relates to maternity care. It is advised that children visiting are an important consideration as the mother will return home with a new baby who will occupy her time. Again, an example is given of a worried child being taken to visit her mother in the maternity ward and on seeing the new baby in a crib becoming happy again. At this time only three London hospital maternity units allowed some visiting by a child. It is again highlighted that there is a need to be careful of children introducing infection to these maternity units and that children should not be allowed to visit on an open ward (Gilbert, 1959). Although historical in relation to disease knowledge, disease management and accepted clinical practice Gilbert's (1959) paper is a valuable resource into the history of the complexities associated with the concept of children as visitors healthcare environments.



Over the following 50 years, there were papers published that continued to contribute to the debate started by Gilbert (1959) from healthcare professionals, including perspectives from both personal and professional experiences. One such paper was written by a member of healthcare staff from the locality where this study is based. Goodall (1982) was a Consultant Paediatrician who reflected upon her professional experiences in paediatrics and in dealing with a mother who was to be admitted to hospital. The mother was worried about how the child would cope with being separated from her, as children were not allowed to visit the ward she was to be admitted to.

Goodall (1982) discusses the reasons children may be refused entry to an adult ward; that it might upset the child, distress the patient or annoy other patients. It is argued that children will be more upset by not knowing what is going on than by being included and this is related to theories of attachment (Bowlby, 1971; Goren et al, 1975 cited in Goodall, 1982) separation and age-related reactions. It is advocated that the younger the child the more important it is that hospitals allow the child to visit a parent and that the effect of protecting children from all unpleasantness could delay or damage the child's emotional development. One suggestion was that as alarm and anxiety are likely to increase with age, "if we are trying to spare distress to children, the ward notice should read more fittingly 'children over 14 years not admitted'" (Goodall, 1982, p.1367).

A number of papers published since 2000 discuss healthcare professionals' experiences and report similar themes: inconsistency with policy, the need to protect children, the lack of collaboration between different specialities and the dependence upon nurse attitudes for visits to be allowed. An exploratory pilot study in the UK used

a qualitative research approach and in-depth focused interviews to examine and describe the experiences and perceptions of trained nurses towards children visiting adult ICU's (Clarke, 2000). A purposive sample of twelve trained nurses who worked on an adult ICU in a District General Hospital was applied, with ICU experience being between eight months and nineteen years. Using thematic analysis four categories were reported to have emerged: bending the rules, building a rapport, protecting and shielding, and coping and collaboration.

Bending the rules referred to the inconsistencies experienced between official and unofficial visiting policies. Nurses appeared to adapt official policies to suit each individual circumstance or patient. This supported the findings of Simon et al, (1997) that adherence to policies was variable and often based on nurses judgements. It is reported that the participants felt that it was the individual nurses' attitudes which determined whether a child was allowed to visit the ICU, rather than any written policy (Clarke, 2000). Building a rapport related to child visitation appearing to depend upon the nurse's ability to establish a rapport with child and adult members of the family involved. Most participants reported that they did not take a proactive stance, but waited for the adult family members to discuss the issue of a child visiting (Clarke, 2000).

Protecting and shielding related to the children, the family, the patient and the nurses. The desire of well family members to protect and shield the child from the ICU environment was reported to be a strong theme throughout the data. Participants perceived this to be the main reason why children did not visit the ICU and as such, in supporting parental choice they often did not provide information about child visitation. It was reported that participant's also dissuaded families from bringing children to visit

due to their desire to protect the patient from noise or infection and the nurses from additional emotional trauma (Clarke, 2000). The coping and collaboration category similarly related to the participants personal experiences and ability to cope with child visitation. It is reported that there were good experiences described, but that in some circumstances the visits had been “emotionally demanding and distressing”. It was noted that participant’s did not appear to collaborate with other paediatric experienced healthcare colleagues, but tried “to cope as best they could by providing children with information and emotional support” themselves (Clarke, 2000).

Clarke (2000) provided a number of recommendations for clinical practice within the ICU. Firstly, that prior to attempting any change in practice, nursing staff needed to explore and challenge their own beliefs and attitudes particularly related to family-centered care and child visitation. The provision of education and training on how to communicate with children based on growth and developmental theories was highlighted, as was encouraging a collaborative team approach possibly with the paediatric unit or hospital chaplains. It was also recommended that information about different sources of expertise and books should be made available on the ICU, and could be a resource for children, parents and healthcare professionals (Clarke, 2000).

Implications for research from the research (Clarke, 2000) were that the concept of family-centred care in the UK needed defining and developing in relation to adult ICU’s. Comparative studies of nurses and parents perceptions and experiences towards children visiting ICU using qualitative research approaches were also highlighted as they could develop greater understanding of the issues and any disparities. Clarke (2000) concludes that the dissemination of research evidence and the relaxing of visiting practices would empower those with parental responsibilities to

make informed choices around child visitation to the adult ICU. In the commentary to Clarke (2000), Pengelly (2000) noted that although there was a large amount of evidence regarding children's understanding, myths concerning their needs persisted and that extensive research is required into child visitation.

Winch (2001), a Paediatric CNS working in a children's hospital-within-a-hospital in the USA, provides an insight into the perspective of a children's nurse. In paediatrics, family involvement was considered of prime importance to the wellbeing of a hospitalised child, with facilities designed to encourage family involvement and sibling visits. Winch (2001) applied the concerns of siblings of hospitalised children as categorised by Craft and Wyatt (1986) to the concerns of a child with a hospitalised parent. Craft and Wyatt's (1986) four categories were: (1) what is wrong? Is my brother/sister going to die? Is he/she going to get better? (2) Could it happen to me too? (3) Is it my fault? and (4) Don't you care about me? Winch (2001) suggests that in addition to these questions when the patient is a parent, children are likely to have additional stresses relating to parental absence and the changing relationship with the well parent. Competing role demands relating to family illness may also lead to reduced attentiveness or parental availability for any children in the family. The ability of the family to cope is raised as a possible source of stress, as parents may be unable to reassure or support their children due to their own distress which may be overwhelming. In turn, their confidence may be affected by the associated feelings of helplessness or fatigue (Winch, 2001).

Winch (2001) reflected upon a clinical situation for which consultation was provided as a Paediatric CNS to a family of a mother of three who had breast cancer. The mother required support to inform the three children of her cancer diagnosis. By collaborating

and applying the mother's knowledge of her children to the Paediatric CNS's developmental knowledge this was achieved with each child requiring different types and levels of information. One child needed factual information, one needed information about the mother's feelings and the third needed the opportunity to participate in the care. It is suggested that in addition to being able to provide information to children and to address fears or misconceptions, child visitation can provide opportunities for improving the care of the patient. Winch (2001) suggests that it provides an opportunity to discuss the patient's role in the family, their anxieties and fears about their children and provides information about the whole family making education and discharge planning more effective.

There were a number of papers which presented personal opinions from healthcare professionals, often based on personal experiences. Bates (2010) who worked in an outpatient department in the UK recalled a friend's visit to the casualty department where the behavior of some parents was described as 'astonishing'. She described how two mothers in the department with three children under school age seemed unaware of their surroundings. The mothers ignored the children's play area and let the children 'run riot', throwing food around the waiting area. One mother proceeded to put the child's food directly onto the floor for the child to eat. Bates (2010) goes on to discuss how in some hospitals children were allowed to visit and that some nurses who made comment upon any behavior by parents were liable to be treated to a 'mouthful of abuse'. She reflected on historical visiting rules which were stringent and allowed no visiting by any child under twelve years of age. The concluding opinion is that nurses "need to have the authority to regulate visiting for children" (Bates, 2010, p.27).

Barchue (2012) and Morgan (2012) provided opposing opinions on the question of whether children should visit patients in an ICU. Barchue (2012) described the personal experience of her sister's ten day admission to ICU following a stroke. She described how her own son was very close to her sister but although she knew he should visit due to this close bond, he was unable to as children were not allowed in the ICU. This personal experience caused a change in practice in the ICU where Barchue worked as head nurse. There was the introduction of twenty-four hour visiting and the rescinding of the ban on child visitation. Barchue (2012) advocates that when done in the best interests of the patient, with family support and preparation for the child involved, a visit to a relative in ICU can be an excellent life experience for the child and rewarding for the healthcare professionals. It is recommended that the child should want to visit, should not be forced or coerced, and is well prepared prior to the visit.

In response to Barchue, Morgan (2012) presented the opposing view, advocating that children under twelve years of age should not be allowed to visit or should have restricted visiting to the adult ICU. It is highlighted that as the ICU can be an intimidating place for adults, that the impact upon a child would be greater and a visit could prove traumatic. Personal clinical experiences were used to support this argument, with Morgan (2012) having witnessed children clinging to their parents because the relative in ICU was swollen and oozing blood. Additional reasons for restrictions are given as adverse physiological effects on the patient, disruption of patient care, an increased incidence of infection and unsupervised children causing incidents such as damage to equipment. The current practice in the authors ICU was that children under twelve years of age were only allowed to visit if a family member was at the end of life. Even in these cases, if the patient had any isolation precautions due to an infection, the child could only say hello from the doorway. Morgan (2012)

advocates that although children are integral members of a family, visiting to the ICU should not occur unless there are special circumstances until more is known from the research.

In summary, healthcare professionals' experiences and perspectives on children visiting adult patients in hospitals have been documented for over fifty years. Early opinions (Gilbert, 1959; Goodall, 1982) considered a child's need to have contact with the mother if she is hospitalised for any reason including childbirth. Attachment theories (Bowlby, 1971; Goren et al, 1975 cited in Goodall, 1982) and child development theories (Piaget, 1969) underpin the later papers (Goodall, 1982) which discuss the issues of mothers as patients. Since the 1980's, the focus has been on whole families rather than just the mothers, with the majority of papers relating to children visiting relatives admitted to ICU's. All report similar themes: inconsistency with policy, the need to protect children, the lack of collaboration between different specialities, dependence on nurse attitudes for visits and the need for healthcare staff to receive some education based upon children's development and needs.

### **Reason for restricting children**

In Vint's (2005a) study 40% of ICU staff stated that over a one year period a decision had been made by a child's well parent or guardian not to allow them to visit the ICU. The reasons given were that the child would not be able to cope and the child needed protection. There was also concern that the child would be disruptive and that children visiting posed an infection risk. Twenty percent were also aware of a decision to restrict visiting by healthcare staff and this was generally attributed to the possible

increased risk of infection. This research paper (Vint, 2005a) reported the findings when surveying staff from ICU's that admitted both children and adult patients.

In a follow-up paper Vint (2005b) concentrated on the findings from ICU's that admitted adult patients only. In this environment 61% of staff stated that a decision had been made to stop a child from visiting by the well parent or guardian over the previous one year and 22% were aware of restrictions being made by healthcare staff. The reasons given again were that it would be too upsetting for the child, the child was too young to understand what was happening, and that visiting would be an infection risk.

Several reasons were identified throughout the literature to account for both who restricted and why they restricted children visiting hospitalised adult relatives. Many nurses, physicians and parents/guardians thought that visiting would be too upsetting for the child involved (Clarke, 2000; Goodall, 1982; Knutsson and Bergbom, 2007a; Knutsson et al, 2004; Morgan, 2012; Vint, 2005a, 2005b). The assumption that children will be disruptive and cause distress to the patient or annoyance to other patients was also a common reason to restrict them from visiting (Bates, 2010; Goodall, 1982; Gremillion, 1980; Knutsson et al, 2004; Morgan, 2012; Vint, 2005a, 2005b). Fear of liability was noted by one author (Gremillion, 1980), whereas infection control issues were frequently cited as a reason to exclude children.

In the 1880's knowledge of the causes of disease and infection resulted in strict visiting rules and the development of isolation hospitals (Mooney, 2009). Although, the understanding of disease processes and medical management has evolved over time, strict visiting rules seem to continue up to present day. Infection control is an important



topic in contemporary healthcare. The possibility that children cause an increased risk of spreading infections or are at risk of acquiring infections is frequently cited in the literature as a reason to restrict their visits to hospitalised relatives (Clarke, 2000; Gremillion, 1980; Knutsson and Bergbom, 2007a; Moore, 2006; Vint, 2005a, 2005b).

Gremillion (1980) reported that an increased risk of infection was a common reason given for stopping children visitors despite evidence in one study of twenty-six hospitals examining cross infection in paediatric wards finding no differences between those that allowed children to visit and those that did not (Watkins, 1949 cited in Gremillion, 1980). Screening during community outbreaks was advocated, with an example provided of one incident on a paediatric oncology unit. The unit had open visiting and there was an incident of twenty cases of varicella occurring simultaneously which involved several of the patient's siblings. Dialysis and oncology units were therefore listed as areas with an increased infection risk associated with visitors, although it was reported that there had been no increased infection found when simple screening and precautions were observed in oncology and transplant services (Gremillion, 1980).

Screening procedures and infection control precautions were common in hospitals in the USA. In the 1990's it was reported that although the Center for Disease Control (CDC) had no official infection control guidelines on hospital visiting policies, strategies were adopted by infection control practitioners to prevent nosocomial outbreaks particularly linked to child visitors (Anon, 1991). Normal practice was to prohibit children from patient areas except in special circumstances, such as visiting a sibling and strict screening for infectious diseases was common when children were allowed to visit (Anon, 1991). Roberta Mirenberg of Lutheran Medical Center in New York, USA

highlighted concerns about recent measles outbreaks, but stated that there had been no recorded cases within the hospital linked to visitors. It is difficult to assess whether screening and visitation policy reduced the infection risk during this outbreak, as although strict visiting policies were in force at the hospital, Mirenberg acknowledged that many visitors did not follow the policy and security was often required (Anon, 1991). Another infection control co-ordinator at Athens (GA) Regional Medical Centre stated that children under twelve years of age were prohibited except for sibling visiting, and in these cases a special pass had to be obtained from the information desk. It is reported that the visiting policy was strictly adhered to and that a play area was available near to the information desk where staff would watch children while parents visited the patient (Anon, 1991).

Children often appear to be the first group of visitors who face restrictions related to infection control procedures, as they were in historical records. In the early 1900's children were banned from visiting hospitals due to risk of smallpox infection (Lindsay, 2009). Similarly, a 2006 news report detailed that Portsmouth Hospitals Trust had drawn up contingency plans to severely restrict children visiting during any diarrhoea and vomiting outbreaks due to the infection risk (Moore, 2006). Whereas, this plan relates to the protection of both patients and visitors, others advocate that child visitation should be restricted in ICU's so as not to expose the children to resistant infections (Morgan, 2012). However, BACCN (Gibson et al, 2012b, p.13) concluded that "the argument for refusing visitors into critical care units due to its impact on increasing infections is unfounded and does not appear to be based upon empirical evidence".

Fear of liability is mentioned by one author (Gremillion, 1980) and was related to incidents where hospitals had been held liable for injuries to visitors due to negligence. It is suggested that if an incident occurred due to failure in enforcing visitor restrictions, then negligence would be easy to prove. Children visitors were viewed as a serious legal liability as it was acknowledged there were difficulties in ensuring absolute enforcement of visitation rules relating to children. This paper may reflect the private insurance system and culture of the healthcare system involved, as this related to visiting in the USA.

Three literature reviews were found, all of which related to children visiting adult patients in the ICU (Clarke and Harrison, 2001; Johnstone, 1994; McIvor, 1998). All were performed by UK reviewers, with Clarke and Harrison (2001) specifying that they had considered only English language studies. Johnstone (1994) reported that there was no conclusive proof that children interfered with the working of the ICU, introduced or caught infections or were more worried about the surroundings than adults. Recommendations were that parents should make the final decision as to whether their child visits an adult relative on ICU and that both nurses and doctors should be able to discuss relevant research with the parent to enable them to make an informed decision. In addition, nurses should be more aware of childrens physical and psychological growth and how to support parents to support their children (Johnstone, 1994).

McIvor (1998) provided the reasons given for policies which excluded children from visiting an adult relative in ICU, which included age, infection risk and that it would be too distressing. Similarly to Johnstone (1994) there was no conclusive evidence found to support restricting all children's visiting. The author suggests that the majority of

children should be allowed to visit if they wish, but with the involvement of their parents, and adequate age appropriate preparation and support during and after visit. There was some evidence to restrict very young children, under the age of nine months, due to the possible increased risk of nosocomial infections related to the establishment of humoral immunity. It was highlighted that there was a need to establish whether infectious disease screening could protect patients vulnerable to infections, such as those with neutropenia, but it was questioned whether this type of screening should only be restricted to children (McIvor, 1998).

Recommendations related to supporting visiting for children and families. Nurses must recognize that children are affected by the admission of their relatives and therefore have a right to receive information. That parents may not always be aware of their own child's needs in visiting the ICU and so may themselves need support from the healthcare team. It was recognised that nurses need appropriate knowledge to provide this support to children and families, and so require training in child development relating to age appropriate concerns, considerations and needs (McIvor, 1998). The author suggests the implementation of a simple statement "Children may visit the ICU. However, to ensure that this is beneficial to the patient and the child, it is advisable to discuss this with the nursing staff caring for your relative before any visit" (McIvor, 1998).

Clarke and Harrison (2001) again report that the literature supports children visiting critically ill relatives in the ICU, identifying it as a constructive intervention to help children to cope. The authors recommend that those in clinical practice in ICU's explore and challenge previously held beliefs, attitudes and assumptions towards children visiting this environment. Also recommended is the provision of education and

training about how to communicate with children, the development and testing of planned systematic support for children visiting and that each child is considered as an individual who is part of a family group. The development and testing of specific written information for well family members, proactive seeking of assistance of the Child Health Team to develop resources and consideration of child friendly facilities are other recommendations. It is suggested that AR could be used to plan, implement and evaluate facilitated support for children visiting an adult ICU and the need to explore the short and long term effects on children visiting patients on ICU is raised (Clarke and Harrison, 2001).

### **Perspectives and experiences of children and young people**

Craft et al (1993) conducted a phenomenological study into the effects of a critical care admission on the family and reported the children's views of parental admission to a critical care setting. Interviews were held with eleven children of nine parents who were patients in a large Midwestern hospital in the USA. Participant inclusion criteria was that the child had a parent who had been admitted to the adult medical or cardiac critical care unit; the child spoke English and was aged between five and eighteen years of age. All participants were male, were aged between seven and eighteen years and were interviewed at the hospital by a critical care nurse who was also a paediatric nurse.

The researchers identified four main themes: emotional turmoil, family disruption, a need for support, and experiencing minor illnesses. Emotional turmoil was described as feelings of shock, anxiety, fear, confusion, frustration and uncertainty. Shock related to the sudden severe illness of the parent. Six children, who had received no

preparation for the visit by family members or staff, reported being frightened by the equipment. In contrast those children who had visited an ICU before or who had received some preparation did not appear frightened. The primary concern of the children was their ill parent's health; relating to the fear that they would die and anxiety about their recovery. Five children reported confusion about the illness or a desire to have more information, as in one quote where the child stated, "I think I would have been a little bit more at ease knowing a little bit more about what happened" (Craft et al, 1993, p.67).

All the participants described some element of family disruption, such as the need to take on more responsibilities at home, the loss of family unity and communication issues. Five of the children described that their relationship with the well parent had changed; with some more parents becoming more lenient and others being stricter. All the children had noticed that the "well parent was irritable, tired or depressed" (Craft et al, 1993, pp.67-68). Ten children reported missing both the ill and the well parent and of feeling lonely. Ten children reported that it was important for them to be able to visit the parent at the hospital. One child is quoted as stating that "now I am not as worried as before, because I got to see her" (Craft et al, 1993, p.68). This supports the examples provided by Gilbert (1959) of children becoming more relaxed and happy once they had seen the hospitalised parent.

Emotional support from family and friends was a common theme, although three children described being frustrated with "pity" from strangers and acquaintances. Six children experienced mild illnesses during the admission and it was concluded that this needed further study. The authors reported that the findings were in keeping with earlier studies on 120 children whose siblings had been admitted to hospital (Craft,

1979, 1986; Craft and Craft, 1989; Craft, Wyatt and Sandell, 1985) and concluded that “isolating children by keeping them away from the hospital with little information is not an effective way to help children to cope” (Craft et al, 1993, p.69). It is therefore important to encourage visits and prepare children using developmentally appropriate strategies.

Recommendations are made for further research into child visitation, related to parent’s decision-making processes; and the short and long-term effects of visiting or not visiting upon the child. The study suggested that parents make the decision whether their child should visit the ICU on a predicted emotional response in their child, such as if they think environment or patient’s condition would be overwhelming then they may decide a visit is not a good idea or change the timing for when the patient is more stable. The authors acknowledge that the parent’s perceptions of their child’s knowledge may not be accurate and that they may think they are protecting them by stopping them visiting. Further research into the short and long-term effects of visiting or not visiting on the child was considered important. In relation to short term effects it was found that strong emotions were associated with a parent’s critical illness. The possibility that these emotions if not recognised and dealt with could lead to long term adverse sequelae was highlighted. It was therefore recommended that that nurses develop and test interventions to assist children “to cope adaptively by meeting their informational and support needs” (Craft et al, 1993, p.70).

Knutsson et al (2008) used Gadamer’s hermeneutic philosophy in the interpretation and analysis of interviews with twenty-eight Swedish children aged between four and seventeen years of age who had visited an adult relative in the ICU about their experiences. The interviews were conducted three-months after the visit and the data

analysis generated four themes; that the visit involved waiting, it was strange, it was white, and it was good. All children thought that it felt good to spend time with their relative and to be included and involved in the situation. Waiting was found to be difficult as it led to tension and concern in the children as they often had nothing to do (Knutsson et al, 2008).

The theme 'it was strange' often referred to the patient's appearance or behaviour which was different than normal. Despite this, many children reported that the patient looked better than they had imagined. The environment was also considered strange, and often described as white and gloomy. Many of the children found the machinery interesting and they had questions about what would happen in the event of a power cut. Many felt that the visit was good because they had not been excluded and could see that the relative was still alive. Some were afraid that the cardiac monitor would show a straight line because they knew from television that that meant the patient was dead (Knutsson et al, 2008) supporting the theory that although most children are excluded from real life death, many are exposed to fantasy violence and death daily on television and the news (Laungeni and Young, 1997).

Children comparing things that they witnessed in the ICU to things they had seen in films and television was also reported in a study conducted in the UK, where one child described seeing their father with tubes and stuff as like the film *The Matrix* (Kean, 2010). This study into how children constructed their experiences of visiting a relative in an ICU interviewed nine families using a constructivist grounded theory approach. Twelve adults and twelve children were interviewed, and the results suggested that there are two levels of understanding depending upon age. Children (under fourteen years of age) spoke about the visit on a concrete level focusing on the ICU



environment. In comparison, young people (aged between fourteen and twenty-five years) seemed to understand the visit on an abstract level focusing upon the function of the ICU (Kean, 2010).

It was noted that children often read things, such as what was written on the intravenous fluid bags, or noted details such as the colours of the monitor lines. The majority of the children were happy to ask their parents or the bedside nurses what things were for and about what was around the bed. However, some children were not inquisitive, and it was acknowledged that quiet children may be constructing meaning using their own imagination. One example given was of a child who decided that the catheter bag contained sperm as they had recently received sex education at school. They believed that as the catheter had been inserted through the penis, the catheter bag must contain sperm. This highlighted that there is a danger that misunderstandings which are not noticed in quiet children may exacerbate the already stressful situation (Kean, 2010).

Young people who focused on the "ICU as a function", like the younger children indicated shock and feeling scared seeing the relative for the first time in the ICU. Not all young people were prepared prior to the visit and one young person who had no preparation described the visit as being a nightmare and not what she had expected (Kean, 2010). The young people interpreted the ICU environment as a method to preserve life and their technological awareness also included why equipment was needed and that "seeing the patient in ICU acted as a trigger in realising the life-threatening nature of the illness" (Kean, 2010. P.874). In relation to nursing staff and their perception of a nurse's competence, the young people spoke about actions which

indicated that nurses seemed to care for their relative or knew what they were doing (Kean, 2010).

Kean (2010) noted that one of the limitations of the study was that different issues may have been raised if the interviews had been conducted separately. However, as the study was interested in the family's experience, the children and young people were considered part of the family and so it was appropriate to interview them together. The study concluded that a constructed and age appropriate approach to support children visiting adult ICU still needed development, and that nurses needed to reflect on current practice, and challenge beliefs, attitudes and ICU education in understanding children and young people's needs in ICU. The authors again recommend further research into the effects of visiting on children.

Many of the findings in the research studies (Craft et al, 1993; Kean, 2010; Knutsson et al, 2008) reflected theories about children's perceptions and experiences surrounding illness and death: that 'bereaved children need help in four main areas: information, reassurance, the expression of feelings and an opportunity to be involved in what is happening', reflecting the needs of the adult population (Monroe, 1995, p.89). All of the studies highlighted the need in clinical practice for nurses to reflect upon practice, challenge beliefs and attitudes, to have age specific information available, to be able to make adjustments to improve the child's experience and for nurses to receive education in supporting children and families.

## **Perspectives and experiences of parents and/or guardians/custodians**

Following an initial paper by hospital administrator Gilbert (1959), Matorin (1985) a social worker in a psychiatric setting in the USA reflected upon their own personal experience as a patient and parent. This paper, published 26 years after that of Gilbert (1959), urged hospital administrators to re-examine policies about children's rights to visit. Matorin's (1985) personal account of being hospitalised for emergency cancer surgery detailed the challenges faced in trying to be able to see her own five month old child and the associated effects this had upon them both. She discussed the perception of a persisting mythology shrouding child visitation in the medical setting which prevented her child from being able to visit. The reasons given were the potential for increased infection, and the disruption of staff routines and procedures.

Matorin (1985) referred to the introduction of playrooms and the relaxing of restrictive rules for children visiting by the US Air Force (Berlow 1960; Gremillion 1980) both of which were not accessible in her case. She described the experience as causing increased levels of fear and stress to the stress of the brief separation imposed by the hospital for surgery. Adding to the stress of the possibility of metastatic cancer, the feelings of terror of the prognosis was the separation from her 5-month-old child. All these feelings were "aggravated by confrontation with traditional administrative bureaucracy" when her request that her child be allowed to visit her in her hospital room was refused. A "compromised 'visit' in a noisy, drafty hospital lobby [was allowed but] left this vulnerable patient and her overwhelmed baby son frustrated and totally unable to connect emotionally amidst wheelchairs, an attending private nurse, the father and housekeeper and an intrusive stream of other visitors and staff" (Matorin, 1985, p.5).

Jones (1984) used a case study of a complaint investigated by the ombudsman in the UK, to encourage nurses to question clinical practice in relation to child visitors. The case presented is that of a thirty-five year old female patient requiring admission to hospital for a hysterectomy. She had two children aged three and five years, and with no local family her husband had had to have time off work to look after the children. This patient had trained as a nurse and it was of the utmost importance to her that her children were allowed to visit during the admission. The patient was aware that children could develop fantasies about mothers dying or worry that something was very wrong if they were not reassured by being allowed to see her. She explained that she was dismayed when the information leaflet about the hospital admission stated that children under twelve years of age could only visit patients on a Sunday afternoon.

The patient checked the details with the ward sister who confirmed the policy and said that well patients were permitted to see their children off the ward. After contacting the local community health council a meeting was held with the nursing officer and ward sister. The patient described a feeling of hostility from the nurses at this meeting and she was offered the chance to see the children in the corridor forty-eight hours after the surgery. The complaint that the ward visiting was unduly restrictive was not upheld by the ombudsman and the consultant surgeon thought that the patient was being selfish by not appreciating how the children could disturb other poorly patients (Jones, 1984).

Knuttsen and Bergbom (2007b) carried out a descriptive study into the views and experiences of thirty custodians (parents/guardians) regarding their children's visit to a relative on the adult ICU. Participants were recruited from five general ICU's located in

different hospitals in south Sweden. The researchers reported that the aim was to recruit fifty participants, but only thirty were found with the ICU's stating that very few children visited. The thirty custodians represented fifty-four children aged between four months and seventeen years of age who did visit a patient on the ICU and ten children who did not visit.

It was reported that visits by children were usually initiated by the custodians and the children rather than by the ICU staff. Sixty seven percent of the custodians had initiated the visit, and a further thirty percent reported that the child had initiated it. Two children were forced to visit when they did not wish too. The importance of giving children adequate information before, during and after the visit was highlighted. The majority of custodians reported that the quality of information given was good or satisfactory, with one respondent reporting that they did not talk to the child after the visit as the information from the staff was felt to be sufficient. Of interest, was the distribution of information provided to children by the healthcare staff, with information provided to the child prior to the visit occurring in only twenty-one percent of cases, compared to sixty-four percent during the visit. Information to children after the visit was also sparse, occurring in only two percent of cases (Knutsson and Bergbom, 2007b).

Twenty-eight custodians answered the question relating to the child's reaction to the ICU visit as a whole, and twenty-seven reported that it was a positive experience. Custodians reported different reactions from the children ranging from fear or no reaction to happiness. Some custodians reported that although the child was frightened at first this emotion changed to curiosity during the visit. Others stated that the children acted normally and did not seem influenced by the environment. Others

were quiet and shy around the patient, and some reported that the unreal, impersonal environment had been frightening. The two children who had been forced to visit were reported to have been frightened by seeing the patient and by the equipment. Visits were felt to be educational as they had resulted in the child having an increased awareness of the patient's condition, their need for help and an appreciation of the healthcare professionals work. Eighteen custodians reported that the children had asked questions about the patient's condition, prognosis and the equipment during the visits (Knutsson and Bergbom, 2007b).

Visiting was not considered to be a risk to the future health of the child by twenty-three custodians relating to the opportunity to provide explanations and answer questions. Twenty thought that not allowing the child to visit was more likely to be a risk for future health and wellbeing relating to unanswered questions, and feelings such as guilt, anger and exclusion. The researchers concluded that nurses need to take more initiative when discussing visits by children and to develop family-centred care including children in ICU's (Knutsson and Bergbom, 2007b).

### **Contemporary practices to facilitate children and young people visiting adult patients**

There are several strategies discussed in the literature which aim to encourage and support children visiting clinical areas (Table 2.4, p.78), although the majority relate to ICU and other critical care areas.

Play facilities/Play rooms	Gremillion 1980 Johnson 1994b Matorin 1985
Facilitated visiting to ICU	Blot et al 2006 Hanley and Piazza 2012 Johnson 1994a Nicholson et al 1993 Pierce 1998 Pinoël 2015
Teddy Bear Therapy/Medical play - Facilitated visiting to ICU	Johnson 1994b Perry and Goulet 2006
Support from Paediatric Nurse/Nurse Specialist	Bruck 2011 Lewandowski 1992 Vint 2005b Winch 2001
Children's workbook- hospice Children's information booklet – Neuro ICU Children's work booklet – ICU	Macpherson and Cooke 2003 Hanley 2008  Davis 2015
Individual family information	Granaas-Elmiger 2000
Resource folder for staff	Vint 2005a
Guidance for staff – ICU	Child Bereavement Charity 2008
Written information for visitors	Vint 2005a Vint 2005b
Child Life Consultation Service (Palliative Care)	Sutter and Reid 2012
Child Visitation Policy (Cancer centre)	Falk et al 2012 Hanley and Piazza 2012

*Table 2.4 Strategies to support child visitors to adult clinical areas*

Historically, some hospitals introduced play facilities (Gremillion, 1980) or babysitting by volunteers which although convenient for visiting adults did not address the question of whether children have the right to visit their ill relative or whether the child visiting was a positive or negative experience (Anon, 1991; Gremillion, 1980).

Facilitated visiting policies and procedures have been a popular strategy in the USA for visits to patients on the ICU (Johnson, 1994a; Nicholson et al, 1993; Pierce, 1998). This strategy has also been introduced in France (Blot et al, 2007) and positive results

were reported from all associated research papers. Nicholson et al (1993) reported that facilitated child visitation in the adult ICU resulted in fewer perceived behavioural and emotional changes in comparison with children who were restricted from visiting, by helping the children to see and learn about their critically ill relative using a planned systematic intervention.

This quasi-experimental, post treatment design study took place in an adult surgical ICU in the USA. It was a small study of twenty families: the children of ten families were restricted from visiting and the children of the other ten families were allowed facilitated visits. The children completed measures on anxiety (Manifest Anxiety Scale) and behavioural emotional changes (Perceived Change Scale). The non-hospitalized adult family members accompanying the children completed measures on anxiety (State-Trait Anxiety Inventory) and mood (Mood Adjective Check List). Family functioning and life event changes were examined as extraneous variables using the Feetham Family Functioning Survey and the Life Event Scale. The researchers reported that the children in the facilitated visitation group had a greater reduction in negative behavioural and emotional changes as measured by the Child-Perceived Change Scale (Nicholson et al, 1993).

Blot, et al (2007) reported on the strategy to open their ICU (a surgical ward with eleven beds, in a cancer unit of 380 beds) to child visitors. Until 2002, general visiting was limited to two and a half hours per day, in two periods, and children's access was restricted. The policy to open the visiting to children was initiated by the psycho-oncological teams and by the group "children of the hospital". Evaluation of the policy was conducted sequentially and prospectively, and reported predominantly positive experiences for children, parents and healthcare staff.



The hospice movement has long considered child visitation to be a positive influence (Gremillion, 1980) and strategies to support this have been developed. MacPherson and Cooke (2003) describe the introduction of a workbook for children aged between five and fourteen years visiting a relative in a hospice. Seven children were involved in the pilot study of the workbook and all enjoyed using it. It is reported that the workbook provided an opportunity for interaction with staff, had the potential to help nurses and parents respond to questions, and stimulated discussion. It was noted that children did use the workbook in different ways which emphasized the need to be flexible in any approach adopted. Similar work booklets have been introduced to ICU's with positive evaluations (Davis, 2015; Hanley, 2008).

Providing individual information using books was also a strategy recommended by Granaas-Elmiger (2000), an Austrian hospice psychologist. She reflected upon two case studies of children who had wanted to visit a hospice patient, and suggested that parents own insecurities about illness and death can be responsible for them being over protective. She points out that children notice when parents are dealing with a grave problem and provides strategies for the care team to support both child and family. Recommendations include direct individual advice for children with the help of their parents, helping to support the parents, encouraging children to show emotions and recognizing the child's emotions. It is advised that any strategies must be tailored to the age of the children and in agreement with the parents and the patient.

Whilst these strategies are aimed at improvements that general nurses had introduced, Sutter and Reid (2012) introduced the use of the child life specialist to adult palliative medicine in relation to the support they provided to seriously ill patients, such as those in ICU. The child life specialist was described as a master's degree

prepared health professional who provides “developmentally driven psychosocial assessments and interventions to pediatric patients, their parents and their healthy siblings” (Sutter and Reid, 2012, p.1363). The child life teams had rarely been used in adult palliative medicine, even though they had existed in paediatric care in the USA for more than fifty years. The team’s interventions have been shown to reduce emotional distress, improve the ability to cope and understand hospital admissions and procedures, and facilitate overall adjustment in hospitalised children.

From 2007, child life specialist support was offered to families of patients with life-threatening illnesses who had children less than eighteen years of age. The focus of the referrals was on issues of communication between the parent and the child. This included support for the child before and during hospital visits, and with end of life visiting. Interventions were provided either directly with child involved or indirectly via the parents, guardians or healthcare staff. These were adapted to suit the individual child’s developmental level and coping style. Following assessment support options were chosen by the family, whose premorbid communication style was not challenged in any way, but supported. Resources such as, art materials, books and dolls were used to informally assess each child’s stresses, misunderstandings, questions and unresolved emotions. The child life specialist also supported the child and family to prepare and structure visits. This included the provision of information and use of activities designed to improve understanding, coping and reduce stress for the child (Sutter and Reid, 2012).

It is acknowledged that there are barriers to incorporating the child life specialist in adult environments, relating to family factors as well as work based issues. In relation to workplace barriers, difficulties integrating into existing programs or accessing child

life specialist teams in hospitals without paediatric services were highlighted. Cultural norms and family factors were also considered barriers to successful implementation, as some adult family members may not be able to focus on the children at the time of the referrals. Despite the potential barriers, it is recommended that hospitals consider the consultation with child life specialist services or consider the provision of broad-based training to enable healthcare professionals to improve the support provided to children when a family member is seriously ill (Sutter and Reid, 2012).

## **Theoretical frameworks**

The main theoretical frameworks underpinning the papers appraised in this literature review were those of attachment (Bowlby, 1961, 1971), child development (Piaget, 1969, 1976) and childhood grief (Bowlby, 1980; Dyregrov, 1990, 1997). Bowlby was a child psychiatrist in the UK who formulated the theory attachment relationship, which was concerned with the relationship between the infant and their caregiver. Bowlby had worked with children during World War Two who had lost their mothers or been separated from their families. During this work he identified three phases in a child's response to separation from their parents. The first phase was protest and often was demonstrated through tantrums and attempting to escape. The second phase was despair and depression, and thirdly was detachment when the child would show indifference towards other people (Bowlby, 1969, 1982).

Bowlby's work into attachment and reactions in children to loss were often used in the literature to consider the potential impact of separation caused by a parental hospital admission. As awareness had been raised that infants of six months of age are attached to their parents, crying when they leave and welcoming them when they

return (Bowlby, 1971) it became clear that it was parental presence which was important rather than the environment where interaction took place (Goodall, 1982).

Piaget's four stages of cognitive development are frequently referred to and underpin many of the recommendations and strategies relating to age appropriate information. The four stages are sensorimotor, preoperational, concrete operational and formal operational. The sensorimotor stage starts from birth and lasts until the acquisition of language. At this time the child's existence centres upon the parents for safety and security (Bowlby, 1961). Separation from the parents at this stage may result in the grief type reactions described by Bowlby (1961). During this time, through imitation and exploration the child gradually learns to distinguish between self, others and the world (Carpendale, Lewis and Müller, 2018).

The preoperational stage, between the ages of two and seven years, consists of two sub stages: preconceptual thought between the ages of two and four years, followed by intuitive thought from four to seven years of age. During these sub-stages children develop from being totally egocentric to showing social awareness and the ability to consider other people's viewpoints. It is highlighted that at this stage children will have awareness that something is wrong and although they are mastering language there is at this stage the tendency to use words without comprehending their true meaning. Therefore, during a family illness, children are likely to know that something is wrong, but will require simple explanations and the opportunity to explain their understanding. Play is often an effective method of communication in this stage and thinking is often described as magical. Although during the intuitive stage child become increasingly able to understand explanations, they remain highly literal in their interpretation of what is said.

Concrete operational thinking develops between the ages of seven and twelve years. Although reasoning and logical thought become more sophisticated children can still be quite literal in their thinking. Children in this stage have a clearer understanding of the irreversible and permanent nature of death, but may struggle to understand the invisible aspects of illness. Finally, the formal operational stage occurs between the ages of twelve and fifteen years. Children now develop the ability to think more abstractly, but their reactions may not always be proportional to a situation. As age and experience increase so does levels of anxiety and stress, a response noted in hospitals by Goodall (1982).

Although there are many debates and critiques of these theories, in relation to child development, they are the main underpinning theories discussed in papers throughout the literature review from 1959 to 2015. The potential of harm to children of causing distress through separation or not providing age appropriate strategies also underpin this study.

## **Recommendations for future research**

All the studies included in the literature review reported similar and recurring themes in the recommendations for clinical practice and further research. In relation to clinical practice, the provision of education and training to healthcare staff about how to communicate with children was recommended. Others were that nurses should take more initiative when discussing children visiting with families and a multidisciplinary approach to improve the support provided to children needs to be encouraged.

A number of recommendations were made concerning future research and these are summarised below:

- Replication of the studies is needed in different clinical areas and in different types and sizes of hospital. They are also recommended using more heterogeneous samples from varied cultures, races and socioeconomic classes.
- Explore and challenge the beliefs and attitudes of the healthcare team prior to trying to change practice or policy.
- Action research or intervention studies could be used to plan, implement and evaluate facilitated support in the ICU.
- Further research is required into the beliefs and attitudes of different groups, including healthcare staff and parents, particularly those who do not allow their children to visit.
  - Studies of the short and long-term effects on the children, parents/guardians and the patients of children who do visit.
  - Study of the epidemiological effects of allowing children to visit to different hospital environments, such as infection rates.
  - Develop and test evidence based planned systematic approaches and written information which support children.

The first three recommendations were most influential for this study. There was evidence from clinical practice (Chapter 1) that healthcare staff at the hospital had concerns relating to children visiting adult patients at the hospital and that children were restricted from visiting in many areas. A number of healthcare staff were interested in exploring how support for children visiting could be improved. This would

involve exploring the issues and challenges associated with the restrictions prior to planning or implementing any identified changes in clinical practice. The study proposed would involve all adult wards and departments within the hospital, and so would not be restricted to ICU or critical care units.

## **Summary of the literature**

The literature highlighted that this is a complex and sensitive subject area which has a long history with evidence going back to the 1950's. Much of the original literature from the 1950's to the 1980's consists of opinions pieces and case reports rather than research studies. Although an advocate of case studies Yin (2009) highlights that they are often not considered reliable or objective by researchers as it is difficult to make any generalisations from a single case. However, the same issues are involved in both the case studies and the opinion papers which often focused upon individual's personal views on a subject. The collection of papers found spanning a timeframe of 50 years does provide the opportunity to build up knowledge in relation to the associated contemporary events and to compare with the current position.

A variety of research methodologies were employed since the 1990's. Both quantitative and qualitative methods have been described, including quasi-experimental post-treatment design, exploratory pilot studies, multi-centre descriptive studies using postal questionnaires, postal surveys, and constructivist grounded theory design. Many of the studies have small sample sizes which could affect the credibility and validity of the results. However, all the studies report consistent results and recommendations for future research despite the differing methods used and across the different countries.

It is clear from the literature that there are benefits to supporting child visitation to adult relatives at the hospital. The possibility of causing significant distress to children and families by the restricting visiting is also clearly evidenced. However, despite this there remains a constant barrier to children visiting hospitals. In the literature, these barriers related to adult values and perceptions, and the need to protect both the children, families, patients and healthcare staff from harm.

Up until now the focus of research into children visiting acutely ill adult patients has focused on ICU's, with even those relating to palliative care being located on oncology ICU's. Although the evidence that it is beneficial for children to have the opportunity to visit their relative is transferable, the resources and facilities in an ICU are very different to those on a general ward. The studies have highlighted the need for replication studies in different clinical areas, intervention studies and further qualitative studies into the experiences of the different groups involved. No research was found which explored children's needs when visiting acutely ill relatives on general hospital wards. This study will constructively contribute to the growing body of knowledge concerning children visiting hospitals as it will critically explore the issues surrounding children visiting adult relatives in all departments in a large acute hospital using an action research approach.



## **Chapter 3**

### **Methodology**

#### **The natural history of my research**

The methodology chapter is recognised as being the easiest part of a thesis to write, according to the messages received from many colleagues and acquaintances that had completed their doctoral theses. Not so, in this case. The dynamic nature of the chosen methodological approach PAR, caused many sleepless nights and a long period of deliberation of how to structure the journey of this PhD. Having explored a variety of formats (Herr and Anderson, 2015; McNiff, 2014), the traditional formal methodological chapter format did not illustrate well the PAR approach. To provide a clearer description of the research process including the difficulties encountered and the changes associated with the PAR approach this chapter is presented using the traditional formal structure combined with “the natural history of the research” (Silverman, 2013, p.355). This process allows the reader to follow the continuum of the research methodology through to the final chapter. In this way, changes to the methods within the PAR approach are illustrated and explored within the context of the research cycle in which they occurred.

This chapter will therefore provide the rationale for choosing the research approach, introduce the research cycles and explore the ethical considerations fundamental to the project. It will introduce how particular components of the approach developed and the inherent ethical consideration. Aspects of the methods and the associated ethical considerations evolved along the continuum of the PAR cycles. Further explanation of

these is detailed in Chapters 4, 5, 6 and 7 which explore the changes as they naturally unfolded in response to participant, internal and external factors.

## **Research aim**

The aim of this study related directly to the issues raised in discussion with the healthcare staff at the hospital where the study was conducted:

- To identify and critically explore the issues surrounding children visiting adult relatives on any ward in one large teaching hospital in the UK in order to improve the support provided.

## **Research questions**

The research questions were:

- What were the issues and challenges experienced by adult nursing staff at the hospital that was resulting in the restriction of children visiting adult patients?
- What strategies would better prepare nursing staff to deal with children visiting acutely ill adult patients?
- How could staff change current clinical practice to improve the experience of children and their families when visiting adult patients?

## Research context

It was important to explore the research context and to be personally reflexive from the outset of this study proposal, as it had originated from reflecting upon incidents in clinical practice. Consideration of the research concern and purpose together with my ontological perspective and epistemological position encouraged interrogation and systematisation on my own assumptions (Mason, 2002) prior to commencement of the research. This was considered to be an essential element in the planning of the study, as there was the possibility that the research questions would involve asking healthcare colleagues to explore and challenge their own clinical practices and associated underlying beliefs as the research progressed.

Reflections in clinical practice involving children visiting acutely ill relatives had elicited that these were particularly stressful situations for both staff and adult relatives, that children were being restricted from visiting due to concerns about them coping or that they represented an increased infection risk. I found myself questioning my own clinical practice and the underlying assumptions which supported decision making in such circumstances. These situations also resulted in considerable discussion within the teams as many nursing and medical colleagues were concerned that they had either very limited (or no) knowledge and experience of dealing with children visiting ill or dying patients.

It was clear from the literature review that there is a long history of evidence that facilitating visiting for children can have positive effects for the children, their families, the patient and the healthcare staff involved, but an understanding of the psychological

needs of children who visit is an important factor in developing age appropriate strategies. It had been identified that there was no guidance within the hospital policy or procedures regarding children visiting the adult acute clinical environment and several nursing staff were interested in how this situation could be addressed. Two important questions had been raised during informal discussions with these staff: How could staff be better prepared to deal with child visitors in the future? How could staff change current practice and improve the experience in their clinical areas for child visitors and their families? These questions underpinned this study's social purpose to improve and provide equity in the support provided to children and their families when visiting a relative at the hospital.

### **Social purpose**

Social purpose refers to “what we want to achieve in the social world, and why” (Whitehead and McNiff, 2006, p.23). Equity in healthcare is most often associated with health inequalities relating to treatments and/or preventive measures and is defined as “the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically” (World Health Organisation (WHO), 2018). Within the hospital there was inequality in relation to how child visitors were supported in the adult clinical areas compared to the paediatric clinical areas. Siblings are actively encouraged to visit on paediatric wards and departments, but in adult wards visiting practices appeared to be inconsistent with some areas banning visitors aged under twelve years. Reasons for restricted visiting and lack of engagement with children who did visit adult clinical areas from discussions with colleagues were based upon infection risks, adherence to policy and a lack of education about supporting children. Many of these reasons were congruent

with the literature, and some such as restrictions due to infection risk had no empirical evidence to support them. There seemed little logic to the situation where a child could visit a sibling in a paediatric ward, but would not be allowed to visit a parent in an adult ward in the same hospital.

If a child can demonstrate a level of cognitive understanding and the ability for rational thought they can be deemed Gillick (Gillick v West Norfolk and Wisbech Area Health Authority, 1985) competent to make decisions about their healthcare. This allows them to retain some degree of adult choice. However, the protective element of the adult persona is reinforced as the child's choice can be overridden if it does not agree with that of the adult. Although this applies to the child's healthcare decisions it can be applied to a child's decision about visiting a relative in hospital and reflects the modernist principles that children should be viewed as separate beings, that they should not be harmed and that they must be protected at all times (Lee, 2001). This belief allows no acknowledgment of the reality that children cannot be protected from real life.

A number of studies into the views and experiences of both ICU staff and parents/guardians demonstrate that this assumption remains embedded in clinical practice despite evidence dating back to the 1990's that facilitated visiting has positive benefits to the child and family. The practices of restricting or excluding children from visiting adult patients could be considered as in contravention of the United Nations (UN) Convention of the Rights of the Child (CRC) (1989). The UN CRC (1989) covers most aspects of children's lives in specific areas such as health, disability, and poverty, but also covers children's rights to be heard and to have their 'evolving capacities' respected.

Underpinning this study are articles three, nine, twelve and thirteen of the UN CRC (1989). Article three states that ‘the best interests of the child must be a top priority in all decisions and actions that affect children’. Throughout the literature review there are papers which provide details of reasons for the restriction or exclusion of child visitors. Many that oppose child visitation used the concept of best interests’ as a reason to maintain restrictions. It is also clear from the research that there is evidence that in some cases it is the best interests of the child to visit and that barriers to visiting could cause harm.

Article nine states that ‘children must not be separated from their parents against their will unless it is in their best interests (for example, if a parent is hurting or neglecting a child).’ Although this is most often considered in relation to child protection, by restricting visiting by age rather than choice, could in some cases constitute separating a child from their hospitalised parent against their wishes and result in psychological harm to the child. Underpinning both the research purpose and the design are articles twelve and thirteen. Article twelve states that ‘every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child’s day to day home life’ and article thirteen that ‘every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is written in law’ (UN CRC, 1989). Consideration in the proposal stages was therefore given to how children could or should be involved in the research process.

In summary, the social purpose of this study, underpinned by the UN CRC (1989) was to achieve an improvement in the support provided to children who visited adult

patients at the hospital and for these improvements to provide equity with other visitors. The social purpose of this research therefore aligned to the position of “dismantling the ideas and practices of the deliberate exclusion and alienation of persons” [the children] and encouraging “others [the staff] to interrogate their own assumptions, and the normative assumptions of their cultures, in search for more inclusive and relational ways of living” (Whitehead and McNiff, 2006, p.25) and working.

### **Ontological and epistemological positions**

The study had a clear practical social purpose. It was also important to explore the ontological and epistemological positions, as these are important issues which can help to identify and clarify issues in research design, and inform which will and will not work (Easterly-Smith, Thorpe and Lowe, 2002) in answering the research aims and questions.

Ontology is the branch of philosophy “concerned with questions about what constitutes reality and how can we understand existence” (Lyons and Coyle, 2015, p.372). Positivists believe that the world is independent of our knowledge of it (Gray, 2018) whereas relativists believe that there are multiple realities with multiple ways of accessing them (Gray, 2018). Interpretivists believe that human beings are actively constructing the social world and so are also involved continuously in interpreting their social environments (Milburn et al, 1995). The ontological position underpinning this study aligns with relativism and interpretivism. There was a recognition that the research questions and social purpose had derived from and (would take action upon) my own and other colleague’s clinical practice. The main concepts would involve

people; such as patients, relatives, staff, and visitors; and the study aimed to accommodate the multiple realities or meanings which may exist between their different belief systems and roles (Mason, 2002, p.15). The values were based on building relationships with the different groups and being inclusive of all who wished to participate. I also recognised that my own and others views of reality could change depending upon the role occupied at the time. Reality was considered dynamic, with changes in perception creating the potential for changes in what individuals considered reality. These could differ on the same subject particularly in comparison between the role of the professional nurse and the role of relative. Taking an objective stance when discussing a patient's situation is vastly different from the subjective stance of being that patient's relative.

Epistemology is the branch of philosophy that is concerned with questions "about how we can know and what we can know" (Lyons and Coyle, 2015, p.369). Constructivism is the epistemology congruent with this study; that truth and meanings are created by individual's interactions with the world resulting in the construction of different meanings and knowledge. With a professional requirement for lifelong learning it is accepted in healthcare that knowledge is constantly being acquired from different experiences and contact with others. Knowledge is therefore constantly being added to or changed. In constructivism it is accepted that multiple contradictory but equally valid accounts can exist (Gray, 2018), and this is a concept which is often seen in healthcare when different people have different perceptions of the same situation.

The overarching paradigm of this study is interpretivism, a stance which looks for "culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p.67). With an insider view as a fellow clinician, the study aimed to



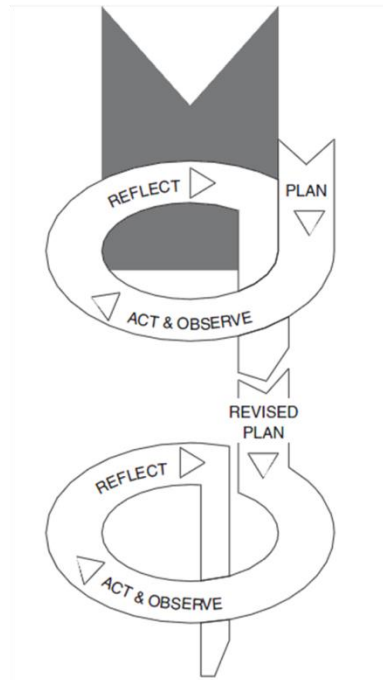
explore the understandings and actions of healthcare professionals in their own environment, and was expected to include the local practices, assumptions and culture. There was an interest in improving clinical practice through research in the local area and an acknowledgement that replicability was not expected or indeed desired. Together with the social purpose, the aim was to not only understand the phenomena of children visiting the hospital, but also to change and improve the current situation (Reason and Bradbury, 2007).

## **Rationale for methodological approach**

Research is defined as a “systematic way of knowing” (Parahoo, 2006, p.8), the systematic, rigorous collection and analysis of data, providing insight into a phenomenon (Parahoo, 2006). There are many different approaches, the use of which is dependent upon the research question, aims and purpose; and the ontological perspective and epistemological position. These were considered alongside the results of the systematic review and were fundamental in identifying the most appropriate research methodology. This process was important in considering what was already known, in order to avoid duplication of previous research and to ensure that the study not only improved support at the hospital but also contributed to the body of knowledge of the phenomena (Parahoo, 2006).

With the aim of improving clinical practice, Action Research (AR) was initially thought the most appropriate methodological approach. AR has been a recognized framework of enquiry since the 1940's when Kurt Lewin introduced the term while attempting to change the social system at the same time as generating knowledge about it (Hart and

Bond, 1995). Lewin's (1946) AR framework consists of cycles of planning, action and evaluation, and is often demonstrated using diagrams (Figure 3.1, p.97):



*Figure 3.1: Action research spiral (Klemmis and McTaggart, 2000)*

The cycle or spiral can be followed several times during a project (Bennett and Oliver, 1988) allowing actions to be implemented, evaluated and modified until a satisfactory outcome is achieved. It is a framework which the researcher and the proposed participants were familiar with as it “mirrors the iterative processes employed by professional staff in assessing the needs of vulnerable people, responding to them and reviewing progress” (Hart and Bond, 1995, p 3), such as the nursing process (Figure 3.2, p.98) and healthcare commissioning cycle (Figure 3.3, p.98)



Figure 3.2: The Nursing Process (>[www.ForumLifenurses-com](http://www.ForumLifenurses-com)<)

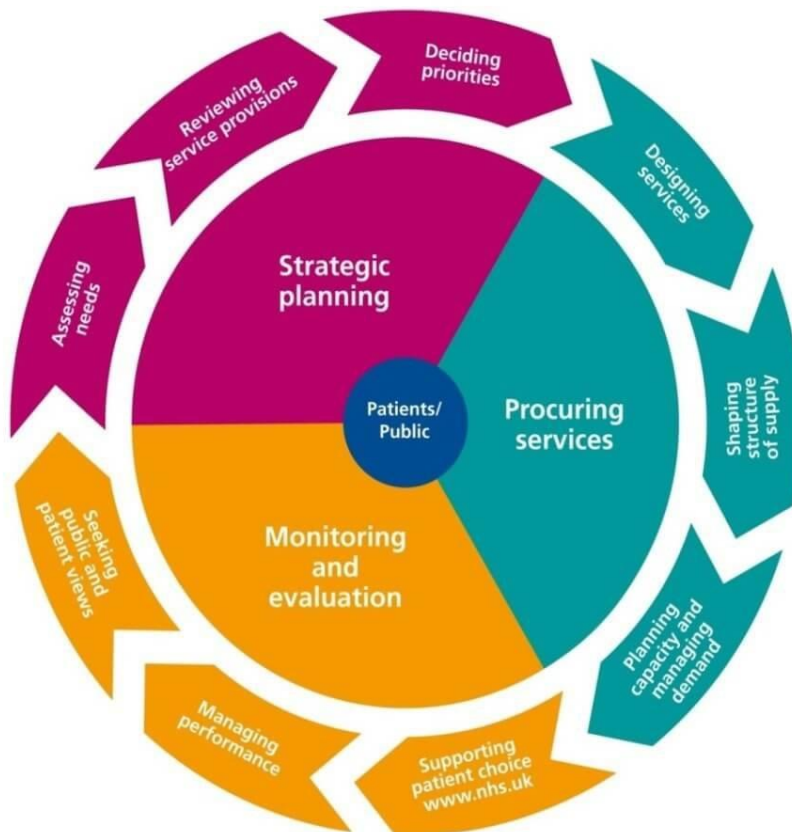


Figure 3.3 Healthcare commissioning cycle (NHS Health and Social Information Centre, 2008)

The ontology of AR reflects that of the researcher and the research objectives. Namely, that there may be multiple perspectives, the values are based on relationships and being inclusive, there is a commitment to action and that there is a place for the 'I' in the research (McNiff and Whitehead, 2006). The perspective that knowledge is a living process generated through experience and learning (Whitehead and McNiff, 2006) also fits the epistemological position of this research. From a methodological perspective Holter and Schwartz-Barcott (1993) list four features which are essential to the application of action research which correspond with the aims of this study:

1. There is collaboration between the researcher and the practitioner.
2. A solution is found to practical problems.
3. There is a change in practice.
4. There is theory development.

Although AR met the requirements of the research aim and objectives, the ontological perspectives and epistemological position were also congruent with using a participatory approach. As a member of the hospital in which the study was to take place I acknowledged my position as a participant in the world of the study setting. It was also recognised that interaction with all stakeholders during the study had the potential to create new knowledge both individually and collectively (Whitehead and McNiff, 2006).

Participation of stakeholders was considered fundamental to the research, as it was clear from the literature review that the subject of children visiting adult patients in

hospital was a complex social process which was based on many assumptions and cultural perspectives. Therefore, any actions or changes in clinical practice would need participants to be engaged in the process and would derive from their own perceptions and ideas. The groups most affected by any actions planned or taken are the nursing staff on the wards, and local children.

## **Participatory Action Research (PAR)**

The methodological approach which combined the requirements of the research objectives of improving practice in a local practice area through collaboration, with the ontological, epistemological perspectives and social purpose was identified as Participatory Action Research (PAR). PAR is described as “the study of a social situation carried out by those involved in that situation to improve both their practice and the quality of their understanding” (Winter and Munn-Giddings, 2001, p.8). Thus, the researcher can remain grounded in the reality of current clinical practice and the research is co-created with the participants. It is recognized that practitioner research allows the practitioner to move beyond being a recipient of knowledge-transfer to having an active role in the creation of new knowledge (Karvinen-Niinikoski, 2005) which is fundamental to the aims of this research. As a clinical practitioner, the researcher will be able to understand and create new knowledge to benefit themselves, the clinical area and academia, rather than solely introducing previous research findings to clinical practice.

One definition of PAR is as a process of “collective, self-reflective inquiry undertaken by participants...to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which

these practices are carried out” (Klemmis and McTaggart, 1998, pp.5-6). It is often used to research issues in a variety of organisations and communities (Chevalier and Buckles, 2013). These include healthcare (Friesen-Storms, Moser, van der Loo, Beurskens and Bours, 2014; Koch and Kralick, 2006), education (Klemmis, McTaggart and Nixon, 2014), indigenous and oppressed communities (Chevalier and Buckles, 2013; Fals-Borda and Rahman, 1991), and in environmental studies (Chevalier and Buckles, 2013). It has often been observed to be a beneficial experience for participants in relation to empowerment, self-confidence and emotional wellbeing (Ditrano and Silverstein, 2006; Lykes, 2009; Smith and Romero, 2010). In health care Koch and Kralik (2006) PAR study findings supported that collaboration and involvement in key identified areas of concern lead to sustained form and/or practice changes.

However, PAR can be a difficult methodological approach to document in some ways as it “is multidisciplinary and multiform; no one perspective can claim authority or authenticity” (Swantz, 2008, p.31). There are several interpretations of PAR’s origins (Brydon-Miller, 2001; Fals-Borda, 2006, Chevalier and Buckles, 2013) in both the northern and southern hemispheres. Following on from Lewin’s introduction of AR, emancipatory educator Freire (1972) developed community-based research processes in which knowledge production and social transformation were supported by the participation of people from the communities involved. Participatory research approaches were also being developed in Africa and India during the 1970’s representing ‘a new epistemology of practice grounded in people’s struggles and local knowledges’ (Kendon, Pain and Kesby, 2010, p.10). Further developments from the 1980’s to today have seen the rise of PAR approaches in community and international development, such as Participatory Rural Appraisal (PRA) and Participatory Learning and Action (PLA) (Chevalier and Buckles, 2013). Fals-Borda and Rahman (1991)

extended Freire’s methodology to AR attempting to close the gap between critical consciousness and scientific reason. This approach intended to transform society and challenge existing oppressive systems, by incorporating “community-based needs, knowledge and action leaning into the inquiry plans and theoretical concerns of traditional science” (Chevalier and Buckles, 2013, p.27).

### Introduction to the research cycles

In this thesis, Coghlan and Brannick (2014) AR spiral (Figure 3.4, p.102) is adopted to demonstrate the research process. This framework was chosen as the pre-step was acknowledged to be fundamental in planning the research. The pre-step looks to understand the context of the research together with the assessment of whether there is a need or desire for the research. This step also includes the establishment of collaborative relationships which was fundamental to this PAR research.

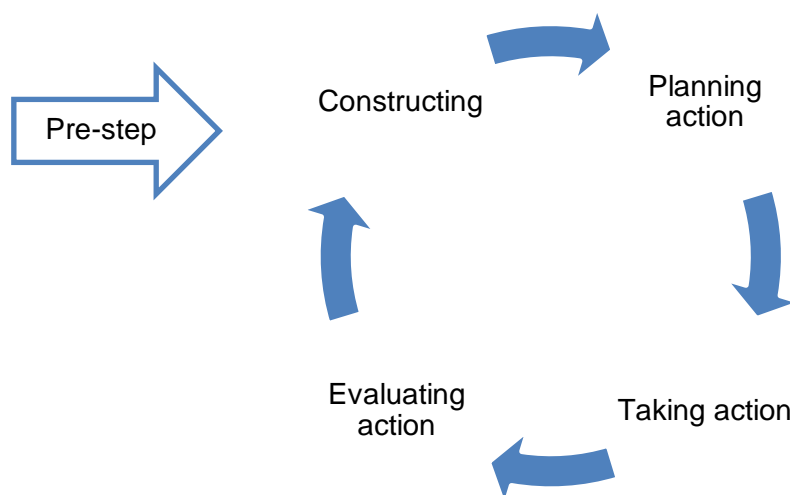


Figure 3.4 The AR spiral (Coghlan and Brannick, 2014)

Although the spiral in Figure 3.4 (p.102) appears clear and unambiguous, it provides a useful way of conceptualising the process. In reality, AR and PAR cannot be considered as linear as cycles often occur concurrently in addition to cycles taking place within cycles (Coghlan and Brannick, 2014). In this research study, Cycle 2 clearly followed on from Cycle 1, whereas Cycle 3 occurred within Cycle 2. A visual representation of the research cycles can be seen conceptualised in the whole study diagram (Figure 1.2, p.35).

## **The Pre-step**

The first, informal consultation was carried out with children and young people to inform the understanding of their opinions of the research aims and methods. This consultation stage was performed prior to research ethics with the aim of informing the research design.

## **Consultation with children and young people**

Children's participation in healthcare research is increasingly important (Fleming and Boeck, 2012) and children were consulted in the initial phases of this research to gain their perspectives. The Medicines for Children Research Network (MCRN) Young Persons Advisory Groups (YPAG's) were asked to provide consultation upon the research question and design, specifically relating to involvement of children in the research. The MCRN was a National Institute for Health Research (NIHR) network established in 2005 with the specific aim of ensuring that studies relating to medicines for children in the NHS had the appropriate support for successful delivery. In 2007, a



new EU Regulation on Medicines for Paediatric Use also came in to force seeking to address this issue and in 2013 the MCRN merged with the Paediatric (non-medicines) Specialty Group to create the 'NIHR Clinical Research Network (CRN): Children'. Originally the MCRN operated via six Local Research Networks which focused on supporting medical research for children in their region. Two regional YPAG's agreed to provide consultation for this research; the West Midlands YPAG and the London/South East YPAG.

The YPAG's consist of ten to fifteen members who are aged between eight and nineteen years. They provide support to clinical research in a variety of ways, including helping researchers with individual projects, working with external organisations such as INVOLVE, the Medicines and Healthcare products Regulatory Agency (MHRA), the National Research Ethics Service (NRES), and the NIHR Central Commissioning Facility (CCF). The groups also conduct their own research.

The consultation process and questions were devised in collaboration with the MCRN West Midlands User Involvement Coordinator. The questions presented to the groups related to their experiences of visiting adult relatives in hospital; exploring what they thought would be helpful if visiting, their suggestions regarding communication; whether any children visiting an adult relative should be approached at the hospital to participate or should this be carried out using other avenues (such as schools and clubs). The consultation document is included in Appendix 2 (p.389). The questions were discussed at the two YPAG meetings and reports from both consultation events were returned by October 2012. The groups consisted of a total of twenty-three young people aged between eight and seventeen years comprising sixteen girls and seven boys.

The consultation reports provided a great amount of information relating to experiences of hospital visiting, opinions upon the research design and potential strategies to improve the experience of hospital visiting for children. A number of the young people had visited adult relatives, the majority being elderly relatives and grandparents. In one group all stated that “they had not had any explanations from medical staff about the relative’s condition”. One participant was not told anything, but they felt “this was OK as she thought she was too young”. In both groups it was acknowledged that other family members had supported them, but that they “did not really explain about the condition or what was happening to their relative”. Helpful things were described as “staff because they take you to the right place”, parents and family.

Unhelpful things were also discussed and related to being ignored, “waiting outside getting panicked”, not being allowed in, nurses “were rude and showed no compassion” and feeling in the way. It was also noted by one group that “the nurses were nice, but no-one explained anything”. When considering what would be important when visiting an adult relative the main themes identified were friendly and compassionate staff; age appropriate language and information; staff to support parents to talk to children; to feel welcome; and teenagers not to be patronised and be treated more like adults.

A number of strategies were discussed in relation to what would be helpful to children and young people visiting adult relatives. The main strategy was to improve communication. It was identified that “staff need to be more friendly and compassionate; to make children and young people feel more welcome and not in the

way; and not to be rushed out at the end of visiting time especially if you're saying goodbye to a relative for the final time".

The majority felt that it should be a close family member that talked to them about their relative's conditions not medical staff. They felt it was better to have someone who knew the child/young person, their maturity level and level of understanding to explain information to them. One group discussed what may be appropriate in a situation where there were no family members available to talk to the young person. One young person suggested a mentor at the hospital, someone who was not directly involved in their relative's care, and the entire group agreed this was a good idea. All members of this consultation group agreed that it shouldn't be a medical professional, as some were worried that "medical staff would give bad news outright and thought they might give too much information". There was also concern that healthcare professionals should not use complicated medical terms. "Being talked to in a way you understand" was considered important.

The age and maturity of the young person was linked to whether they thought they should be told honestly what was happening to the relative. It was also felt that young people (teenagers) should not be patronised and "should be treated more like an adult". Both groups thought that aids, such as jigsaws, books and DVD's should be used to help understanding particularly with young children. Other suggestions were "explanations of the different needles and monitors and what they were used for as these were very scary at first". Other suggestions were "ask me if I want a drink", ask if you want a chair, "friendly people telling you where to go" and staff to "not be nosy ...ask child lots of questions".

One of the main aims of this consultation was to gain an understanding of young people's current opinion upon involvement in the research to aid the research design and methodology. The majority felt it was not appropriate to speak to children and young people at the time of visiting relatives in hospital. A small number thought that it may be "OK after they have seen their family member if the child is emotionally stable". In this case, it was the opinion that they should only be asked a few questions and that they were not given a questionnaire. There was concern that they were "not bombarded" with questions. One group discussed that it would be better to speak to the young person at "a later stage once relatives had been discharged from hospital". This was dependent upon the outcome and it was felt that it would be inappropriate if the relative had died. The point was raised that the opinions of experiences might differ from memories depending upon the different patient outcomes; that "if it was a positive outcome a child might only remember positive experiences".

One group felt it would be better to speak to young people from different groups and schools, whereas the other group thought that schools should not be visited as this could draw attention to children who had an ill relative and that children probably would not be interested. The group that thought schools and groups may be the best option "felt the only difficulty might be if children had experiences they might not want to talk about it in a classroom setting so smaller groups might work better". This group also thought that any consultation would need to have a variety of different aged children involved. They went on to debate the age of the youngest children involved and the "general accord settled on aged 4 years".

The consultation confirmed that there remained significant issues relating to children and young people visiting adult relatives in hospitals in the UK; and that further work

was required in addressing these. Their experiences of feeling ignored, not being allowed to visit and not receiving information reflected the findings in the literature review. The research design was revisited following the consultation and it was decided that the initial research cycles would involve staff members from the hospital but that children and young people visiting the hospital would not be approached.

### **Consultation with nursing staff**

Informal consultation has taken place with interested members of nursing staff. These were predominantly those who had been involved in the situations discussed in the introduction. It was planned that these would be the staff that would form the research working group and would take ownership of the study.

### **Ethical considerations**

The ethical issues involved in the research process were reviewed throughout the project using a structured ethical reflection framework (Brydon-Miller, 2012) (Appendix 3, p.391), as it was acknowledged early in the process that predicting the ethical issues associated with this PAR study could prove difficult (Morton, 1999) due to the dynamic nature of the approach meaning that issues could change as the research progressed. The initial ethical considerations related to consent, confidentiality, non-maleficence and the vulnerability of participants in relation to the PAR commitment to social justice. It was accepted that these may develop as the research progressed as “given its emergent quality and responsiveness to social context and needs, PAR cannot limit the questions of ethics to the design and proposal phase. The ongoing

assessment of expectations that are met or not met is key to success and must take place at the appropriate time, as the project unfolds” (Chevalier and Buckles, 2013, p.174).

### **Consent**

The dynamic process associated with PAR made it is difficult to predict exactly where the research journey would take the participants (Williamson and Prosser, 2002). This was explained to those interested in participating prior to Cycle 1. Consent forms (Appendix 4, p.394) and an Information Sheet (Appendix 5, p.397) were developed, and potential participants were informed that they had the option to withdraw from the study at any time.

### **Confidentiality and anonymity**

It can be difficult to preserve anonymity and confidentiality in AR due to the collaborative nature of the process. In PAR it is accepted “that ‘recognition’ and ‘being heard’ may matter more than privacy and confidentiality” (Chevalier and Buckles, 2013, p.174) to participants. Respect for those who wish to be heard and identified must be shown through steps such as proper quotes, co-authorship or granting intellectual property rights.

## **Non-maleficence**

Non-maleficence, meaning non-harming or inflicting the least harm possible to reach a beneficial outcome was an important consideration due to the sensitive nature of the research topic and the involvement of discussions about children. The possibility of anxiety and distress occurring if painful memories were recounted was recognised and access to specialist support via the hospital staff support services for the participants was agreed in advance. Any informal debriefing required for members of the MDT was not to be recorded as part of the research process. As the study involved discussion about work with vulnerable populations and settings any unsafe or unethical practice disclosed would be dealt with on a case-by-case basis. This would follow professional guidelines, Research and Development (R&D) procedures and hospital policies, in discussion with the research supervisory team.

## **Social justice**

It is well recognised that due to the commitment of PAR to social justice and transformative action, participants may be critical of existing social structures and policies and this can result in “negative consequences for some individuals or groups” (Chevalier and Buckles, 2013 p.174). The NHS has been experiencing many internal and politically driven changes and challenges over the past ten years. During the course of the data collection for this study the hospital was undergoing sustained internal and external political pressures. The risk that these stresses and challenges could influence the nursing staff and hospital management’s motivation, resource and commitment to the research was acknowledged. Personally, as a senior nurse within

the hospital I was also experiencing these challenges and so had to be aware of the effect upon my role as the researcher, in addition to that of an ANP.

## **Ethical Approval**

All research has associated ethical considerations and ethical approval was gained from the University's Research Ethics Committee (Appendix 6, p.401) and approval from the hospital R&D Department, as fitting with all research conducted in the NHS. The ethical approval process resulted in a seven month delay in commencement of the research, the effects of which are discussed in Chapter 4.

## **Recruitment**

Following consultation with the MRCN YPAG's and local nursing staff it was decided that the main research group participants were to be nursing staff who had expressed an interest in the project. It was expected that the research framework would follow at least two research cycles with differing participants and differing recruitment processes:

1. The nursing action research cycle during which the nursing staff investigate the concept, identify the problems and examine possible actions to resolve the problems. Recruitment was planned to be by direct invitation to those nursing staff who had engaged with me in conversation about children visiting during usual clinical working time. Posters were also to be distributed to all wards and departments, and via the hospital intranet. In addition, invitation emails were to



be sent to all Matrons. The latter two strategies were planned in order to identify other nursing staff who may wish to participate in the research.

2. A multi-disciplinary working cycle used to examine actions in relation to all teams which become involved through collaboration with other disciplines, both inside and outside the hospital. Recruitment in this cycle would be by direct invitation and would be led by the participants of Cycle 1.

Recruitment was challenging in Cycle 1 and so adaptations were made in response to these. Further information detailing the recruitment processes used in each of the PAR cycles will be discussed in the relevant chapters (Chapters 4, 5 and 6).

## **Data collection**

Face-to-face discussions with interested colleagues and focus groups at the hospital were the initial methods of data collection. The rationale for this was that as a nurse practitioner I was experienced in eliciting information through face-to-face communication, and was skilled in verbal and nonverbal communication. Secondly, Parahoo (2006) suggests that the most effective method of revealing people's attitudes, beliefs or perceptions is through verbal communication which meets the requirements of the study as there was a need to explore these in addition to engaging the staff in the study.

Focus groups are congruent with the constructivist perspective of the study. The use of pre-existing groups of participants who work together could allow the observation of naturalistic interactions and interactions are a central analytical resource for the

constructivist researcher (Kitzinger, 1995). Focus groups are used in PAR to explore different perspectives if the facilitator encourages participants to express different views than those already presented (Kemmis et al, 2014) and explore “why particular views are held by individuals and/or groups” (Liamputtong, 2011, p.6).

## **Data analysis**

Data analysis occurred both concurrently during data collection and retrospectively once all transcripts were transcribed. In Cycle 2, initial concurrent data analysis took place with findings from the previous focus group being presented at the beginning of the next. This process of using feedback cycles is crucial in the PAR approach to provide validation (Koch and Kralik, 2006). Initial data analysis performed in this way allows data generation and the emergence of new understandings to occur with the participants in addition to maintaining findings that are congruent with the participant’s experiences (Koch and Kralik, 2006). It also allowed the themes to develop throughout the research cycle as the main themes were expanded upon or explored further.

Initial concurrent data analysis of the focus groups was performed using the classic analysis strategy (Krueger and Casey, 2015) where the audio recordings were listened to several times to gain familiarity with the data. Initial themes were noted and categorised using a colour coding system. These were compared with the notes taken during the focus groups and reflections written immediately afterwards which detailed the emotions displayed and the general feel of the group.

Retrospective data analysis occurred once the transcripts were complete. Thematic analysis using the Braun and Clarke (2006) six phase model (Table 3.1, p.114) was carried out to further elicit themes. This predominantly occurred after the research cycle was completed.

Stage 1 – Familiarisation with the data
Stage 2 – Coding
Stage 3 – Searching for themes
Stage 4 – Reviewing themes
Stage 5 – Defining and naming themes
Stage 6 – Writing up

*Table 3.1 Six phase thematic analysis model (Braun and Clarke, 2006)*

Stage one, familiarisation with the data started within the focus groups. Facilitating each focus group enabled the observation of group dynamics and observable reactions which were not captured on the audiotapes. This was further aided during transcription. As a novice transcriber I was surprised how the act of having to listen and re-listen resulted in so much new data. This is a well-known advantage of completing your transcriptions as “to some extent they will have the social and emotional aspects of the interview situation present or reawakened during transcription and will already have started the analysis of the meaning of what was said” (Kvale,

2007, p.95) Any new themes and reflections upon the emotions or dynamics of the group were noted at this point.

In stage two, coding the transcripts was performed using both deductive and inductive reasoning (O'Reilly and Kiyimba, 2015). Deductive reasoning is considered 'top down' and is usually associated with quantitative research where general observations are made and refined down to more specific findings. Deductive reasoning is used to test a hypothesis and assess whether an original theory can be confirmed or disproved (O'Reilly and Kiyimba, 2015). Deductive reasoning was considered important in the data analysis as there was both a large amount of literature spanning over fifty years and personally twenty years of nursing experience. Both meant that I could not discount my own assumptions, knowledge and experiences; or those analysed in the literature review. In contrast, inductive or 'bottom up' reasoning, refers to that which moves from the specific to broader generalisations, detecting patterns and developing general conclusions or theories (O'Reilly and Kiyimba, 2015). When using an inductive process only, care must be taken not to jump to hasty inferences or conclusions (Gray, 2018). By using both deductive and then inductive reasoning in the coding and data analysis, I was able to look for previously known patterns, and then explore further for any new meanings or themes.

The deductive codes (Appendix 7, p403) predominantly resulted from the literature review. There were some codes which were based upon personal clinical experiences as it was acknowledged that as an insider to the study setting I did have some pre-existing ideas from my own clinical practice. In the deductive phase of the data analysis specific codes were actively sought which matched either the previous literature or my experiences from clinical practice. Following this the transcripts were

examined for inductive codes, those derived from the close reading of the data without trying to fit them into pre-existing concepts or ideas from theory (Green and Thorogood, 2018).

In stage three both deductive and inductive codes were compared and the active process of looking for similarities and grouping them together was performed. In this stage it is important to look for themes which address the research questions, as in focus groups people regularly deviate from the research topic or expand in detail aspects of minimal importance to the study (Krueger and Casey, 2015). This was a risk as conversations were not discouraged as the nature of PAR is to allow participants to lead the development of the research and I did not want to lose any potential inductive concepts by leading the discussions.

## **Researcher positionality**

The iterative and evolving nature of all qualitative research requires the researcher to take and maintain an ethically reflective position (Flewitt, 2005) as there is the prospect of new ethical dilemmas emerging across the research continuum. Consideration to the researcher's positionality is part of reflexivity and can also contribute to demonstrating validity and trustworthiness (Herr and Anderson, 2015). Having commenced this project following reflection on my own clinical practice an insider position was demonstrated. This developed into an insider working in collaboration with other insiders as the issues and ideas were discussed with interested colleagues. Over the course of the project this positionality was to change multiple times and so Herr and Anderson's (2015) (Table 3.2, p.117) continuum of researcher positionalities was used throughout to reflect upon my evolving and

changing relationships with the participants and organisations involved in the study. The changing positionalities will be discussed in the PAR cycles to demonstrate the evolving nature and impact involved.

- Insider –researcher studies their own practices or self
- Insider working in collaboration with other insiders
- Insider working in collaboration with outsiders
- Reciprocal collaboration
- Outsiders working in collaboration with insiders
- Outsiders studies insider
- Multiple positionalities

*Table 3.2 The continuum of researcher positionalities (Herr and Anderson, 2015)*

## **Summary**

This chapter has identified and clarified the methodological processes used within the research. The research cycles have been introduced along with discussion of initial ethical considerations. More detailed explanations and explorations will be presented in the next chapters as the results are presented following the natural history of this PAR study.

## **Chapter 4**

### **Cycle 1 Starting out**

#### **Introduction**

Cycle 1 contained the most personally challenging phases of the research and spanned a period of three years. The realities of attempting PAR in a large healthcare organisation where exacerbated by the organisation undergoing a significant and politically sensitive merger with a neighbouring organisation. Cycle 1 was expected to have four distinct phases: constructing, planning action, taking action and evaluating action, as illustrated in Figure 4.1 (p.119) with the pre-step phase (Chapter 3) shown highlighted in dark blue. However, the cycle did not develop as planned. It did provide challenges, which in turn were used as learning opportunities guiding the subsequent research cycles. These challenges will be discussed in this chapter.

#### **Recruitment**

Staff that had engaged with me in conversations about children visiting during normal clinical time and who were still working at the hospital were invited to participate in the research (n=11). Posters (Appendix 8, p.405) were distributed to all wards and departments in the hospital and via the hospital intranet. Invitation emails were sent to all Matrons (n=14) with the poster attached. This strategy of snowball sampling, where a small number of people assist in identifying others who may be interested, is useful in situations where the research is sensitive and so the knowledge of insiders is used to locate others (Biernacki and Waldorf, 1981). The changes within the hospital

structures meant that this was a useful strategy in identifying potential participants who were not known to be interested or had moved around within the organisation and so had lost touch. Those that decided to participate would be invited to attend four focus group discussions over a period of one year.



*Figure 4.1 Cycle 1 Starting Out: Expected PAR Cycle*

## **Setting**

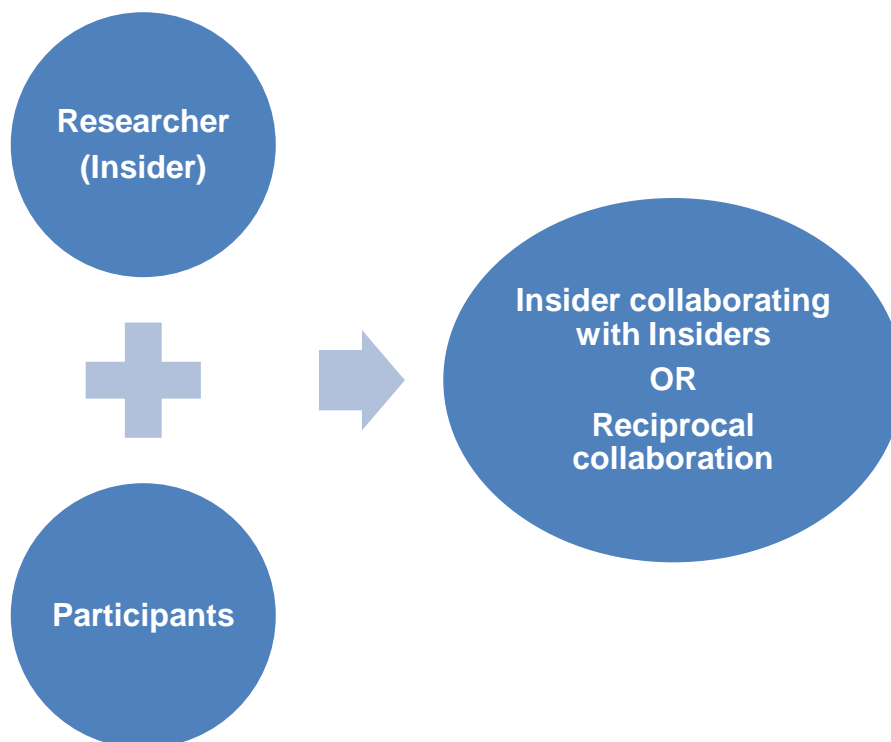
Five focus groups were planned for the constructing phase and these were based on the initial informal conversations that had taken place between the researcher and interested staff members. These were to be located in different areas of the hospital to allow easy access for interested staff. One was planned for the Cancer Centre, two for the Emergency Department and two in general areas of the hospital. All those who



had expressed an interest via informal conversation were given the focus group details. Information was also distributed using emails to all Matrons and by advertising on the hospital intranet site.

## Researcher positionality

It was expected that an insider and reciprocal positionality would predominate in the PAR cycle (Figure 4.2, p.120). As an ANP reflecting upon my clinical practice and positionality within the study I considered myself an insider. Rather than complete a self-study or autoethnography, the aim was to study the outcomes of PAR in my own organisation including studying myself in relation to the study as it progressed (Herr and Anderson, 2015).

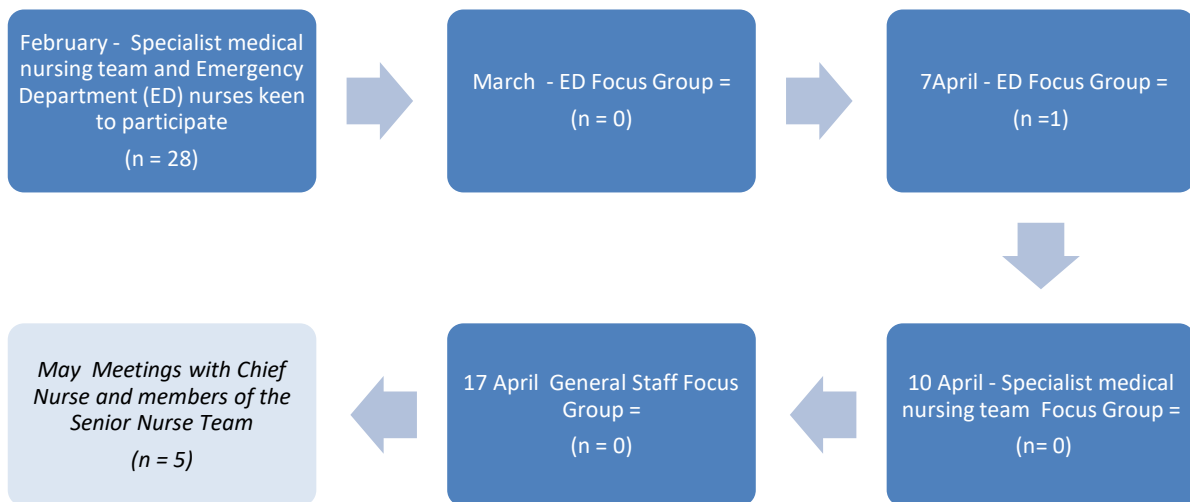


*Figure 4.2 Expected researcher positionality*

An insider collaborating with other insiders was the main positionality, as the study setting was in the hospital where I worked and participants were my nursing colleagues. This positionality is considered to have the potential for greater democracy; however power relations remain in a setting even when insiders aim to be collaborative (Herr and Anderson, 2015). As a senior nurse within the hospital, there was the potential that power relations affected this positionality as a number of potential participants were more junior in status. The PAR methodology encourages a collaborative approach and so a reciprocal positionality was the gold standard objective. By adopting a participatory approach it was hoped that more equitable power relations would develop with participants engaged in all aspects of the research cycles.

## **Results**

Despite positive conversations with many staff members and colleagues, the process of organising these focus groups resulted in the realisation that greater flexibility and creativity was required in the approach to gain access to participants. Out of all five focus groups, only one participant was able to attend (Figure 4.3, p.122). This participant ran into the focus group in the Emergency Department five minutes from the end of the allocated hour, having been unable to leave the clinical area any earlier.



*Figure 4.3 Cycle 1 Focus Group Attendance*

## **Constructing and planning action**

As a result of the lack of engagement by participants there was no construction phase or planning of actions. This was deeply disappointing and could easily have resulted in the research being abandoned. However, I was aware that staff had wanted to participate and therefore it was important to analyse what had caused the difference in interest and attendance.

## **Evaluating actions – analysing and reflecting**

As no actions were planned or carried out, the evaluation phase focused on what could have contributed to lack of attendance at the focus groups. The main focus was

in analysing and reflecting upon the organisational challenges and in evaluating the learning gained from this experience (Figure 4.4, p.123).

Firstly consideration was given to what pressures I had experienced on the days the focus groups were planned. Throughout the planned time I had received many emails from senior management demanding action in relation to daily pressures experienced at the hospital. Frequently these would ask that all work that did not involve reviewing and discharging patients was to be cancelled or stopped immediately. During one attempted focus group my bleep was going continuously with requests to attend wards to review patients.



*Figure 4.4 Cycle 1 Starting Out: Actual PAR Cycle*

Organisational barriers rather than a lack of participant engagement seemed to be the main cause of the lack of engagement with the focus groups. Hospital pressures would not only have affected me on the days the focus groups were planned but were likely to be stopping participants from leaving their work areas too. On the day of one focus group, one interested team reported that during the morning, reception had booked them extra afternoon clinics despite the focus group being clearly blocked out in their diaries. Samples of my journal entries below for these focus groups demonstrate the frustration and challenges of this first research cycle (names have been replaced with letter X to preserve anonymity as they had not consented to participate in the research):

*Journal entry - 24 March First Focus Group -*

*In Emergency Department. I arrive 30 minutes early armed with cookies and drinks. X still negative when I collect the key to the Seminar Room, but I am hopeful. She has e-mailed throughout the department. Matron is keen and 20 odd staff said they would like to join in last year (prior to Ethics Approval). Oh well. After 1-5 hours I leave with my stuff. No-one showed. X seems pleased that she was right, rather than at me. She again discusses the issues in the department. Staff are fed up, over worked and lacking in time. Most fear doing anything in case they make work for themselves.*

*Journal entry - 7 April Second Focus Group*

*In the Emergency Department again 30 minutes early to set up. Did a lot of e-mails. Gave up 10 minutes prior to the end time given and just as I was leaving ED Nurse ran in. This was the staff nurse who had e-mailed me recently after the new advertisement. Shame – unable to do Focus Group with 1, but at least someone has shown up. We had a good chat about the project. She is interested in helping and would be willing to join other groups*

### Journal entry - 10 April Third Focus Group

*First attempt at Focus Group with one of the specialist medical team nurses. Should be OK as they have all responded and accepted the date and time. I arrive 15 minutes early to set up. Turn on the computer to check e-mail while I wait. Arrgh – there is an e-mail from one participant. They have had patients booked in for the afternoon even though they have no clinic and so another one cancelled. I shoot down to their office for a quick chat and they too are fed up. We decide to try again at a later time in the day in case this happens again. We sort out a date for late May as there are loads of holiday's up to then.*

In addition to the daily pressures at the hospital I became aware that several interested staff were no longer working in the hospital. During this time the hospital had been supporting a neighbouring hospital which was undergoing significant operational and political challenges. This resulted in substantial disruption to staff workloads and positions as some staff were moved to other departments and some relocated. The Annual Report of the neighbouring hospital gave an indication of the local healthcare situation at the time and clearly showed that between April and October 2014 the hospital involved in the research had provided both clinical and managerial support to the neighbouring hospital. It is therefore likely that the local healthcare situation was contributing to the recruitment challenges of this research, through workload pressures, relocation of staff and staff departures.

## **Re-engaging with the real world – Planning for Cycle 2**

In recognising that a number of the original planned participants had now left the organisation and that the significant daily pressures of the staff were affecting recruitment, liaison with the senior nursing team (SNT) was carried out through a

number of one-to-one meetings. The SNT represents the hospital's senior nursing management structure and consists of the Chief Nurse, Director of Nursing Education and Workforce, Director of Nursing Quality and Safety, Senior Nurse Education and Workforce and the Deputy Director of Nursing Quality and Safety. The aim of these was to consider how interested staff could be supported to participate in the research. The main suggestion was that the initial focus groups be planned for one of the quality nurse (QN) meetings. These full day meetings with a planned agenda are held monthly and are attended by all the QN's from the hospital. The view of the SNT was that as this is a protected day there would be greater chance that participants would avoid being blocked from attending.

## **Summary**

This chapter has discussed the phases of Cycle 1 and presented the challenges encountered in organising the initial focus groups. Organisational barriers have been discussed alongside actions taken to attempt to facilitate participation in liaison with the SNT. Cycle 2 was developed in response to the challenges of this cycle and is presented in the next chapter (Chapter 5).

## Chapter 5

### Cycle 2 Building on lessons learnt

#### Introduction

This chapter will describe the process and findings of Cycle 2. This cycle was expected to have four distinct phases; constructing, planning action, taking action and evaluating action, as illustrated in Figure 5.1 (p.127). It followed on from Cycle 1 considering reflection upon the strategies used to access participants and the suggestions of the hospitals SNT. The chapter begins by revisiting of the ethical considerations related to the change in participant recruitment.

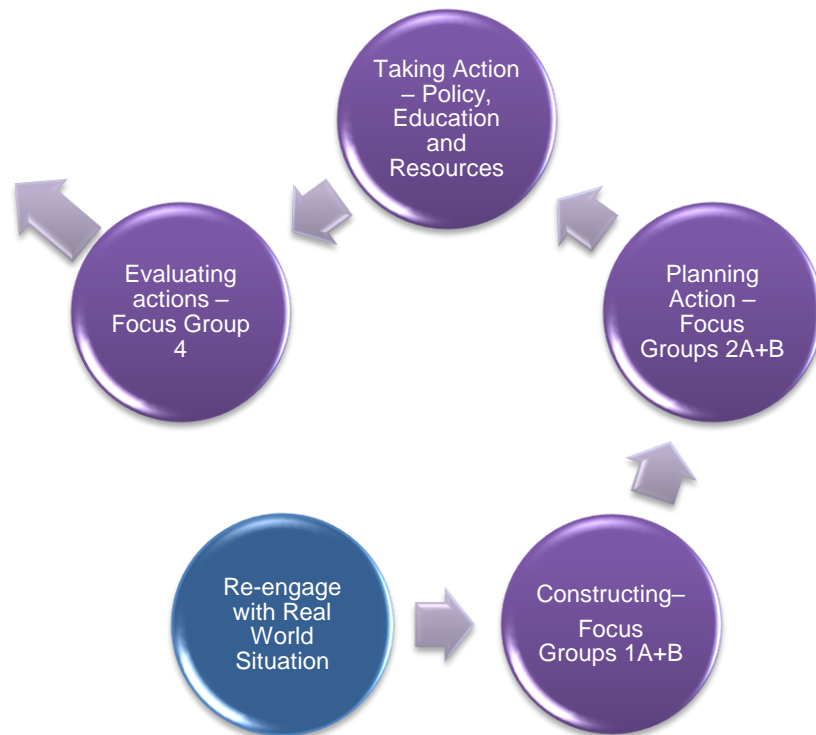


Figure 5.1 Cycle 2 Building on Lessons Learnt



## **Revisiting ethical considerations**

The initial challenges encountered during the re-engagement with the real world situation phase between Cycle 1 and Cycle 2 were both personal and professional, relating to researcher positionality and role duality (Coghlan and Shani, 2015). Previously, in Cycle 1, as an insider collaborating with other insiders who had been active from the outset and engaged in the research proposal development, meant that the power relationship did not feel as unbalanced as in Cycle 2, where active recruitment was to occur. In response to the challenges of Cycle 1 and the subsequent changes made to participant recruitment and engagement the structured ethical reflection framework was revisited post Cycle 1 (Brydon-Miller, 2012) (Appendix 9, p.407). The main values considered to require reflection prior to the next cycle are discussed below.

### **Self-awareness and consent**

The dynamic process associated with PAR made it difficult to predict exactly where the research journey would take the participants (Williamson and Prosser, 2002) and there was an acute awareness that the participants in Cycle 2 had not started this journey at the beginning but had been actively recruited during the QN meetings, attendance at which was a requirement of their QN role. Consent was gained (Consent Form Appendix 4, p.394) and the Information Sheet (Appendix 5, p.397) was provided to all participants. Time was allowed for participants to individually ask questions about the study aims, methods and any associated risks. Participants were given the option to withdraw from the research. It was important to ensure this was explicit recognising that the SNT had been involved in the planning of this method of

recruitment and access to protected time for the focus groups. There was the potential that staff might feel coerced into participating by the involvement of the SNT. I was also aware that my own senior position in the organisation may influence participation.

### **Responsibility and confidentiality/anonymity**

The difficulty in preserving anonymity and confidentiality in AR and PAR has been discussed previously. The responsibility to limit any harm to the participants in the pre-step phase and Cycle 1 concentrated upon ensuring that the research question was valuable, that participants were aware of consent process, the research purpose and any expectations of them. In Cycle 1, the SNT would have had no knowledge of any of the participants. However, in Cycle 2, the use of the QN days meant that by taking part in the focus groups participants could be identified by management. To assist in maintaining anonymity no participant was highlighted in transcripts using name, age or gender. Maintaining gender anonymity was considered particularly important due to the low number of male participants in keeping with the known UK male to female nurse ratio of 10.8% (NMC, 2017). Gender identification would have significantly increased the possibility of management being able to directly attribute quotes to individuals. Transcript codes did include the participants background, such as adult nurse (P-AN) or children's nurse (P-CN) to allow for analysis of the data collected from these two distinct nursing specialities.

### **Social justice and the duty of candour**

As a registered nurse I am very aware of the duty of candour and my responsibilities to patients and colleagues; that "every healthcare professional must be open and honest

with patients when something that goes wrong with their treatment or care causes, or has the potential to cause, harm or distress” (General Medical Council (GMC) and Nursing and Midwifery Council (NMC), 2015, p.1). Ethically, as a researcher, I felt that this duty of candour must also be applied to the research process. Therefore, it was ethically appropriate to report what went wrong as well as what went right. This meant being open and honest about Cycle 1 not only with the participants in Cycle 2, but also during dissemination. It was important then to acknowledge that negative consequence might result from any critical analysis of the situation at the hospital given the politically sensitive hospital merger which occurred during the study.

## **Recruitment**

Following discussions with the SNT at the hospital, an invitation was accepted to present the research proposal at the next QN meeting. The QN’s are senior clinical nurses based on each ward and department whose role includes responsibility for the management of the clinical area on a shift basis, participation in innovation and evidence based nursing practice and being a professional role model encouraging and empowering other staff to develop both personally and professionally. They meet on a monthly basis for a full day with a set agenda. This group agreed to allocate one to two hours to selected meeting dates at which time focus groups could be held. Initial meeting dates were set for April, May, July and November.

Participation in the research was voluntary and it was made clear to participants that there would be no penalties for those who did not participate. The focus groups were timetabled around lunchtimes and so any QN who did not wish to participate was

offered an extended break time. This was important given my senior position in the hospital as an ANP and the mandatory nature of the meetings to the QN role.

## Data collection

In this cycle, the focus group approach was successful in bringing together nursing staff that had an interest exploring the issues surrounding children visiting relatives at the hospital. Conducting the focus groups during the QN meeting day resulted in participant's who had not considered this issue prior to recruitment and in the recruitment of children's nurses. The first focus group was exciting as is demonstrated in my journal entry:

### Journal entry Focus Group 30 April

*Finally I get to do a Focus Group with people. X had said I may get up to 12 people, but there are 23. It goes really well. A little large for my first go, but I hardly needed to speak as people shared their thoughts and experiences. I leave so excited but so nervous about the tape. I had checked the recorder 4 times, but did it work? I reflect on what was said. All seemed positive and were happy that I attended again in future to carry on the work and improve things.*

Attendance numbers for all six of the focus groups varied and are illustrated in Figure 5.2 (p.132). Overall 38 QN's (n=38) participated in the focus groups, although the maximum number who attended at any one time was 23 (n=23). This was the first focus group where the expected number was 12. As in my journal entry above this number was large especially as this was the first focus group that I had facilitated. In discussion with the meeting organiser and the participants it was decided to allocate two back to back focus groups. This meant that the first group was halved, but the numbers would allow space for all to participate.

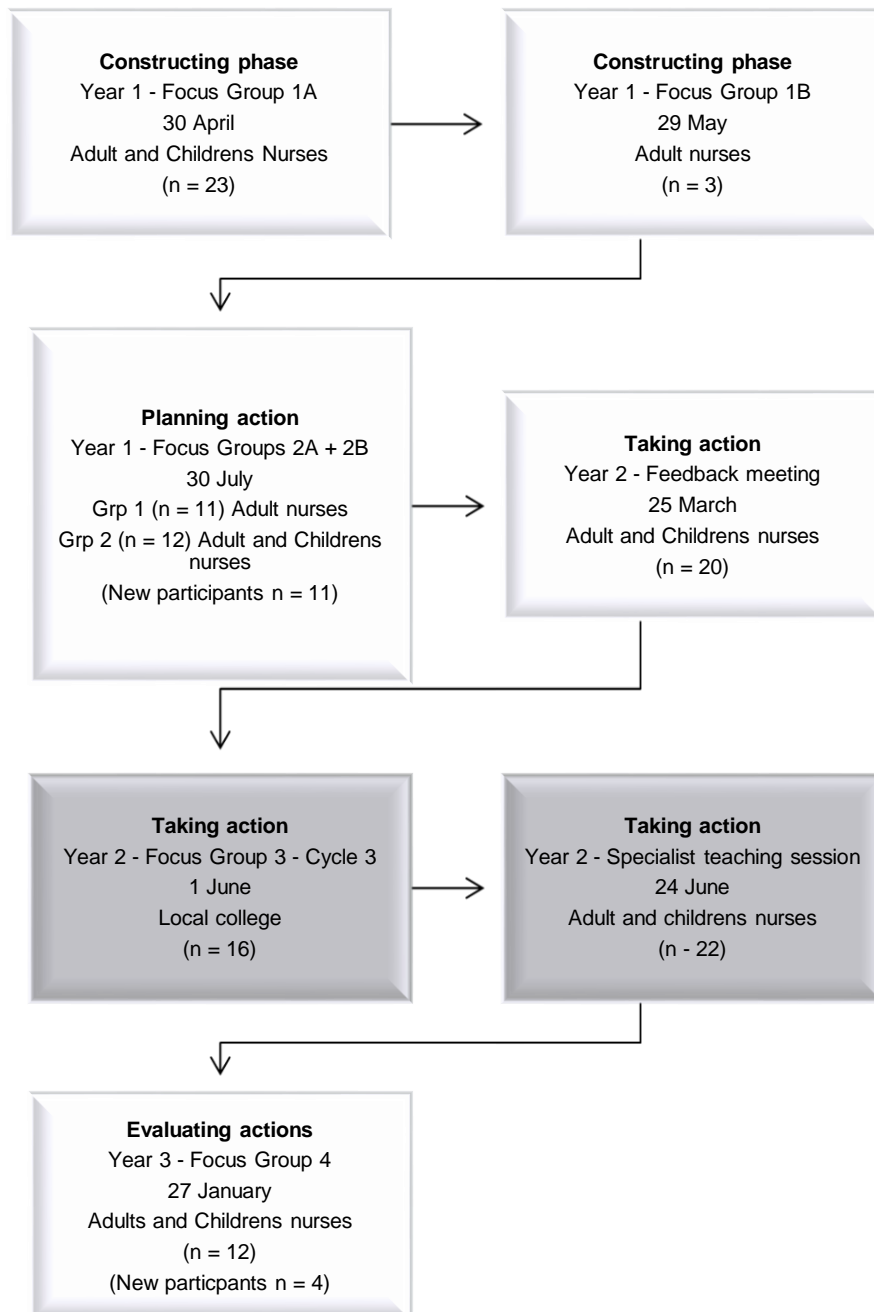


Figure 5.2 Cycle 2 Focus Group Attendances

Challenges were expected and related to focus group sizes and planning. A schedule was constructed to aid facilitation of the focus group (Appendix 10, p.411). The aim was to encourage the participants to have a conversation about the study topic rather than to have a conversation with the facilitator. Questions in the schedule were clear

and open ended which can encourage explanation and description (Krueger and Casey, 2015). The initial opening question did result in immediate answers from some participants which lead on to a debate of the issues of child visitation.

Participant engagement and ongoing organisation pressures from restructuring were also a concern following Cycle 1. Being able to engage with the research process was again a worry to participants as noted in my research journal at the time.

*Journal entry 30 April*

*Some had been concerned about doing more than one focus group in case they could not make all of them.*

Over the course of the research fifteen participants withdrew from the study. It is unknown why this happened on an individual level as none formally withdrew from the study or made known why they were no longer attending. It was thought that the withdrawals predominantly related to staff relocation and staff turnover, as several of the new participants explained during the information and consent process that they had replaced staff that previously attended the focus groups but had now left the hospital.

## **Data analysis**

Initial data analysis in Cycle 2 occurred concurrently with findings from the previous focus group being presented at the beginning of the following one. This process of using feedback cycles is crucial in the PAR approach to provide validation (Koch and Kralik, 2006). Initial data analysis performed in this way allows further data generation and the emergence of new understandings to occur with the participants in addition to

maintaining findings that are congruent with the participant's experiences (Koch and Kralik, 2006). It also allowed the themes to develop throughout the research cycle as the main themes were expanded upon or explored further.

This initial concurrent data analysis was performed where the audio recordings were listened to several times to gain familiarity with the data (Krueger and Casey, 2015). Initial codes were noted and grouped into preliminary descriptive categories. These were compared with the notes taken during the focus groups and reflections written immediately afterwards. These detailed the emotions displayed and the general feel of the group. These preliminary descriptive categories were presented back to the next focus groups. Table 5.1 (p.134) shows the initial data analysis for focus group one which was the starting point for the next two planning focus groups 2A and 2B:

<b>Experiences as children and young people</b>	<b>Experiences as parents/guardians/relatives</b>
Hospital admission equals death Long lasting effects	Empathy – that they would want their own children to visit if they were a patient Children unwelcome Family dynamics
<b>Experiences as healthcare professionals</b>	<b>Reasons for restricted visiting</b>
Personal professional conflict Disruptive children* Messing with equipment* Distracting* Requesting food Family dynamics Long lasting effects	Hospital culture Following policy - No under 12's allowed* Space Responsibility Abandonment
<b>Current practices to facilitate visiting</b>	<b>Policies and procedures</b>
Assessment of family dynamics – child health	Age limits - No under 12's allowed* Open door Lack of guidelines or policy* No known resources* Lack of education* Child protection
*Blue denotes deductive codes	

Table 5.1 Initial descriptive categories from data analysis of Focus Groups 1A and 1B

This initial data analysis strategy and associated cyclical feedback aided the development and preservation of the distinctive features and common themes from each group as the research cycle progressed (Koch and Kralik, 2006). However, there were distinct challenges. Working full-time in a clinical role with no allocated time for the research resulted in these stages of the data analysis strategy being basic as it was quickly recognised that I was unable to transcribe each focus group fast enough to perform a thorough data analysis before the next focus group occurred. Koch and Kralik (2006) describe having a clerical person transcribing verbatim during focus groups, which allowed immediate access to the transcriptions for data analysis. On reflection, this method would have aided the cyclical feedback process and collaborative data analysis in this study.

Stage 1, familiarisation with the data (Braun and Clarke, 2006) continued as the focus groups were transcribed. This was completed verbatim so as to represent what actually was said with no editing or tidying up (Poland, 2002). Transcribing in this way ensured that I could not only analyse the participant's contribution, but also consider my own influence (Poland, 2002) in terms of how I had facilitated and contributed to the focus groups. The disadvantage of this was that the transcription took a long time to complete. With multiple voices sometimes taking over each other it was sometimes difficult to distinguish the individuals in the conversations (Bryman, 2008) and on average five minutes of audio recording took one hour to complete. Due to time constraints the final two focus groups were transcribed by a specialist company. Although this was expected to save time, the act of having to listen, re-listen and correct the transcripts in part negated any time saved. On reflection, it was felt that I did not get the same amount of familiarisation as with those that had been personally transcribed. The result of this was that the audio recordings had to be listened to more often during the final parts of the analysis.



Once the transcriptions were Stage 2, generating initial codes (Braun and Clarke, 2006) commenced. Transcripts were coded manually using both deductive and inductive coding. Deductive coding was considered essential as it was not possible to remove myself from the research data. I was aware of the published research and literature, in addition to having worked within the clinical teams involved in this PAR study. Deductive codes were searched for first, in order to allow a second coding phase giving full attention to each data item (Braun and Clarke, 2006) specifically looking for unexpected and new inductive ideas and codes. Transcripts were coded by writing notes next to the data (Appendix 11 p.414) and then using colour coding to identify patterns in the codes.

Stage 3, searching for themes (Braun and Clarke, 2006) derived from grouping both the deductive and inductive codes from each focus group, together with the preliminary descriptive categories from each focus group. Visual methods were used in this stage with coloured post-it notes used to move and organise all the codes into themes (Appendix 12, Number 1, page 418). This initial thematic map was very complex with multiple themes and sub-themes. It did allow the whole data set to be considered, incorporating codes from each stage of the PAR cycle, including data from Cycle 3. Stage 4, reviewing the themes (Braun and Clarke, 2006) involved reviewing the initial thematic map and all the included coded extracts. Once the themes were identified, to illicit more meaningful themes, they were further reviewed against the whole data set and the research questions:

- What were the issues and challenges experienced by adult nursing staff at the hospital that was resulting in the restriction of children visiting adult patients?  
(Appendix 12, Number 2, page 420)

- What strategies would better prepare nursing staff to deal with children visiting acutely ill adult patients? (Appendix 12, Number 3, page 421)
- How could staff change current clinical practice to improve the experiences of children and their families when visiting adult patients? (Appendix 12, Number 4, page 422)

These thematic maps (Appendix 12, pages 418-422) were constructed and compared to aid the process of mapping the themes and any relationship between them (Lyons and Coyle, 2015). These were defined and constructed into the final themes representing the phases of the PAR Cycle 2 (Figures 5.3, p.138; 5.4, p.178; 6.1, p.199; 7.2, p.238).

## **Themes**

Themes will be presented in the phases of the research cycle; constructing phase, planning action, taking action and evaluation of action. The nature of the focus group method had resulted in experiences and issues being revisited and in some instances there was repetition of discussion at each cycle. It was expected that there would be a degree of recurrence as the PAR cycle progressed, as the themes developed and new ideas about strategies emerged. However, the repetition was exacerbated as new participants replaced those that withdrew at each stage of the PAR cycle due to staff promotion. These new participants often wanted to revisit their own personal and professional experiences. Therefore, themes which developed in the constructing phase continued to be developed throughout the research cycle.

## Themes from the constructing phase

There were five main themes with associated sub themes in the constructing phase of the research cycle; current visiting practice, reasons for restricting children, making memories, role conflict and family structures (Figure 5.3, p.138). These all originated in discussions about personal and professional experiences and were evident throughout all four phases of the research cycle.

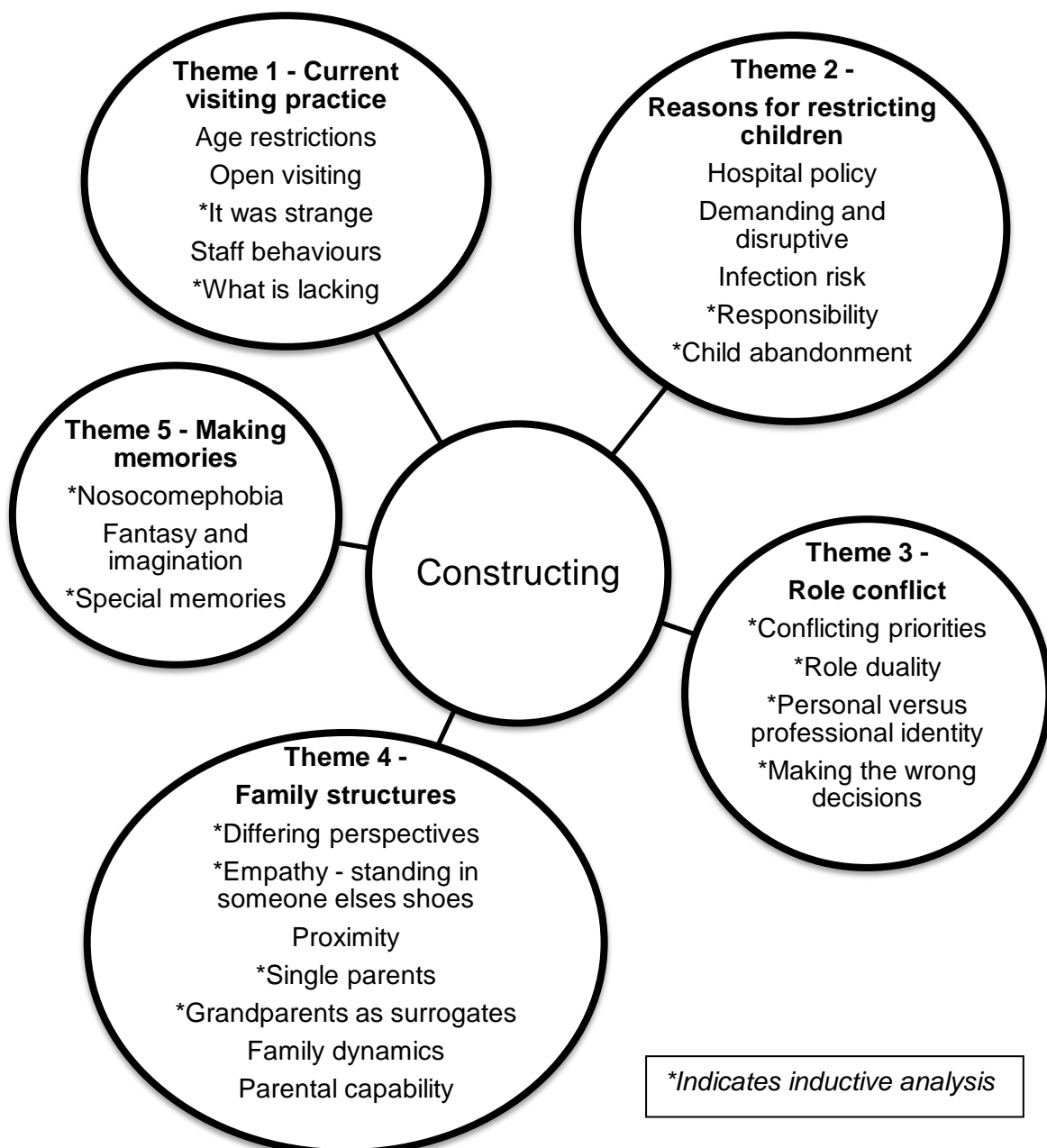


Figure 5.3 Themes and Subthemes of the Constructing Phase

## **Theme 1 – Current visiting practices**

Constructing is the first phase of the research cycle engaging the participants in a 'dialogic activity' constructing the issues and developing the working themes on which all the other steps are based (Coghlan and Brannick, 2014 p.10). As such, gaining an insight into the current visiting practices at the hospital and the challenges experienced by the healthcare staff formed the basis of the first theme and related to the first research question.

**Age restrictions:** When discussing experiences of children visiting their clinical areas participants provided both positive and negative experiences. The discussions gave an indication that there was wide variation in practice relating to children visiting across the hospital with some areas allowing visits and some adult clinical areas restricting visiting due to age. This was consistent with current information provided to the public on the NHS Choices website (2016) which states that children can be restricted from visiting detailing that "in some wards, you need to ask permission for children to visit, and some wards insist that children under 12 are accompanied by an adult".

A number of the adult nurse participants discussed age restrictions, and twelve years of age was repeatedly used as the age below which visiting was most restricted. This age limit was linked to hospital policy, but this did not stop all participants from allowing children under twelve years of age to visit:

*...so they'll always say even though children under 12 aren't supposed to be on the wards anyway I'll always try to sneak them in just for a quick kiss and cuddle and then they have to go it's not fair on other people (P-AN04 - FG1A Lines 117-123).*

This lack of adherence to perceived policy based upon individual nurses clinical decision making was also found in the studies of Clarke (2000) and Simon et al (1997) where nursing judgements based upon patient assessment, patient choice and the family situation resulted in adaptations to official visiting policies.

**Open visiting** was mentioned by some participants, but in adult clinical areas this was linked with allowing parents to make the choice whether to bring their children visiting after staff had provided them with some information. These cases were not planned or facilitated visiting practices. They were individual nursing staff providing their own explanations:

*We get patients from all over the country...it's quite major surgery you know and the families travel a long way and a lot of the time they have to bring the children with them so to say to them oh sorry you can't bring your child in it just seems wrong anyway but they've always asked is it Ok to bring little Jonny whose 5 or whatever I'm like well we can't stop you but just be warned that there are lines and you know they might have a CVP or a catheter in or something if you want us to explain we can do erm with the family we leave it with the family we just say to them we'll leave it with you We've never ever stopped any family children visiting at all (P-AN07 - FG1A Lines 223-231).*

There was a clear distinction between adult environments and paediatric clinical areas, where there was a culture of open visiting and clear procedures relating to visitors:

*We don't ban parents, children, at all we don't ban them from ward rounds we don't ban them from resuscitation if they if the parents chose to be there they're allowed to be there exactly the same for the siblings of the child that's the inpatient so if the parents feel their child is old enough or capable enough to deal with what they're seeing we leave it up to the parents discretion (P-CN22 - FG1A Lines 58-63).*

Sibling visitation is now common practice in UK paediatric areas, with many hospitals providing information to guide and support parents (Great Ormond Street Hospital NHS Foundation Trust, 2018). There was a strong emphasis on the initial holistic assessment of the family in the child health teams. Importance was given to the family situation by participants from these teams, who highlighted the importance of understanding family dynamics from the outset. Knowledge of the family's opinions about children visiting was seen as important in planning potential sibling visits and support:

*What I'd say straight away is on the admission process we get the family dynamics straightaway so then we would probably try and get the siblings you act in the best interests of the family you'll have a family there that will want the siblings there and you'll have people who don't want siblings there straightaway like you say we get a rapport with the family you get to know them but initially the admission process is the dynamics of how many children you've got where are they have you got other carers do you want husband here or can he be at home with the children that kind of thing (P-CN23 - FG1A Lines 48-54).*

Within adult ICU's child visitation appears to depend upon individual nurses abilities to establish a rapport with a child and family (Clarke, 2000). The participants from the child health team in this study felt that building a rapport with the family was seen as an important part of the assessment process, and helped the staff to be proactive in planning actions related to the hospital admission. This type of proactive action by the child health team contrasted with adult assessments which did not explore issues about the family in this detail. The discussion caused some to reflect that when discharging some younger patients the idea that they may have parental duties at home had not occurred to them as it was not part of the initial assessment documentation.

Holistic assessment was also discussed on a number of occasions throughout all stages of the PAR cycle by the participants from the child health team in relation to questions and fears from the adult nurse participants about responsibility and child protection. These issues will be discussed later in this chapter.

***It was strange:*** The deductive code of 'it was strange' emerged during the discussion of ward experiences. From the deductive standpoint this code related to the experiences of children visiting where they had described the patient's appearance or behaviour, and the ICU environment as strange (Knutsson et al, 2008). In this study, the description of strange was used to describe the feelings of the adult nurse when children are present in the adult clinical environment. One participant described how it felt strange to be asked for resources for a child who was visiting:

*Something similar happened last week in my ward. One of the healthcare's, she came to me. She said, 'Can we have coloured pencils and paper for a child in the ward whose come to visit?' 'No.' So it is how - for me it was very strange. Coloured pencils and paper for a child? (P-AN30 - FG2A Lines 53 – 56)*

This experience also demonstrated the differing reactions to the child's presence on the ward. From this description the healthcare seemed comfortable to ask about simple resources to occupy a child visiting, whereas the nurses response was an initial 'no' and I noted in my field notes that this participant seemed genuinely shocked by the idea that the child was visiting, but also that the healthcare had thought to ask for pens and paper.

**Staff behaviours:** The participants revealed their personal experiences of visiting hospitals as a relative or friend, and these were diverse, with both positive and negative perspectives shared. Healthcare staff being rude was a deductive code relating to the perceptions of children and had resulted from the Pre-step MCRN YPAG consultation results, where some children had described some nurses as rude or showing no compassion. In the QN focus groups this was an experience also felt by adult visitors:

*I'd not long had my daughter and felt that I needed to take her in because my nan had been hospital for such a long time and I was told to leave. (P-AN34 - FG2A Lines 152 – 154).*

*I'd only been there a minute... She was in a baby sling. She wasn't on the bed, she was on me. I wasn't sitting on the bed. But I found that quite rude. (P-AN34 - FG 2A Lines 156 -159).*



***What is lacking:*** In constructing the current situation participants discussed what they felt was lacking which would enable the support of children visiting the hospital. The deductive codes identified which formed the subtheme 'what is lacking' were space (play rooms), resources such as leaflets (written information) and toys (play facilities), and education for healthcare staff. These were the main assets identified as lacking in the adult clinical areas.

There are numerous cases discussed in the literature where children visiting parents who were inpatients had had to conduct these in the corridors due to restrictions on children entering wards (Jones, 1984; Matorin, 1985) and this was the case in some clinical areas in current practice at the hospital. However, space was a recurrent theme throughout the research cycles, relating to difficulties in finding appropriate spaces in the hospital, not only to provide patient visitation, but also to conduct any kind of communication activity. Many participants had experienced situations where there had been difficulties in finding an appropriate space to speak to just the adult patient and highlighted that at these times having a number of relatives in attendance would have been very difficult:

*Well now I've just been down to two wards now and we've sat and discussed diagnoses in the sister's office. And I'm not joking, you can't swing a cat. And there's, if they've have got relatives with them we'd have had no chance (P-AN26 - FG1B Lines 29-31).*

The lack of space was predominantly related back to difficult conversations with patients and families, but it was acknowledged that if there was no space for these situations how could there be space dedicated for children visiting adult wards:

*You can't even find a ward to have a difficult conversation away from the bedside in this place. Some wards haven't even got that space, let alone a play area. (P-AN25 - FG1B Lines 26-28).*

In addition to the general lack of space for conversations with patients and families, it was also identified that many adult clinical areas were not child friendly and lacked any resources to support children who did visit:

*Yea, It's not child friendly, is it? We've got not a toy on the ward for a child (P-AN24 - FG1B Line 44).*

The lack of resources included not only things to occupy children, such as the toys, but also information and leaflets which may be beneficial for the whole family in supporting a child:

*I've got a few books but nothing much because we've had families that have asked for information for the children (P-AN24 - FG1B Lines 76-77).*

Participants spoke about a lack of training and education in relation to children and young people. This included participants who worked in clinical areas that cared for both adults and children (excluding dedicated child health areas):

*We run children's clinics I mean fair enough when the children are well but we've got no child nurses we've got no one that's ever had any training and sometimes I find it difficult just with children' (P-AN15 - FG1A Lines 490-492).*

Concern that they will not be able to support children and their families due to a lack of knowledge and understanding about the best way to approach them was common, with a lack of education often cited (Gibson et al, 2012).

*In summary*, at the start of the PAR study, visitation practices relating to children at the hospital were variable and inconsistent across different clinical areas. There was a culture of open visiting and holistic family assessment on admission in the child health areas, in contrast to adult clinical areas where in many places there was restrictions. In line with the literature, the restrictions often related to those aged twelve years and under, but adherence to this rule was inconsistent depending upon the individual situations and the clinical decision making responses of individual nurses. It was identified that there were some important assets unavailable in adult clinical areas which contributed to the environment not being conducive to children visiting.

## **Theme 2 – Reasons for restricting children**

There are many reasons for restricting or excluding children and young people from visiting in the literature, and these were reflected in the deductive codes (Appendix 7, p.403). Three of the subthemes (hospital policy, demanding and disruptive, infection risk) were consistent with the literature. Two inductive subthemes were identified in the analysis and these related to nurses concerns of responsibility and child abandonment.

*Hospital policy*: From the first focus group the spectre of the hospital policy was identified in relation to restrictions placed on visiting. This was the reason provided by one participant as to why children under twelve years of age were not

allowed to visit, and it caused quite a debate with some participants who were confident that it existed and others stating that they had never heard of such a policy:

*... children under 12 aren't supposed to be on the wards (P-AN04 - FG1A Line 118.)*

*...where did the age 12 come from? I didn't realise that (P-AN05 - FG1A Line 150).*

The policy debate also included questions as to why the age limit was set at twelve years to which no-one was able to provide a clear answer. The debate is demonstrated in this exchange between two participants:

*It's a Health and Safety thing more than anything else (P-AN04 - FG1A Line 151).*

*Where's the risk then? Why up to age 12 and what's the risk? The Health and Safety issue. What's the risk?*

*There probably isn't a risk (P-AN05 - FG1A Lines 159-161).*

The issue of the policy returned throughout the focus group and appeared to be one of the main reasons that nurses were not allowing children onto several adult clinical areas to visit:

*But it is Trust policy so (P-AN04 - FG1A Lines 212-216)*

Although in contrast, the existence of the policy was always challenged by others in the group:

*I worked here for 13 years and that's the first I've heard of it (P-AN07 - FG1A Lines 223).*

*...it's just I've never heard of the 12 thing (P-AN08 - FG1A Lines 232) .*

*It's on the website, it's on the Policy (P-AN04 - FG 1 Line 540).*

*But I've been in charge for 14 years without knowing this Policy (P-AN06 - FG 1A Line 556).*

It is interesting to note that it was stated that the age restriction was on the hospital website, although when accessed the website had no visitor information. The existence of the policy will be discussed further in the planning and taking action phases of Cycle 2.

The repetition of this issue and the ensuing debates is seen by looking at where in the focus group these quotes relating to the policy fit. It starts in Focus Group 1 Line 151 and recurs in the middle (Lines 200+) of the focus group, and then again at the end (Lines 500+). One participant returning to this policy so many times throughout the focus group indicated that this was a significant personal concern. This was noted in the observation notes and so was considered an important theme to analyse.

The analysis of extensiveness and frequency showed that the issue of the hospital policy in focus group 1A related predominantly to one participant. Extensiveness is about how many different people say something, as sometimes one person can keep returning to the same theme (Krueger and Casey, 2015). The insistence that there was a policy which restricted visitors under twelve years of age came from one

participant throughout the focus group, whereas the challenges to this came from several different participants.

The assessment of frequency in focus group data analysis relates to the potential of assuming that the most important issues are those said most frequently and missing a key insight which may have been said only once in a series of groups (Krueger and Casey, 2015). Although 'no-one under twelve years of age' was one of the deductive codes linked to my professional experience; as I was aware that some wards did have this age restriction as a visiting rule: the basis of this rule was unknown and the insistent that there was a policy was a surprise.

Within this subtheme assessment of both extensiveness and frequency proved to be important. As it was one participant who kept returning to a policy containing age restriction in the constructing phase of the research cycle, it would have been easy to discount this issue as unimportant. This was possible initially as there were more participants questioning and challenging the existence of the policy, than upholding it. However, the policy issue did keep recurring throughout the whole of the PAR cycles and was still evident in the evaluation stage. This demonstrated that although it was only raised by one participant in the first focus group, it clearly indicated that it was an issue of significant concern for some healthcare professionals.

***Demanding and disruptive:*** Child visitation causing disruption in clinical areas was one of the codes used in the deductive analysis as it is frequently cited in the literature (Bates, 2010; Goodall, 1982; Gremillion, 1980; Knutsson et al, 2004; Morgan, 2012; Vint, 2005a, 2005b). One participant shared their experience of being a patient

when another patient had children visiting. This was a negative experience which highlighted one of the difficulties encountered if children are behaving in a disruptive manner or if there is minimal supervision from the visiting adult accompanying them (Bates, 2010):

*The girl next to me had about three children visiting her which were all quite naughty and the sister asked them to go, just to come in one at a time and the mother objected to that. It was absolutely horrendous. And it made me ask if I could go home that night. It was just they weren't being supervised. The sister had no authority over them. It was horrible. (P-AN31 - FG2A Lines 91 – 96).*

Participants also shared professional experiences of disruptive behaviours echoing the experiences above:

*I had kids running around the bed (P-AN04 - FG1A Line 153).*

*It's always been a difficult one, hasn't it, with some families that they've come in and let the kids run riot. (P-AN24 - FG1B Lines 386-287).*

Within this theme, in focus group 2A there were not only experiences discussed in relation to demands or disruption felt or witnessed by the participants, but also the challenge of how to approach parents in these situations:

*I think it's the difficulty of not knowing where we stand when it comes to telling parents about children that are running round (P-AN29 - FG2A Lines 189 – 190).*

*What do you say? 'Your kid's being a little brat. Can you please - two to a bed?' They're crawling all over the floor sometimes, aren't they? [16:48 - participants talking over each other] 'Look at them swinging off that drip!' 'Actually, that's your antibiotic and you've pulled your venflon out. (P-AN27 - FG2A Lines 198 – 201).*

On observation of focus group 2A, which had only adult nurse participants there was no resolution from the group in relation to these challenges. In contrast when discussed in focus group 2B which comprised of both adult and children's nurses, it was acknowledged by the participants from the child health team that this could also be a challenge when siblings visited children's wards. In this focus group the children's nurses shared their experiences of how to approach some situations with parents:

*We do have siblings who do can run riot and you do have to say to the parents can you rein them in and they will but it is just a case of just asking the parents stop little Jonny playing with the defib and or whatever (P-CN22 - FG1A Lines 269-271)*

**Infection risk:** Children visiting being at increased risk of acquiring an infection at the hospital or carrying an infection into the hospital which puts patients at risk was the third subtheme in the deductive analysis. As with children visiting causing disruption, increasing infection risks were also frequently cited in the both historical documents (Mooney, 2009) and more current literature as a reason for exclusion (Clarke, 2000; Gremillion, 1980; Knutsson and Bergbom, 2007a; Moore, 2006; Vint, 2005a, 2005b;). As expected, infection control issues were identified in the deductive analysis and related to both personal and professional experiences:



*A lot of the experiences I've had both professionally and personally have been you that can't bring your children in because they're going to pick something up (P-AN01 -FG1A Lines 311-312).*

The increased infection risk to the child visiting was often linked with children's disruptive or perceived inappropriate behaviours:

*...but the predicament sometimes you have it that when they're really dinky you let them run around with no shoes on they're all over the place they're touching and they're so little and important you don't want them getting any infections and then they're running up and down (P-AN09 - FG 1A Lines 245-248)*

There were challenges to the idea that there was an increased risk of a visiting child acquiring an infection from the hospital visit. From the participant's personal perspectives as a member of a family themselves, it was questioned whether as a parent who worked in a hospital, whether their children had already been exposed to infections from their contact at home:

*...and my and my, when I was bringing my 6 month old son in to see his Dad I was like well I work in the hospital he's he's probably been open to everything I've been bringing home anyway so (P-AN01 - FG1A Lines 314-316)*

Two subthemes were identified in the inductive analysis providing further understanding of the current concerns of adult nurses in the local area. These may also represent more widespread concerns in the UK. The subthemes were responsibility and child abandonment.

**Responsibility** for any children visiting was a major concern for the adult nurses, particularly related to the question of who was responsible for any child that visited. There was an assumption that the healthcare staff were responsible for all visitors to their clinical areas, and so if a child visited they would ultimately be responsible for that child. Additionally, there were experiences where patients had assumed that the nurses would take responsibility for the care of a child as demonstrated in the quote below which although rare had contributed to the apprehension felt in allowing any to visit:

*I think that the problem is also is that we had a single parent mother come in that obviously she was the main carer, she didn't have anybody else and she needed surgery and she expected the nurses to look after the child (P-AN11 - FG 1A Lines 357-359)*

The multidisciplinary discussion involved in this subtheme, together with that of child abandonment, highlighted the action of knowledge transferability from the first focus group 1A. Participants from the child health team were able to offer information and reassurance regarding responsibility for children; that responsibility was not with the ward nurses, but with the adult accompanying the child:

*...and the fact that the parent or whoever is bringing the child in is responsible for the child at that time (P-CN23 - FG 1A Lines 217-218).*

As had occurred in the discussion about the challenges of approaching the parents of children who are being disruptive, the nurses from the child health team provided examples of how these issues are approached in paediatric clinical areas. They explained the information provided on the ward leaflets, in addition to what may be explained verbally to parents or other adults:

*We have this thing now that you say your children are your responsibility and they're not allowed to be running around and to be poking and you do have to say as a nurse you know people are unwell (P-AN04 - FG 1A Lines 251-253).*

**Child abandonment:** Closely linked to responsibility was child abandonment, explained as children left without parental or guardian support. The issue of abandoned children featured within the clinical experiences described by staff and was an area which caused great anxiety. This concern seemed to be one of the main reasons underpinning why some nurses did not want children to visit. In my personal reflections (Chapter 1) one of the clinical situations which had lead me to the research project involved children who were alone at the hospital with their dying mother after arriving in the ambulance with her. I had considered this a rare occurrence and not thought of it as relating in any way to child abandonment. It was therefore, not considered in the deductive analysis.

Evidence from the participant's experiences demonstrated that children may be left without parental or guardian supervision for a number of reasons inclusive of being abandoned:

*We had a guy... he'd got I think a 7 or 8 year old son and there was a lot of family dynamics going on ... and his family came to visit erm with the son and then left without him...they just left him on the ward and this guys just ... been in Intensive Care ... and they just left him in the side room and it was only like when one of the nurses went in and where's the family gone and he's like they've left him I don't know what do. But the patient was scared what was going to happen to this child understandably so he didn't tell us that the kid was there so (P-AN12 - FG1 A Lines 375-384).*

Other examples were not so extreme but involved parents leaving children at the hospital with the patient:

*We had a parent last week... Childcare let them down so dad dropped child off with mum at the hospital so he could go to work. (P-AN27 - FG 4 Lines 439 – 441).*

Again the participants from the child health team were able to support with their extensive knowledge and experience of dealing with families in challenging situations. They explained that the issue of responsibility for the visiting siblings is explained to parents, including the legal issues around child abandonment. It was also highlighted that in child health, the nurses have had to phone parents who have left siblings at the hospital and inform them of the legal position:

*No with ourselves we do say you know if siblings come in you take responsibility for them and we have had occasions when parents have snuck off and left the siblings. We've phoned them up and said sorry you can't do this effectively you have abandoned that child (it is abandonment) and (we're not insured, we're not insured to look after the siblings) they are suddenly like oh OK and (P-CN22 - FG 1A Lines 369-373).*

**In summary**, the theme reasons for restrictions, resulted from both the deductive and inductive analysis. Five main reasons for restriction were identified during data analysis, and these were divided into the five subthemes. The deductive analysis identified three of the main five reasons which were hospital policy, demanding and disruptive and infection risk. These were congruent with the literature and caused debate amongst the participants. Hospital policy seemed to have

considerable impact in relation to the restricting of child visitation as shown by the frequency with which it was discussed, even though initially it could have been discounted as it was predominantly raised by one participant. The final two subthemes, responsibility and child abandonment, were identified in the inductive analysis. These subthemes appeared to be of great concern for adult nurses, who were able to provide examples of situations where children had been left with patients causing distress to all involved. Discussions held relating to these themes, resulted in the demonstration of knowledge transferability in multidisciplinary working as the participants from child health were able to provide information and reassurance to the adult nurse participants relating to strategies and legal issues.

### **Theme 3 – Role conflict**

The theme of role conflict was multifaceted, relating to both personal and professional perspectives. The subthemes which underpin this theme were identified during the inductive analysis, and consist of conflicting priorities, role duality, personal versus professional identity, and making the wrong decisions.

**Conflicting priorities:** The first sub-theme was not unexpected and related to the conflicting priorities resulting from service demands. Additional requests from children, patients or parents demonstrated role conflict and frustration resulting from competing demands:

*... 'have you got some biscuits for them?' And it's, 'Actually no, we're not here for that. We're here to look after your poorly mum or your poorly dad.' It is difficult (P-AN29 - FG2A Lines 45 – 48).*

The dilemma of the extent to which caring for relatives is a nursing role was also evident when talking about children visiting. Despite the growing promotion of family centred care (Clarke and Guzzetta, 2017; NMC, 2015), family presence (American Association of Critical Care Nurses (AACN), 2016) and holistic assessment (NMC, 2015), adult nurse participants did not consider that they had any role in providing any care or support to children visiting. The patient was seen as not only their priority, but also as the sole focus of care:

*As long as the patient's safe and I suppose - because we're here for the patients. We're not here for the kids at all (P-AN27 - FG2A Lines 291-292).*

This total concentration upon the patient to the exclusion of the family and children may link with the fears expressed about responsibility for children and child abandonment.

**Role duality:** Role conflict was also found in relation to personal and professional roles boundaries. In action research role duality is associated with the researchers differing roles, and the challenges of valuing each role whilst managing the differing demands particularly if there are conflicts between them (Coghlan and Shani, 2008). Role duality had been considered from a personal perspective as my role as researcher and my organisational role as ANP could have resulted in conflicting priorities. I had not considered the potential for role duality in the daily lives of the participants. However, it was identified that a similar conflict in roles was felt between the role as a parent and the role as a professional nurse. Within the clinical environment, this type of conflict was also identified when roles changed from day to day, such as between working on the ward within the nursing team and then taking the role of nurse-in-charge of that team.

Several participants discussed the experience of being a parent who wanted to allow their child to visit a hospital with them:

*...on a personal point of view I've had my husband in hospital and a young baby and I wanted that baby near me at all times he came to the hospital to visit his Dad and he was only 6 months but I needed him there (P-AN01 - FG1A Lines 21-23).*

**Personal versus professional identity:** In discussing their experiences and role as a parent, the theme of personal professional role conflict began to emerge. The idea that as a parent you wanted your child to be able to visit, but that without having had these types of experiences, consideration for other patients visiting may be sidelined to fall in line with management decisions:

*This is it, this is it if you've had like a personal experience of it you want your children there from the word go (Lots of Erm, yea – in the background) but if you haven't you'll go with what the majority and what your management are saying no no no they can't come in (P-AN01 - FG1A Lines 146-149)*

This may also be representative of the switch from personal identity to social identity. The social identity (the sense of being a member of a group) is perhaps considered most appropriate (Dickerson, 2012) when a nurse is lacking in experience and so defaults to the group perception and behaviours.

There was appreciation from those participants that are parents that this role may bias views and responses towards other parents in the clinical environment:

*...oh no, no. This is wrong. This shouldn't be happening.' But why? Do you know what I mean? I don't know, sometimes being a parent can make you a bit more biased to say, 'You shouldn't be doing that. (P-AN10 - FG4 Lines 139-141).*

There was recognition that feelings and responses in their professional role of the nurse were often different than the responses they would give out in the community in their personal lives. This linked with what was seen as professional behaviour and acceptability. The quote below again demonstrates the potential conflict between the personal identity and the social identity (Dickerson, 2012) of being a professional nurse

*...they'll say to you, 'Oh, look at the baby in the bed.' You feel actually really horrible because in normal life without the job I'd be, 'Oh, that's really nice. The baby's nice.' But actually that's not professional. Within the hospital setting it's not acceptable. So it can be quite difficult because then you upset relatives. So I think it's quite a difficult place. (P-AN27 - FG2A Lines 31-35).*

Nurse professional identity is defined by the “values and beliefs held by nurses that guide his/her thinking, actions and interactions with the patients” (Fagermoen, 1997, p435). It is also influenced by opinions of the general public, the work environment, education and culture (Ten Hoeve, Jansen and Roodbol, 2014). There was evidence of a clash of these different influences in the adult nurse participants where some expressed that their actions in work did not reflect their personal views. There was a perception that the public may find certain socially accepted behaviours, such as admiring a new baby, unacceptable in the clinical area.



***Making the wrong decisions:*** Conflicting thoughts around decision making were evident with adult nurse participants expressing that they were not sure if they were doing the right thing; whether that was restricting visitors, allowing a visit or being asked for advice:

*Sometimes we're withdrawing treatment erm and when there's younger kiddies especially like toddler age we don't really know as a professional what the best thing to do is. The family tend to be asking your viewpoint on whether or not the kids should come in and from a personal point of view you're saying yes yes yes bring them in you know but from a professional point of view you're thinking well how much information would they take from this experience being so little seeing all the machinery if they can see every other patient on the unit as well (P-AN01 - FG1A Lines 12-18).*

This concern that inadequate support or information will be provided to children and their families due to a lack of knowledge and understanding about appropriate methods to support them is well recognised within the literature (Gibson et al, 2012). Nurses dissuading families from bringing children to visit due to a desire to protect themselves from additional trauma was also reported in the literature (Clarke, 2000). It was unclear in this PAR study whether this was the case with the adult nurse participants, although there was evidence that children visiting did cause additional stresses relating to decision making.

Families' transferring the responsibility for decision making to nursing staff at times of stress had been experienced and again there was conflict about making the right decision in relation to allowing children to visit:

*...it's one of those very vague areas where you don't know if you're doing the right or wrong thing and because of the stress of what the family are going through it tends to get put on the nursing staff the decision of whether or not they come on to see their loved one (P-AN01 - FG1A Lines 23-27)*

When children did visit, one particular stressor for the adult nurse participants was how to deal with any challenging situations arising which involved the families with the children:

*I think it's the difficulty of not knowing where we stand when it comes to telling parents about children that are running round (P-AN28 - FG2A Lines 189-190)*

This was raised a number of times with adult nurse participants expressing concern about approaching parents if there was any disruptive behaviour from the children. In contrast, the same adult nurse participants were not concerned about approaching adult visitors in relation to any disruptive behaviour from them:

***In summary***, the theme of role conflict included the subthemes conflicting priorities, role duality, personal versus professional identity, and making the wrong decisions. Conflicting priorities linked to the earlier subtheme of responsibility. It was felt that the patient was the priority and that was no responsibility to care for any children visiting. Despite this, there was conflict for some between their personal identity and their social identity as a professional nurse. It was acknowledged that practices in the clinical area towards child visitors did not always reflect how they felt on a personal level, and that there was concern about the professional image portrayed to the public. There was also an element of role duality, with participants

explaining that their actions may be different depending upon their role on any given shift; between being a member of the nursing team and being the designated nurse-in-charge of the ward.

#### **Theme 4 – Family structures**

In addition to discussing their own experiences and perceptions as relatives, patients and professional nurses, participants also acknowledged their parental role and discussed their thoughts in relation to their own children.

***Differing perspectives*** were discussed in relation to parental decisions about visiting and that individual families will have their own opinions:

*If you're leaving it up to the parents to make the decision if they think their child should come in everyone's going to have a different way because how I bring my child up might be different to how you would bring your child up (P-AN06 - FG1 A Lines 177-179).*

There was an awareness of the different reactions of children to events depending upon their ages, although these related to personal experiences rather than knowledge gained through education:

*When I had my daughter she was in special care. My son was two. He thought all babies were born into incubators. He had no idea that that was not normal because he had no idea what normal was. So I don't think that young children have got a problem (P-AN24 - FG1B Lines 140-143).*

**Empathy:** Participants not only discussed differing viewpoints but also displayed a range of empathetic responses towards parents admitted to hospital relating to the different challenges encountered in different age groups. Teenagers were considered to be the most challenging group:

*It's difficult for parents of children, well teenagers particularly. Bad enough bringing a teenager up when you're well and outside in your own home let alone trying to do it from a hospital bed. (P-AN24 - FG1B Lines 204-206)*

Empathy was also shown towards the feelings of the parents, especially from those who were parents themselves. A number of the adult nurse participants worked in clinical specialities with large numbers of young patients and there was an emphasis on the parental position if an admission was required:

*You know for any parent ... it's the most important thing in your life. And at that point when you're ill it's probably even more so because that's your first thought is oh 'God, what am I going to do with the kids? What are the kids going to think about this?' (P-AN24 - FG1B Lines 453-456).*

**Proximity:** During the discussions about personal experiences the subtheme of 'proximity' emerged. This related to consideration of family dynamics and individuals patients situations. In the quote below the participant highlighted that some patients with small children may not have other family members close by who could help with babysitting:

*No extended family, no Grandparents on hers or her husband's side well that means then that her husband wouldn't have been able to have visited because he would have had nobody to look after the siblings and so she's then not got any support in hospital from the relatives point of view (P-AN08 - FG1A Lines 233-237).*

This case highlighted that although a well parent could take care of the children at home, the lack of any close family or significant others who could provide childcare could result in a patient having no visitors. Increased mobility in recent years has resulted in families with both regular contact through technology, and families with no contact (Chambers, Allan, Phillipson and Ray, 2009). Therefore, even those with regular family contact using technology, may not have the proximity to provide child care support during a hospital admission.

Other participants discussed differing family structures which may impact the family dynamics and affect children support for visiting the hospital. In addition to those who lived a distance from their intended family, patients who were single parents stood out as an area of specific concern. Participants had described situations where children of single parents had been left at the hospital with the patient (reasons for exclusion theme); raising the issue of child abandonment as a reason to restrict child visitation. This concern reoccurred throughout the PAR cycle and despite information and reassurance from the child health team participants, it was still highlighted as a concern during the evaluating action phase.

**Single parents:** Linked to the changing structures of families, such as single parents, were the changing roles within families. The adult nurse participants raised the perception that there were increased numbers of grandparents caring for their grandchildren during the day and this was associated with an increasing closeness and dependence upon them:

*The other thing as well is there's quite often in erm single-parent families where the parents have split up, if the children are, say, with the mother then she will quite often be supported by her parents so the child will be quite close to the grandparents in that case. Because I know quite a few of my daughter's friends who've been in that situation where her granddad runs her everywhere you know. So he's like a surrogate father, if you like. (P-AN24 - FG1B Lines 181-186).*

**Grandparents as surrogates:** Research has demonstrated that there are many different types of grand-parenting styles, with some highly active in the lives of their grandchildren whilst others have only intermittent contact (Chambers, Allan, Phillipson and Ray, 2009). Those with very active involvement may increase the exposure that adult nurses have with children in the future. It had been noted by adult nurse participants that patients attending some outpatient clinics often did so with their grandchildren even when accessing treatment:

*And grannies bring them as well, don't they? Quite a lot of kids are looked after by granny in the school holidays and quite often granny will be the one that's having the treatment (P-AN24 - FG1B Lines 88-90).*

**Family dynamics:** The different family structures and situations discussed resulted in the introduction of family dynamics and family systems by the child health team. Illness within the family can have a profound effect and each family will react differently depending upon its structure, reactions to stress and levels of resilience (Price, Price and McKenry, 2010). The participants from the child health team shared their admission process and the importance attributed to the initial holistic assessment of the child and the family:

*What I'd say straight away is on the admission process we get the family dynamics straightaway (P-CN23 - FG1A Line 48).*

A detailed history about a patient's family is not a feature of the admission assessment in adult clinical areas. However, the clinical experiences discussed by the adult nurse participants contained the issues relating to family dynamics, family structures, and responses to stress. In the cases where children had been left with single parents, knowledge of the family structures and support mechanisms may have prevented the crises that occurred due to family stress responses and a lack of childcare.

Some adult nurse participants initially considered that decisions relating to children visiting clinical areas should be made by the parents and so nurses would not need to provide any support to those children. However, as the focus groups progressed they began to question whether the parent's ability to make decisions and provide support to their children could be affected by the family illness:

*You'd hope the parent or the guardian would do it but you don't know whether the parent or guardian's in the right frame of mind at the time. (P-AN29 - FG2A Lines 425-427).*

There was a link with role conflict and role duality. There was also the acknowledgement that even as a registered nurse, there may be times when you need support with your children. One participant related this back to a situation where it was noted that even as a nurse her confidence was affected (Winch, 2001), as she was unsure of how to provide support in her role as a parent to her own children:

*I think there are situations where you need support with children. I'm a nurse and I certainly didn't know how to deal with my little ones going through - I took the older one but there are times when you think, 'I wish somebody was here to give me a bit of advice on this. Am I doing the right thing?' (P-AN55 - FG4 Lines 103– 106).*

**Parental capability:** The stress related to parental capability in the acute clinical situation was illustrated by one participant who shared feelings associated with having one very ill child:

*But me as a mother, my worst worry was, 'How do I support one child when I've lost another?' (P-CN23 - FG4 Line 72-73).*

Although related to a young child who was ill, there are situations within adult clinical nursing where this could also be an issue. A number of the adult clinical specialities have young patients aged from eighteen years, particularly respiratory, oncology, ICU and the emergency department. Any of these patients may have younger siblings and so this parental situation is relevant in both paediatric and adult clinical areas.



“Illness typically occurs within the context of family systems, where family members are seen as mutually influential” (Yorgason, 2010, p.97), and as such hospital admissions and bereavement affect the whole family including the children. When discussing parental capability one participant shared that she had stopped her own children from going to her mother’s funeral as it would be too upsetting for them, a reason often given for also restricting hospital visiting (Clarke, 2000; Goodall, 1980; Morgan, 2012). On reflection, she attributed to this decision to her own inability to cope and distress (Winch, 2001) at the time. During this discussion, a link to the potential long term effects on children of excluding them from hospital visits and death rituals was evident when another participant shared the long lasting impact that exclusion following bereavement in childhood had had for them:

*I was 13 and they didn't let me see my Nan at the chapel of rest and I hate my parents for that still to this day. Isn't it weird? (P-CN23 - FG4 Lines 81 – 82).*

It is well recognised that children have differing needs depending upon their development stage and individual personalities. Some may want factual information, some emotional support and others the opportunity to participate (Winch, 2001). Research has found that children need information during family illness in order to feel safe and secure (Davey, Tubbs, Kissil and Niño, 2011; Maynard, Patterson, McDonald and Stevens, 2013). They will also need information and support in order to be facilitated to make informed choices. Distress can be caused if a child is forced to visit a patient in hospital (Knutsson and Bergbom, 2007b), in the same way that distress was caused to the participant by their wishes being discounted.

**To summarise**, the theme ‘family structure’ consisted of five subthemes; proximity, single parents, grandparents as surrogates, family dynamics and parental

capability. The changing nature of family structures was recognised and the challenges that this presented during family illness was discussed. Empathy was shown for those parents and guardians who may require hospital admission or who may need to support a hospitalised parent without a social network to support them. Throughout discussions related to this theme, the issue of parental responsibility and capability evolved. Initially, many adult nurse participants felt that as the parents were responsible for the children, there was no requirement for nurses to be involved with supporting them. There was however, an evolving awareness that some parents and guardians may not feel confident in their decision making about the children and so may require support from the nurses.

### **Theme 5 – Making memories**

The themes making memories evolved from the participant's awareness that visits to the hospital could result in either positive or negative memories. The subthemes evolved from both the deductive and inductive analyses. The subthemes imagination and good memories evolved from the deductive analyses, whereas negative experiences related to hospital phobia developed from the inductive analysis.

***Fear of hospitals*** or nosocomephobia was mentioned by several participants. For many hospital phobias related to childhood experiences involving them and their siblings. It was expressed by some participants that there was huge potential of long term harm if children were banned from visiting patients at the hospital except for when death was expected:

*You can't just exclude it all, we're going to ban children unless it's really bad and then we'll involve them you're going to end up in 20 years with a bunch of kids that'll think you only ever die when you go to hospital (P-AN04 - FG1A Lines 472-474).*

Participants personal experiences and perceptions were consistent with this idea that if children only visited when a relative was about to die, then they would forever associated hospitals with death. A number of participants spoke in detail about their memories of childhood experiences of hospital visiting. This included the different responses for individuals within the family. In some cases, the same experience had resulted in different long term effects with one participant comparing her role as a nurse with her brothers evolving dislike of hospitals which was attributed to visits to dying grandparents during childhood:

*From personal experience as children who've visited Grandparents in hospital when they've been poorly to the point where it doesn't bother me coming into hospital but then I'm a nurse whereas my brother would never step into a hospital again unless it was an emergency he doesn't like the smell doesn't like the environment so you can't say that it doesn't not have an effect on them because it effects people in different ways it didn't affect him then but as he's grown older he associates hospitals with death (P-AN06 - FG1A Lines 180-186).*

This association between hospitals and death was a recurring issue and was often related to memories of childhood experiences. The frequency of the association provides some evidence that by only allowing children to visit if the patient is likely to

die can result in bad memories and associated psychological effects such as hospital phobias:

*It's that perception that I mean my husbands in his you know his late 40's and he says he doesn't like hospitals, I don't like going into hospitals because everybody that goes into hospital don't come out again because his experience of Grandparents coming into hospital was that they never came out or they came out in a box and that's that's his preconceived and I go home and he's like go get changed you smell of hospitals. (P-AN16 - FG1A Lines 532-538).*

One participant provided a detailed discussion about the different experiences that she and her sibling had had during childhood. They had very different experiences as children with the participant having visited the hospital regularly with her mother who was a nurse. In contrast, her sibling only visited the hospital to see their grandparent who was dying. As they have become adults, the participant became a nurse and the sibling 'hates hospitals'. This participant's perspective is that although age is important, the experience of visiting hospitals as whole is most influential:

*I remember when I was a little girl I came into hospital, my Mum was a nurse and I came to hospital all the time visited did everything and that made me want to be a nurse but I mean my sister she came and visited her Nan about an hour before she died. My Sister hates hospitals now she would never do it and I know when I used to come in all the nurses were like so lovely to me and talked to me about everything and I think it isn't just the age of the child or what they're seeing it's the experience as a whole (P-AN07 - FG1A Lines 192-198).*

This perception that the whole visiting experience is crucial in supporting children to have positive memories and avoid psychological effects was also raised in relation to family illness that did not result in bereavement. The following quote relates to a patient's child who struggled to visit as an adult due to negative experiences related to the mothers hospital admission ten years before:

*...eight, nine at the time and that completely stopped her being able to come in this time round with the treatment from what she'd experienced ...then, she'd become hospital phobic and couldn't come in and see her so there was an absolute rift with her there and she was distraught about it. (P-AN26 - FG1B Lines 148-154).*

***Fantasy and imagination:*** Negative experiences and perceptions resulting in long term psychological effects were also linked to children imagination. Professional experiences were discussed which demonstrated the power of a child's imagination in relation to death following bereavement. One participant shared an incident in which a mother had arrived at the hospital after being called in urgently by the nurses to her dying father. The mother was accompanied by her children and the adult nurse participant described how as a professional she had been unsure about allowing the children to visit their grandfather, but that the mother had insisted:

*Straight way I'm an adult nurse and I'm thinking you can't take those children in there and I said to mum erm you know did you bring the children purposively and she said you are not stopping me from taking my children in and she was glaring at me over you know the big old and I went all right then and she went in and he died (P-AN13 - FG1A Lines 403-407).*

The participant went on to explain that afterwards the mother had approached her to explain why she had insisted that the children stayed with her. The children's father had died in an accident and they had had prolonged psychological effects which she associated with not seeing him:

*...she came out and she said I'm really sorry for being so rude she said their dad was killed in a really horrific accident and they were never allowed to see him she said and those children had had nightmares for years and years thinking deaths so scary so scary and they came out and this little girl went thank you nurse and tripped off as if and you know it really that changed my opinion and I think parents all the way (P-AN13 - FG1A Lines 407-412).*

Children have reported that seeing a relative can lead to relief as it can address their imagined version of the situations, with fantasies often worse than reality (Dyregov, 1990). Children's physical presence is seen as important in concretising the situation and helping them to understand the situation (Dyregov, 1990; Hanley and Piazza, 2012). The situation described supports this premise, as the children were involved, thanked the nurse and did appear coerced into visiting. The adult nurse participant explained that this positive experience had altered her opinion of allowing children to visit, as previously she would have thought it a bad idea for the children.

**Special memories:** Other positive experiences were shared relating to actions that been taken by healthcare staff to support family visiting which had resulted in what they perceived as the creation of special memories for the families involved:

*We knew him as well as his family, really. His daughter was having her first child and they'd given him days to live and he was like, 'I just want the baby to come,' and our consultants had agreed if the baby was delivered then the baby could come straight up and that happened. In that way we were all really tearful because we thought, 'Actually, he's survived enough to see his first grandchild.' So actually it makes me feel upset thinking about it now. (P-AN27 - FG2A Lines 175-181).*

*I've had youngish mums down there terminal and the kids have stayed, slept in the bed with them, been in the bed while they've died. (P-AN55 - FG4 Lines 351-352).*

It had been noticed that grandparents seemed better when they had been visited by grandchildren:

*I think for older adults we don't tend to have that many children come, I mean occasionally we have a family brings a few in but I think it's something that should, it should be encouraged because a lot of the grandparents they like to see the children you know they like to see, it does them good to see them (P-AN17 - FG2B Lines 149-152).*

Visits by children to ICU's have been associated with positive patient reactions, such as creating a diversion, giving a sense of hope and normality (Halm and Titler, 1990) and maintaining identity (Gjengedal, 199 cited in Gibson et al, 2012). Within elderly care environments children visiting has been also been shown to result in patient's heightened self-image (Dopson, 1989). The positive patient responses witnessed by

the adult nurse participants that raised this issue, had resulted in their opinion that child visitation should be encouraged.

**To summarise**, the theme of 'making memories' evolved from the discussions relating to both positive and negative experiences. Positive experiences were shown to have resulted in changing attitudes towards children visiting, even though some of these involved dying patients. The inductive analysis demonstrated that negative experiences of illness and hospital visiting can contribute to psychological harm, such as hospital phobias. This fear of hospitals was shown through some experiences as having a detrimental effect on an individual's ability to cope with family illness in adulthood.

### **Summary of the themes of the constructing phase**

The constructing phase of the PAR study provided the opportunity to engage with the participants. Discussions held in the focus groups resulted in the construction of the current situation of visiting practices and opinions related to children within the hospital. The visiting practices were shown to be variable and inconsistent throughout the hospital. There was a culture of open visiting and holistic assessment of the patient, including family details on admission within the child health team. In contrast, childrens visiting adult clinical areas was restrictive and inconsistent. Some participants were confident that children under twelve years of age were not allowed to visit as it was hospital policy, whilst others insisted that this policy did not exist. This was consistent with my personal clinical experience, where some wards had notices prohibiting children under the age of twelve and others did not. The age of twelve was also consistent with the literature, as this age restriction has been identified nationally



and internationally. Congruent with the literature, was the practice of non-adherence with hospital policy, as some participants described how children would be admitted to visit based upon individual circumstances or clinical decisions.

The adult clinical areas were considered child unfriendly, as it was identified that there was a lack of space, and resources, such as books and leaflets. A number of reasons for restricting children visiting adult patients were identified. Infection risks, hospital policy and children causing disruption were consistent with the literature. During the inductive analysis, two unexpected reasons were identified, responsibility and abandonment. These were closely related subthemes, with the fear that children would be abandoned on the wards contributing to concerns about who was responsible for them. Examples of situations where children had been left on adult wards demonstrated the distress these rare events caused. Responsibility also related to how to approach disruptive children in clinical practice. Within these discussions, knowledge transferability was demonstrated as the child health team provided information and reassurance to the adult nurse participants relating to strategies and legal requirements.

Conflicting priorities relating to service demand and role duality were evolving subthemes in this phase. Service demand underpinned issues such as responsibility for adult nurse participants, as the patient was seen as the priority and so the nurse had no responsibility to care for any child visitor. Opinions related to children visiting were variable with some participants believing that they should not be allowed to visit, and others expressing the opinion that it should be encouraged. There was empathy shown towards different family structures and situations which may cause challenges to visiting practices. Single parents, those with no local family support and

grandparents in surrogate parental roles where all considered as having additional challenges. It was highlighted in these discussions that the admission assessment for an adult patient did not include a holistic view of the family network, in contrast to child health who performed a detailed family assessment.

Much of this phase involved the sharing of experiences and reflecting upon both personal and clinical situations. The concept that hospital visiting creates memories for both staff and families was evident, with both positive and negative experiences and perceptions shared. Positive experiences had resulted in a change in opinion relating to children visiting, with some describing how they had gone from thinking it was a harmful action to thinking it should be encouraged. Negative experiences were most often linked to psychological harm, with some describing hospital phobias developing in adulthood.

The participants were keen to further contribute to the PAR study and further focus groups were planned to take forward the themes in the planning action phase.

## Themes from the planning action phase

There were four main themes with associated sub themes in the planning action phase of the PAR cycle; the hospital policy, education, creative problem solving and perceived barriers (Figure 5.4, p.178). Consistent with the constructing phase, the themes had again been evident throughout all four phases of the PAR cycle.

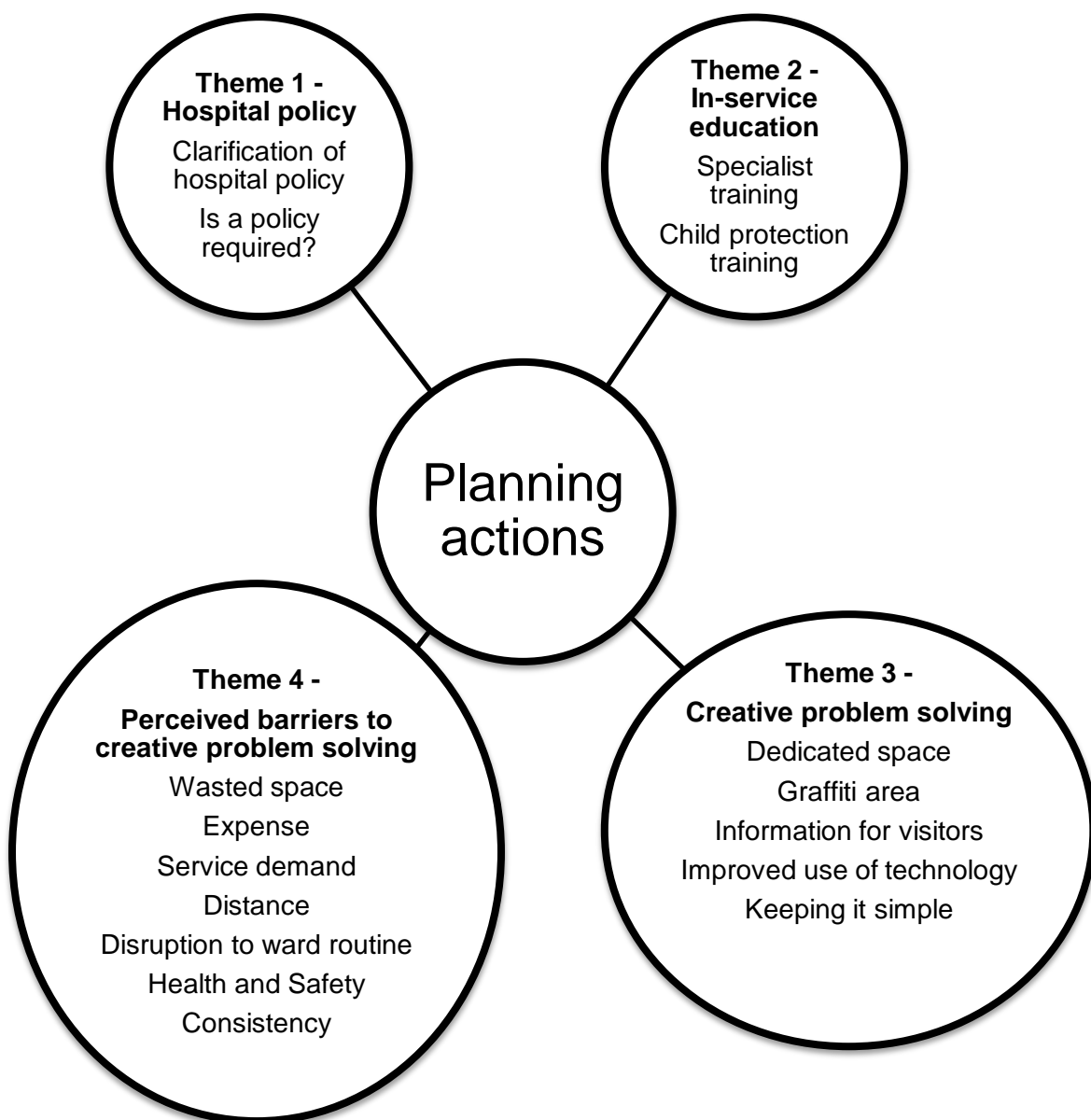


Figure 5.4 Themes and Subthemes of the Planning Phase

## Theme 1 – Hospital policy

**‘Clarification of hospital policy’:** The first plan was to establish whether the policy restricting visiting based upon the age of twelve years existed. The participants agreed to look for this policy in their own clinical areas and I would seek clarification through a thorough search of the hospital documents, websites and liaison with the SNT.

A discussion was held as to whether a policy was required, and what actions were preferred based upon the search results above. Initially in the planning phases it was expressed that a policy may be a method of assisting nurses to challenge visitors who behaviour was inappropriate or deemed disruptive:

*I think some clear-cut policy about what we can say to them, what sort of level of behaviour, which is the problem in a lot of cases, is expected. Age and reasons for coming in aside, just levels of behaviour. (P-AN28 - FG2A Lines 195-197).*

As the focus group discussions progressed the viewpoint changed as it was debated how one policy could cover so many different areas and specialities:

*I don't think you're going to get a definite policy, are you, because it's such a wide-ranging issue that it would be a policy that would be too long to process, I think. But yeah, guidelines (P-AN28 - FG2A Lines 233-235).*

Guidelines were discussed as an alternative to a policy, but the need to have flexibility for different clinical areas was raised as an issue with guidelines too:

*It doesn't sound like a guideline would work then because obviously every area is going to have different rules so a guideline would be too rigid wouldn't it [yeah] or a policy would be too rigid (P-CN21 - FG2B Lines 95-97).*

Barriers to the use of guidelines and policy related not only to their ease of accessibility and use, but also to consistency in their application in practice. Inconsistency with visiting practices was deemed to be a barrier in relation to maintaining standards. It was also a cause of confusion and stress for families and healthcare staff:

*It depends who's on. As senior nurses, we all look at things differently whereas something I'll find acceptable another one's, 'Oh, she was here yesterday and she was in the bed yesterday.' 'Well, I'm in charge today and I'm sorry, unfortunately I'm not going to ...' and that causes problems then as well. Yeah, it's difficult (P-AN29 - FG2A Lines 48-52).*

When discussing policy, standards and guidelines inconsistency was seen a significant barrier with the public not adhering to the rules of only two visitors to a bed at present, and so it was questioned whether introducing standards or guidelines for children to visit would have any effect:

*It's horrendous. That's been there for years and that's never adhered to so how are you going to get anything in place from that? You're going to have labels everywhere, aren't you? 'No kids.' 'Two to a bed.' You might as well just ban visiting all together. [laughter] But you're not going to, are you? We struggle with that. I get sick of saying it. And consistency. Some of us are like, 'No, two to a bed,' ... because people are really poorly. You can have*

*seven to a bed. 'Oh, we're leaving in a minute, duck.' And you're made out to be the one who's the tough one, really, and actually you're not there for that. You're there to look after the patient, aren't you? (P-AN27 - FG2A Lines 249-257).*

Ultimately it was decided that a policy would be too rigid for use by all, and that guidelines although preferable would have to be carefully designed as these too had the potential to be too rigid. The difficulty in locating policies and guidelines was a significant issue and resulted in them being considered not congruent with the ideal of having something easy to find and easy to use in clinical practice. Information or standards for children visiting in each ward welcome pack were deemed most appropriate as these could be adapted for each area. It was also suggested that information relating to expected behaviours and the consequences of disruption could be included in the information so that nurses could use these to support their decision making in challenging situations:

*...you know how you used to have standards for visitors, standards for this, it would be quite straightforward, in a way, wouldn't it? It's things like you don't mess with the defib or the drugs' trolley, things that you could say - or run round or be under certain things that we could, I don't know, maybe could use to back up ... (P-AN29 - FG2A Lines 241-245).*

## **Theme 2 – In-service education**

Research has demonstrated that there is a lack of appropriate education to support adult nurses in the area of child visitation in acute adult hospital areas and its provision

a concluding recommendation (Clarke, 2000; Clarke and Harrison, 2001; Gibson et al, 2012b; Johnstone, 1994; McIvor, 1998). There was awareness amongst the participants that their actions in clinical practice could have a long lasting impact related to a child's perception of the actions:

*Dealing with kids in any area of life is always challenging. It's just how you deal with that. It's the perception, isn't it? It's how they're going to perceive things and that's going to impact their life. So I think it could be just one small visit to the hospital and they see one thing, probably a nurse talking to them, anything they would see, it has impact. So it's really, really very strong. We really need a proper training and education if you really want to achieve what you want to achieve. (P-AN30 - FG2A Lines 439 – 444).*

**Specialist training:** Experiences that were shared highlighted that adult nurse participants had been asked by relatives for help in giving bad news to children and that a lack of training in how to communicate and support children in these situations was common:

*Sometimes the relatives want you to tell the children that somebody is dying and you know it would be a good idea to have some training on how to communicate things like that to children. I had to tell erm two that girls who were about this big that their Nan was going to heaven then take them to see her and you know get them on the bed and give her a kiss and a cuddle say goodbye and stuff. I've not got kids I don't know how to communicate we just had to do the best we could so some training on that would be brilliant (P-AN16 - FG1A Lines 498-504).*

The concern about how to support families with bad news was not associated with any personal parental role. Participants that were parents themselves found this clinical situation as challenging as those without children. Options for education and training were discussed and the participants from the child health team suggested approaching two local children's hospices. It was agreed that I would approach the SNT and the childrens hospices to request specialist training in communicating and supporting children during family illness. It was also agreed that if this training could be facilitated then it would be provided to the QN Team initially who would provide an evaluation of its suitability.

***Child protection training:*** In addition, full child protection training as part of the adult nurse's mandatory training was requested. Although this would not directly impact upon the adult nurses' knowledge and skill in supporting children visiting with families, it addressed the concerns raised in the construction phase of child abandonment. This was a significant concern to the adult nurse participants causing some to dissuade families from bringing children to visit. The child health team had provided information about the child protection process, which had provided some reassurance, but also highlighted to the adult nurse participants there lack of knowledge in this area. It was agreed that I would approach the SNT and request that this was considered for implementation.

### **Themes 3 and 4 – Creative problem solving and the perceived barriers**

There were a number of ideas discussed in response to the identification that there was a lack of resources in most adult clinical areas to support children visiting. During the discussions, the perceived barriers to success were often immediately presented in response to an idea. The two themes are therefore presented together in this section.



Many participants reflected upon what they thought they themselves would want if they were the patient or relative. Some ideas were creative representing the ideal situation, whilst others were very practical taking into account current resource challenges. Some ideas were further developed through discussion across specialities, as participants shared knowledge of what was available already. The child health team were able to share many ideas about resources and techniques used in their clinical areas, and debates were had about how to adapt them for adult clinical areas.

***Dedicated space:*** Lack of space had been identified as an issue in the constructing phase and this was related to patients in addition to visitors. Participants had shared experiences of not having enough space to give bad news to patients alone and so questioned where space could be found for families to attend these types of meetings accompanied by children. Despite these reservations, empathy was expressed for the patients and parents. It was acknowledged that as a parent you would want to see your children but that you may wish for this to be in a dedicated space that was child friendly:

*If you were ill and you were stuck in hospital for six weeks and your three, five, eight-year-old child was coming to visit you then it would be nice to have a room where you could take them so that they weren't erm in a hospital environment and they weren't destroying other people's peace and quiet, where you could take them where they could play and they could have cartoons on and watch the telly with them and play games with them. (P-AN24 - FG1B Lines 15-20).*

It was also felt that the children may need a separate space where they could play or remove themselves from the environment and be children:

*...and because of that reason they definitely need their own space on your individual wards, they need a little corner or little space where they can just zone out of what's going on if someone's dying, like say someone's got loads of medical stuff, because they don't understand it (P-CN23 - FG2B Lines 124-127).*

**Wasted spaces:** Although dedicated spaces were considered important in supporting children who visit, there was little that participants felt that they would be able to change to implement these. It was identified that there was a large amount of potential space that was considered wasted around the hospital:

*So there seems to be a lot of wasted like between the wards there's lots of wasted gravelled areas isn't there that's just not used.*

*It's such a shame because it would be ideal spaces for people to go, not just visitors to patients as well.*

*It's like we're in the xxx building and you've got the like patio looking areas out there but the door's always locked, you can't get at them (P-AN04 - FG2B Lines 137-143).*

No strategies for addressing dedicated space were identified during the PAR study, as the barriers were perceived to be too great for success. Barriers included **health and safety** issues with outside spaces and the **distances** between clinical areas if a dedicated space was developed in only one location:

*...but the problem is xxx is miles away from xxx you know it is the logistics of of of somebody - if it's not the parent, who's going to take these children a*

*quarter of a mile away to the other end of the hospital? And you know I think the logistics of this plan are very difficult ... (P-AN25 - FG1B Lines 21-24).*

**Information for visitors:** There were many suggestions for possible resources which could be used to support families with children of all ages at the time of visiting. A number of adult nurse participants suggested having a bookshelf or leaflet area dedicated for age appropriate resources for children. This could then include factual information about diseases or treatments, in addition to non-medical books which could be used as a distraction:

*Even just a bookshelf with an age range of books you know would be - if you go up to the nurses' station there's a little bookshelf there you know. You might just find a book or two. And I mean there are. And if you start doing searches there's a plethora of books out there about when mummy's ill or when daddy - and they could be very pointed books. So they could be, 'Let's just have a fun book. Let's just have "Charlie and the Chocolate Factory," and whatever. Or there could be some with a hidden message in it (P-AN25 - FG1B Lines 63-69).*

**Expense:** The cost of funding resources was highlighted as a potential problem in providing specialist leaflets as these had to be purchased and there was a perception that they could be taken by people that did not need them:

*It just gets taken by people who don't particularly need it and it's expensive and difficult to get hold of. We had to pay for quite a bit of that stuff that I ordered. (P-AN24 - FG1B Lines 279-280).*

There was a counter argument to this perception that resources were being wasted, that these were people that had not as yet been identified by healthcare as needing

the resources. This did not mean that they were taking leaflets without thinking, but that there may have been an unknown issue that meant that taking the leaflets was appropriate:

*But who are we to say who the wrong place is, though, really? If somebody picks it up then maybe they've picked it up because they're interested and they might be interested because they're a grandparent. And we haven't identified them. They've identified themselves. (P-AN24 - FG1A Lines 286-289).*

Information about visits was a strategy considered to support families in bringing children to visit, but also to empower nurses to approach families about the expectations relating to behaviour. In the constructing phase it had been identified that nurses often felt uncomfortable approaching families about children who were being disruptive to other patients. Having standards for children visiting, in a written form was considered a possible tool that could be used to empower the nurses to challenge parents and could possibly reduce conflict as the parents would have already been made aware of the rules:

*...and that could be given out when - you know the leaflets that we give out for the home for lunch and like - because our discharge facilitator or ward clerk gives them out when people come to the ward. That can just be given out as well. And then they've got forewarning on there. They know that if the children are misbehaving they're going to be asked to leave. (P-AN34 - FG2A Lines 388 – 392).*

*...then they know that this is what's expected if children come in to hospital. They may not, like you say, adhere to that but it's there in black and white for them to see. And then they can't say, 'Well, we weren't told.' It's there. (P-AN34 - FG2A Lines 327 – 330).*

Ensuring that families do not feel alienated and that there is equity in the information provided was considered:

*I think a leaflet could, in some circumstances, work. About what you were saying how we expect - what behaviour we expect. But it's if they're given out to all families because if you're only giving it out to families that you think are unruly then you're going to get those double standards. You should be giving it out every time people come in with children right from the start. (P-AN36 - FG2A Lines 319 – 324).*

It was thought that information in the ward leaflet or a dedicated leaflet for families who would like to bring children to visit could encourage parents to bring in their own resources for the children to ensure that they had something to occupy them if needed, reducing the need for lots of resources on each ward:

*But when you're coming visiting a poorly relative in hospital the last thing you think of is entertaining the kids. But if it's in the admission pack or even if they come once next time you come just bring some. It's whether they read it isn't it? (P-CN23 - FG2B Lines 216-218).*

**Graffiti area:** Other resources were considered such as colouring books and toys. Concern was raised about the lack of storage space and where any toys or colouring books could be stored. A central store was suggested that would address concerns about storage and infection control:

*Couldn't we get something like a toy library because we couldn't facilitate space on our wards and infection control wise [15:40 – inaudible] at least if there's a toy library then things would be going back and having a proper clean as well. (P-AN17 - FG2B Lines 199-202).*

Easy access to drawing materials was discussed at length. Participants from the child health team provided many ideas which were easy to access and required little storage space or time including electronic colouring pictures, whiteboards, and graffiti areas:

*Something electronically then if you have things electronically on your computer you can go to a printer, print out the picture of whatever. So then you won't have to keep the paper, just a few crayons (P-CN23 - FG2B Lines 220 – 222).*

*You can get that sheeting, that whiteboard on a roll, tear it off like cling film and it sticks to a wall so you've got an instant either projector screen or whiteboard and you could always stick that up in the cubicle wall and have some pens, the kids would have a great time. (P-CN21 - GF2B Lines 259 – 262).*

When discussing these ideas, it was noted that there was a detachment between the hospital and other public spaces. Below is one example, that in restaurants simple resources such as packets of crayons are widely available:

*The little packs of crayons like they give in restaurants you know the little, a few packs of them. (P-CN21 - FG2B Lines 226 – 227)*

The ideas around using a graffiti area with whiteboard sheeting included taking the sheeting into the patient's room or bed space so that the child could remain close to the patient. This was also linked to the subthemes in the constructing phase of making memories and disruption. It was considered a space saving solution that would provide a productive activity for the child whilst visiting, thereby reducing boredom and the risk of disruptive behaviour but could also be picture that is taken home by either the patient or this child:

*I'm just thinking from a space point of view, for you to keep your space to a minimum, you know they can take it home with them if they wanted to then at the end of it, they could roll it up and take it home. (P-CN21 - FG2B Lines 265 – 267).*

**Service demand:** Responsibility for the supply and maintenance of any resource was a concern. It was thought that this would need to be completed by someone interested who was happy to do it in their own time, as service demand meant that there was no time as part of a person's work role:

*You couldn't say, 'You're going to do this.' And even if it's just like getting a few books together. 'Here's 50 quid. Go and get a few books on Google,' it would have to be someone who is going to say, 'Yeah, I really like that idea. I'll do that in the evening in my own time.' (P-AN25 - FG1B Lines 234-237).*

**Improving the use of technology** was considered in respect of communication and maintaining family contact, particularly for those families where proximity was an issue or where there was stress relating to hospital phobias.

*I think if you can put Wi-Fi in for people here that's your first start and then people can make up their mind, do you know what I mean... So I think that would be a very good way of keeping people in touch. (P-AN26 - FG1B Lines 618-622).*

The use of Wi-Fi for family communication was also considered an option for patients with visiting restrictions due to treatments or where there was a high risk of infection to the patient. This could also be a consideration in cases where the patient has an infection which requires greater isolation, such as influenza:

*There would be, yeah. If anyone's got an infection is banned from coming in here, basically, is what we would say. And that's the message we always preach to them when they go for the chemo talk. (P-AN26 - FG1B Lines 625-627).*

**Disruption to ward routine:** In child health, siblings could visit at any time and this was not seen as distracting to the routine of the clinical areas. There was concern however amongst the adult nurse participants that some strategies, particularly the improved use of technology to aid communication could cause disruption to ward routines:

*'But then it's the whole thing, you're on the ward round in the morning. You can't hear anything because everyone's on the phone or they're on these - you've got to look at why you're in hospital. (P-AN27 - FG 2A Lines 584 – 589).*

However, in addition to the benefits for patients and relatives of having another method of communication, increased use of Wi-Fi and platforms such as Facetime, was seen by some participants as potentially beneficial to the healthcare team rather



than another disruption. Use of technology such as this was linked with a potential reduction in telephone calls to the wards and reduced complaints related to information given by staff. It was discussed that relatives would be able to see the patient and so potentially be reassured by their condition, but also that the patient could give more information to their relative than the healthcare staff that are bound by confidentiality rules:

*It would be better for us as well. [48:09 - participants talking over each other]*

*But with Wi-Fi for anything it would make their communication much easier*

*(P-AN27 - FG2A Lines 576-577).*

There was a consensus that most patients now have their own mobile phones or iPads, although it was recognised that this would not apply to all patients and so it was questioned whether the hospital should provide equipment:

*What are you going to do if they haven't got access to a phone, though? Are we going to supply them with iPads and stuff? (P-AN27 - FG2A Lines 565 – 566).*

**Health and safety** concerns were raised for those patients bringing in their own equipment:

*Do you actually need to bring your - the laptops they shouldn't be using until they're PAT tested, should they? But by the time you've got them tested they're home, aren't they? So we're bringing up another discussion there, aren't we, really? (P-AN27 - FG2A Lines 584 – 589).*

The risk of theft if the equipment was provided by the hospital was seen as a risk:

*I was going to say it's getting it back, we can't keep hold of teaspoons or pillows, we're not going to keep hold of iPads are we, got no teaspoons or pillows. (P-AN27 - FG2A Lines 250 – 251).*

Role conflict in relation to **service demand** was a common barrier presented to providing support to children and families. This related to both procurement and care of resources, but also related to time factors. There was for some participants a clear dilemma between providing a service for the family unit and not having time to provide fundamental patient care:

*So they will dump the relatives. It's a case of do you dump the relatives, or do you dump the patient? (P-AN24 - FG1B Lines 532-533).*

In this regard, there seemed to be a disconnect between the person as patient in hospital and their wider role in society, within a family structure.

**Keeping it simple:** A viewpoint did evolve, in response to the creative ideas and associated barriers. That whatever strategies were considered perhaps it was the more simple things that needed to be implemented rather than complicated plans which would be expensive or time consuming. I had shared with the focus group some of the children's perspectives from the literature and from the pre-step consultations with the MCRN YPAG, that children wanted to feel welcome, not to be rushed or made to feel like they were in the way, to be given directions to the patient, to know what was wrong with the patient and to ask if they wanted a drink. The quote below followed this discussion:

*You've probably spent too much time sitting around trying to think, 'What can we do?' and trying to be clever about it. What do we say? When actually it's get led by the child, really. You've got what the children want. You know what it is. How do we pass that out to everybody else to stop them getting too clever? (P-AN26 - FG1B Lines 371-375).*

The idea of making things simple was also applied to potential information for children and their families, which could enable to a less stressful visit by knowing what they could and could not do:

*And, again, it might just be like information like, 'Yes, the child can sit on the bed,' or, 'No, absolutely not' you know. If families have these things right from the beginning they sort of have an idea of ground rules that everyone feels comfortable (P-AN25 - FG1B Lines 379-382).*

### **Summary of themes from the planning action phase**

Four main subthemes evolved during the planning phase. The need to clarify the existence of the hospital policy highlighted in the constructing phase was identified. It was decided that a hospital policy would not help to improve the support provided to children visiting. Policies were frequently difficult to locate and not easy to navigate. Clear standards and information for families who wished to bring children into visit were considered to be of greater utility. They could be incorporated into the patient information packs and so contain additional information relevant to individual specialities. They could contain clear instructions relating to the expected behaviours and so provide confidence for nurses to challenge families with disruptive children. It was also hoped that by providing information on activities to bring with them, families

would bring in their own resources. The possibility of this information resource being developed by a local college was discussed, as I had been approached with a request for a number of college students to participate in the PAR study. It was agreed to discuss with the college representative whether the students would be interested in designing age appropriate resources for the hospital.

Education was an important issue during the planning phase. Adult nurse participants identified the need for education relating to providing information to children and families. An approach to the local childrens hospices requesting education was identified as an action, as was requesting that child protection training was incorporated into the adult nurse mandatory training scheme.

A number of strategies were discussed which could be introduced to individual clinical areas. The child health team adapted a number of the strategies used in their areas to try to aid the adult nurse participants in finding achievable plans. The use of computer generated colouring pictures and whiteboard sheeting were strategies considered to be most appropriate as they would involve minimal storage and infection control procedures. Space and infection control were seen as barriers in the adult clinical areas to the introduction of resources, such as toy boxes and play areas.

## **Taking action**

The planning action stage generated ideas for strategies to improve the care provided to children and young people who visit adult relatives at the hospital. The three main plans as a group were to; clarify hospital policy, pilot an educational session with the QN's and engage with local young people to design information resources for visitors. These did require collaboration and assistance from other stakeholders; the SNT, the local children's hospice and a local college.

### **Clarification of hospital policy**

An extensive search of all the current hospital policies and protocols was carried out. There was no policy or protocol that gave an age restriction for visiting adult patients. Liaison was also made with the SNT, including the Chief Nurse and no-one had an awareness of any policy or protocol which had any visitor age restriction. There were two pieces of documented evidence of an age restriction at the hospital. The oldest was found in The Staffordshire Sentinel April 23, 1912 (Figure 1.1, p.25). In this hospital report the age restriction is given as children under fourteen years of age. In 1982 Goodall, a Consultant Paediatrician based in the same locality wrote an article which implies that the restrictions relating to children under fourteen years of age may still have been in operation at that time.

Agreement was given by the Chief Nurse that if the nursing staff decided that a policy was required this could be developed and referred through governance channels. The Chief Nurses' preferred option was that the hospital welcomed any visitors rather than

had any strict restrictions. She was supportive of information and standards for visitors who wished to bring children to visit as had been discussed in the planning phase.

### **In-service education**

I organised a specialist training session which was delivered at a QN meeting by staff from a local children's hospice. This was a two hour session which covered age appropriate communication methods, myths and assumptions associated with children and illness or bereavement, and strategies used by the hospice. I expected only the adult nurse participants to attend this training but attendance was from both the adult and child specialities (n=25). There was a lot of discussion held during this training which from observations was very positive.

### **Engagement with local young people**

One strategy identified was the need for appropriate resources on the wards and the hospital internet. I had previously been approached by student representatives at a local college expressing an interest in participating in the PAR study by designing any resources identified. The college was contacted and were still interested. The students also asked if they could have their own focus groups to reflect on their work within the project and to provide a young person's perspective. The students were studying a Level 3 qualification and hoping to go into careers such as nursing, social work, midwifery, pre-hospital care and teaching. They were all aged between sixteen and nineteen years of age. This participant engagement formed a cycle within Cycle 2 and is discussed in detail in the next chapter.

## **Chapter 6**

### **Cycle 3 – Engaging the voices of local teenagers**

**‘In silence I must take my seat**

**And give God thanks before I eat; ...**

**I must not speak a useless word**

**For children should be seen, not heard ...’**

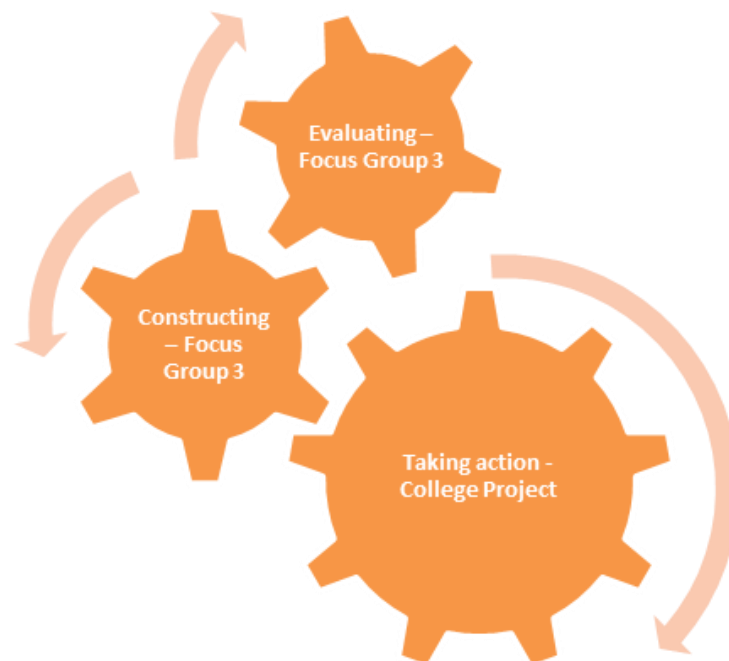
**(Anon, 19<sup>th</sup> Century cited in Bennett, 1993, p.42)**

#### **Introduction**

This chapter will describe the process and findings of Cycle 3. This was the result of actions planned in Cycle 2 and in essence represents a cycle within a cycle. One of the planned actions was the production of resources, such as leaflets and web-based information for families and children. The hospital had a widening participation programme which included after school clubs for students interested in the NHS. A Health Society was established in each participating school and college to act as a key contact for healthcare careers and health promotion activities. The co-ordinator of this programme had made contact to express an interest in taking part in the study, having seen one of the posters (Appendix 8, p.405) on the hospital intranet. The inclusion of the Health Societies was discussed in the QN focus group and it was agreed that having a local college assist in designing resources for children would be beneficial as they would be able to give a different perspective. Rather than the children staying silent while the adults decided what was best, local children would be taking the lead informing the hospital what resources would be most appropriate.

Initially it was thought that engaging the college students in designing resources would not involve a separate research cycle. However, when the meeting took place to describe what the nursing staff wanted to produce, the college students did want to design the resources, but also they wished to take part in a focus group to evaluate their part in the PAR study process. An evaluation focus group was therefore planned to take place at the end of the timescale set for the action of producing the resources.

Cycle 3 concluded with three distinct phases: constructing, taking action and evaluating action, as illustrated in Figure 6.1 (p.199).



*Figure 6.1 Cycle 3 Engaging the Voices of Local Teenagers*

It did not follow the standard PAR cycle as in Cycles 1 and 2, as it was expected that there would only be the planning, taking and evaluating actions stages. The constructing phase was an unexpected result of the evaluating action focus group



where the college students shared experiences of visiting different healthcare organisations to illustrate what they felt were important actions to be taken by healthcare staff. The involvement of the college students required an application to the Ethics Committee to amend the study, and this chapter will commence with revisiting the ethical considerations involved.

## **Revisiting ethical considerations**

The offer of participation from the college students required an application to the Ethics Committee to amend the study and approval was granted (Appendix 13, p.423). The structured ethical reflection framework completed in the Pre-step and Post Cycle 1 stages (Brydon-Miller, 2012) was again revisited in response to the change in participant engagement (Appendix 14, p.425). Alderson and Morrow (2011) highlighted that the differing levels of risk and potential harms to young participants mean that different forms of ethical consideration may be needed in health and social care research. In this study, informed consent, inclusiveness and non-maleficence were the main ethical dilemmas considered in the planning of this cycle.

## **Consent and inclusiveness**

Although the participation of the college students in the project was an exciting proposition and would add a valuable perspective, the issue of consent caused an ethical dilemma. Could the students consent themselves to take part in the project or would parental consent be required? (Jervis, in press). There is no statute in England, Wales or Northern Ireland which governs children's' right to consent to participate in research except in the case of Clinical Trials of an Investigational Medicinal Product

(CTIMP) (NHS Health Research Authority (NHS Health Research Authority (NHS HRA), 2018). Common Law presumes that sixteen to eighteen year olds are predominantly competent to give consent for medical treatment and case law supports this, stating that if a young person can give consent to treatment they are deemed Gillick competent (NHS HRA, 2018). The Gillick ruling (1985) established the principle that all parental authority “yields to the child’s right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision”. This principle is also applied to a young person’s ability to consent for research (NHS HRA, 2018)

In this regard, parental consent was therefore considered unnecessary, as the students’ involved had left school and were at college studying a level three qualification. Examples of this level of qualification in the UK are AS and A levels and access to higher education diplomas. These college courses aim to provide a range of knowledge, skills and understanding at a detailed level and are appropriate for those planning to go to university. All the students involved in this study were hoping to go into healthcare careers and were teenagers aged between sixteen and nineteen years of age. It was identified through dialogue with the tutors that although parental consent was often requested, the students also gave their own consent for some college matters.

During the dialogue with the college tutors it was considered that asking for parental consent might alienate the students. When the study had first come to their attention they had made the decision to participate and the aim was to actively involve the students as partners in this cycle rather than recruit them as research subjects. Providing information in a format that was understandable for the students and was

delivered in a style that fostered true voluntary decision-making, (NHS HRA, 2018) was a challenge, as this was not an area of which I had great experience. To facilitate this principle, a meeting was held with the students who had expressed an interest in the study. It was held at the college and tutors also attended to provide support and continuity. Information sheets were provided and the students were given the opportunity to ask questions in order to aid understanding of the study and processes involved.

As the students already gave consent for some college projects, my main concern had been that by asking for parental consent the balance of power might be affected. The college students were legally able to consent to behaviours, such as sexual activity, and so asking for parental consent for them to participate in focus groups relating to project work that they were leading seemed contradictory. On review of the literature regarding the involvement of children and young people in research (Fleming and Boeck, 2012; Heath, Charles, Crow, and Wiles, 2007; Kirby, 2004), it was considered that allowing the students to consent for themselves was the correct decision. This decision was based on the social context (Heath et al, 2007), as the focus groups would take place at the college, and the study context. Parental consent for a young person aged sixteen and over is recommended in the following circumstances; conducting interviews with young people under the age of eighteen years of age in the family home, participants are vulnerable sixteen to eighteen year olds (for example if they have a learning disability), or the research is on an exceptionally sensitive or troubling topic (Shaw, Brady and Davey, 2011), and none of these circumstances applied to this study.

The NHS HRA (2018) suggest that although it is normally good practice to involve families in decision making even when a young person is competent, if that young person objects, then their privacy should be respected. This was taken into consideration together with the UN CRC (1989) when the consent process took place, with students being asked if they wanted parental consent to be sought. None did and they were all keen to have copies of their own consent forms for use in their future curriculum vitae's (CV's).

### **Non-maleficence**

As with all stages of this PAR study, the principle of non-maleficence, doing no harm, was considered. The potential of psychological harm is not always transparent and obvious (Parahoo, 2006). The focus of the student's participation in the study related to designing resources and evaluating this process. However, the chance that discussions about visiting acutely ill relatives might occur, with the possibility of associated anxiety and distress if painful memories were recounted was recognised. To address this issue, access to specialist college support services for the students was agreed in advance. A Counselling Service was available at the college together with Learner Managers who support students with all their holistic needs.

A further consideration relating to the principle of non-maleficence was the natural power imbalance between me as the researcher and the students who were the participants. It was recognised that this power imbalance could have an effect upon the data collection process and that although steps could be taken to minimise any impact on data collection, the effect could not be eliminated (Shaw et al, 2011). National guidelines (Shaw et al, 2011) were followed to mitigate the impact of the

power imbalance. These included conducting all study activity at the college, using an informal seating arrangement, providing soft drinks and snacks and dressing informally to encourage a relaxed atmosphere during the focus group. Two college tutors known to the students planned to attend to provide support to the participants. Although there was awareness that this action could also affect the power imbalance, as the tutors were the gatekeepers to the college students (Stuart, Maynard and Rouncefield, 2015), and I was not in a position to fully know the dynamic between the groups in the college.

## **Recruitment**

The co-ordinator of the hospital Health Society programme had made contact to express an interest from college students in taking part in the study, which had come to their attention from the posters on the hospital intranet (Appendix 8, p.405). Involvement of local schools and colleges had been discussed with the QN participants in Cycle 2 and it was agreed to discuss the designing of resources, such as leaflets, with this college group.

Participation in the study was voluntary and it was made clear that there would be no penalties for those who did not participate in either the designing of the resources or the focus group. Participation was not linked to the students college work and so would not affect their grades, however they did indicate that one incentive to participating was that it could be used in their portfolios and CV's. Consent forms (Appendix 15, p.428) were signed by all students prior to the focus group and copies were made available to individuals. Information sheets (Appendix 16, p.431) had been

distributed and there had been an opportunity to ask questions. All students accepted a copy of their own consent form with the intention of using them within their own college portfolios.

## **Data collection**

One evaluation focus group was held at the college. The focus group method was again used as it was congruent with the constructivist perspective of the study. The students had worked on the resource design project as a group and so in evaluating their contribution it was deemed important to explore the views held by the group (Liamputtong, 2011). Also the focus group had been requested by the college students who were keen to experience the process and to share their views. Therefore, conducting the focus group was in keeping with the key characteristics of PAR of being collaborative and treating the students as competent, reflexive and able to participate in all aspects of the research process. (Kindon et al, 2010). A schedule was constructed to aid facilitation of the focus group (Appendix 17, p.435).

Fourteen students (n=14) participated in the focus group. There were two additional students who had been involved in the project but who were unable to attend the focus group as they were away on holiday. Two college tutors also joined the focus group. Initially this was to support the students in the event of any distress. They were invaluable in supporting the facilitation of the focus group as initially the student participants were reluctant to engage with any questions or conversation.

## Data analysis

Initial data analysis in Cycle 3 occurred concurrently with initial themes being presented at the end of the focus group. This process was crucial in the PAR approach to provide validation due to awareness that further contact and access to the students might have been limited.

Transcription and thematic analysis was then carried out using the same process as for Cycle 2. Initial codes were again identified using deductive and inductive reasoning (Table 6.1, p.207) The deductive codes used were based upon the literature review results (Appendix 7, p.403) but categorises in this cycle were grounded in the questions from the focus group schedule (Appendix 17, p.435). These related to any experiences of visiting adult relatives in hospital which had helped with the project, the ease of access to any information or guidelines concerning children, what was needed at the hospital to support children including resources they thought would help staff. In relation to the project, their evaluation of the process, including advantages and disadvantages was considered.

The deductive analysis was used to explore whether previous research findings discussed in the literature review were still relevant in relation to children's perspectives and whether strategies adopted in other areas were considered important in this study setting. Inductive analysis was used following this to identify new themes or new meanings relating to deductive codes. Once both sets of analyses were complete the codes and categories were analysed together in order to further develop the conceptual data analysis. This involved actively looking for similarities that could

be grouped together into themes, but also to search for the meanings associated with the deductive codes particularly those that differed from previous literature.

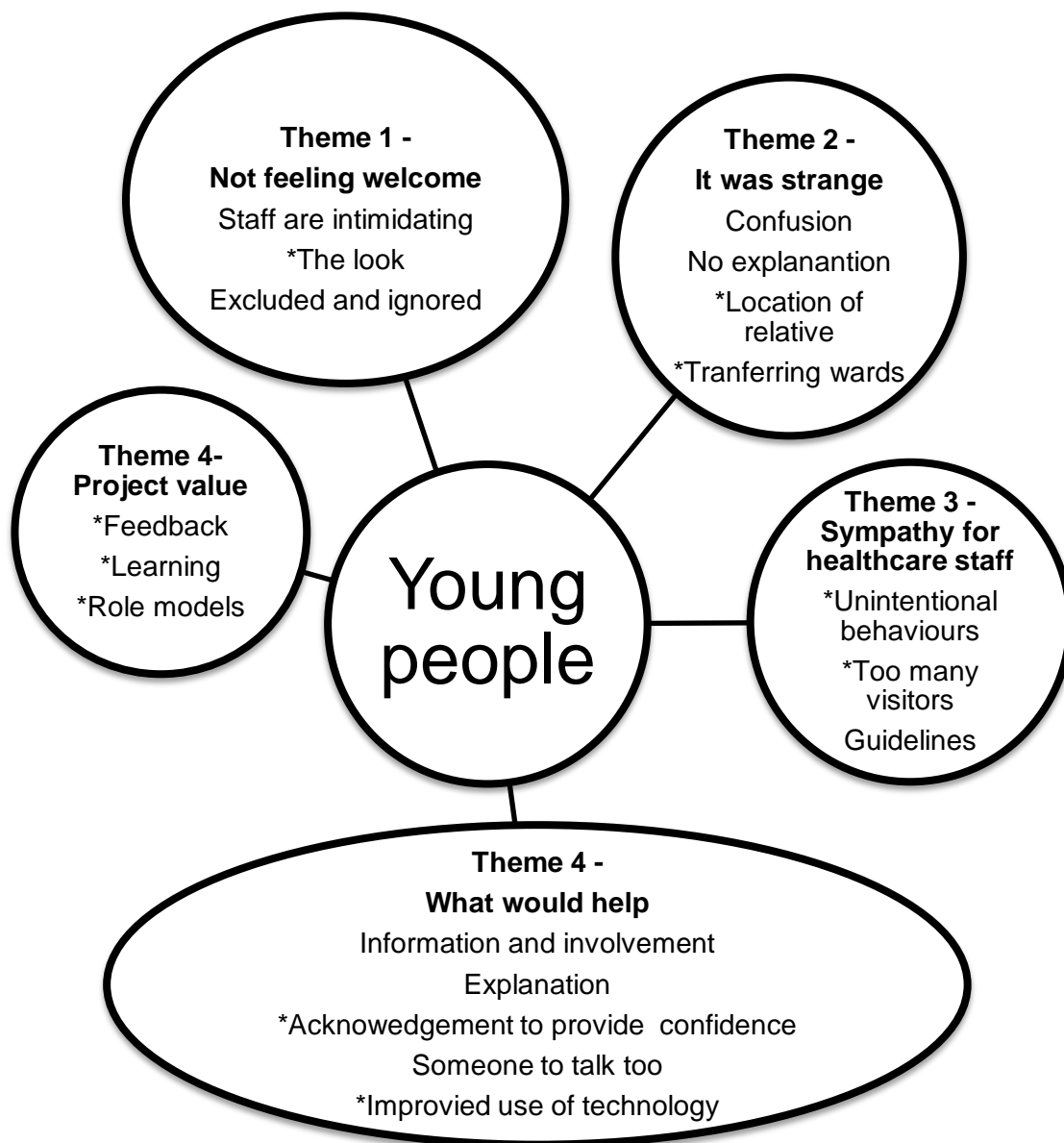
<b>Experiences which helped the project</b>	<b>Ease of access to information</b>
Not welcome Staff attitudes Rude Intimidating The look Too busy Excluded Ignored Overlooked Won't understand Patronised Distressing to see other relatives upset It was strange Confusion Location of patient Ward transfers No explanations Unintentional Too many visitors Transition Parents withholding information Parental protection It's OK to be upset Doing own research	Not easy No introductions Too busy
<b>What resources would help</b>	<b>Value of the project to the students</b>
Guidelines for visiting Leaflets	Learning Role models
<b>Value of project to the others including the hospital staff</b>	<b>What is needed to improve the experience of children and young people visiting the hospital</b>
Feedback Learning	Communication Information Age appropriate Explanation Involvement Acknowledgement Confidence Someone to talk to Knowledge of staff Approachable staff
*Blue writing denotes deductive codes	

Table 6.1 Initial codes from data analysis of Focus Group Cycle 3



## Themes

Five conceptual themes evolved from the deductive and inductive data analysis. These were 'not feeling welcome'; 'it was strange'; 'sympathy for healthcare staff'; 'what would help' and 'project value'. These are presented with the associated subthemes in Figure 6.2 (p.208):



*\*Indicates inductive subthemes*

Figure 6.2 Themes and Subthemes Cycle 3

The majority of the students had had experiences of visiting a variety of local and national hospitals and hospices. Some experiences shared were from the perspective of a patient, but the majority related to visiting family and friends. The ages of those visited ranged from elderly grandparents to new born nieces and nephews.

### **Theme 1 – Not feeling welcome**

It was disappointing but not surprising that the students reported not feeling welcome when visiting hospitals or hospices. This had also been a feature of the consultation feedback in the pre-step phase and so was one of the deductive codes. When asked directly by one of the college tutors if they feel welcome all the students reacted by either saying 'no' or shaking their heads. The main reasons related to staff attitudes and communication, and were perceived by the students as occurring both when they were a patient and a visitor.

***Staff are intimidating.*** One of the main experiences was that healthcare staff were perceived as often being intimidating and therefore unapproachable:

*Some of them can be quite intimidating as well - walk up to the bed and give you the look and you have to just sit there and not really bother them (P-CS42 - FG3 Lines 275 – 276)*

***The look*** evolved through the inductive analysis as, although the theme of feeling unwelcome was part of the deductive analysis, this term was new. 'The look' featured a number of times throughout the focus group and was described as always resulting in the teenager involved feeling uncomfortable or unable to approach

healthcare staff. This seemed to exacerbate feelings that healthcare staff had little time to speak to or support young people visiting. This was also highlighted as happening when the young person was a patient. There was an impression that within NHS organisations the staff had little time to talk with young people which was not an experience shared when receiving private healthcare:

*I don't feel like they have time for you like when you go to the NHS. Cos like if you go private you get like more one to one and they'll sit there and talk to you and tell you what's up. Whereas if you like go the hospital you just feel like rushed (P-CS44 - FG3 Lines 243 – 245).*

The students explained that a contributing factor to their perception that children and teenagers are not welcome visitors was the differences in how adults and teenagers were treated by healthcare staff. This not only related to healthcare staff, such as nurses and doctors, but also to all adults encountered. Receptionists had been noted to engage with adult visitors having a conversation and providing directions, whereas with teenagers there was little engagement or conversation, leaving them feeling as though they had substandard assistance:

*You just get a sticker and then they tell you where the room is and you've literally got to find it yourself and sort everything out yourself. Whereas my dad, he'd get a 'hello', asked if he was okay, he'd get his visitor sticker and then they'd show him where to go (P-CS41 - FG3 Lines 421-424).*

**Excluded and ignored.** This perceived lack of engagement, due to their age in contrast to that provided to adult visitors, contributed to feelings of exclusion. Children were often assigned the role of the 'silent listener' at times when healthcare staff have allowed them to visit, where although seeming to accept the presence of the children,

the staff do not involve them leading to the children feeling ignored which is often felt to be unfair (Kean, 2009):

*I think we get overlooked a lot because they see us as not being as mature so we probably won't get it or we won't understand anything (P-CS39 - FG 3 Lines 441-442).*

This feeling of exclusion related to a lack of information and engagement from healthcare staff had also been experienced by students who had experienced care in adult wards or departments:

*...and they'd always come in and explain to my mum, but they'd never tell me or ask if I was alright or anything (P-CS39 - FG3 Lines 493-495).*

It is widely accepted in sociology and healthcare literature that parents have the power to be gatekeepers over their children (Coyne, 1998; Mayall, 2000) and that controlling information is often used by parents to protect and reassure children during times of critical illness in the family (Clarke, 2000). This is often achieved by managing the content, timing and process of information giving to their children (Kean, 2009). The students in this study confirmed that parents did not always help in situations of family illness due to this control of information:

*Parents hold back things as well. Like my Dad didn't tell us for 6 months that my Granddad was ill. And then it took us to actually ask questions about it... as whereas the nurses don't tell us anything and then whatever they told my Dad he'd kind of hold back things he didn't think was appropriate. It was like you had to find out for yourself really (P-CS42 - FG3 Lines 148 – 152).*

Parents may not always have an accurate perception of their child's knowledge (Craft et al, 1993) or the ability to reassure and support their children due to their own distress (Winch, 2001). The quote above may reflect such a situation, as the student was left searching for information. Children will often 'fish for information' during family illness by the use of direct and indirect questions to adult, and in hospitals have been observed to position themselves between family and healthcare staff during conversations in an attempt to understand the situation (Knutsson and Bergbom, 2007b; Kean, 2009).

*In summary*, all of the students (n = 14) expressed the opinion that they did not feel welcome when visiting hospitals, either as a patient or a visitor. These feelings related to staff attitudes and a lack of communication which left them feeling excluded. They were very perceptive and observant in relation to differences in how they were treated compared to adult visitors and to the perceived protective behaviours of their own parents.

## **Theme 2 – It was strange**

Previous research has reported children and young people describing visits to ICU as strange which related to the environment and the patients' appearance or behaviour (Knutsson et al, 2008). The young people in this research also used the word 'strange' frequently, but in the context of being confused due to a lack of information or support. Some described feelings of confusion when there was little information given about the location of their relative. From one experience this was not isolated to the young person, but also seem to be reflected in the adult visitors:

*When we went to see my Mum they called up telling us she was in hospital but they told us just to come to this unit but they never actually explained which building or where it was so when we got there we were all confused and didn't know where to go and when you go to reception they weren't exactly helpful sometimes (P-CS39 - FG3 Lines 29 – 32).*

Children can experience a level of emotional turmoil during family illness, relating to feelings of shock, anxiety, fear, confusion, frustration and uncertainty (Craft et al, 1993). These feelings were exacerbated in circumstances, such as when relatives had been moved to different beds or wards, or when on arrival the receptionists were perceived as providing little assistance. Healthcare staff not interacting with the students also seemed to elicit the feeling that the experience was strange and that they were being excluded:

*It was like a bit surreal cos there was like no, there was doctors around but they weren't interacting with us and telling us what was going on... it was just strange (P-CS41 - FG3 Lines 270 – 371).*

***In summary***, the theme 'it was strange' evolved from the deductive analysis as this was a term used to describe the environment and patient appearance or behaviour in previous research. However, for the students in this study, the term strange was related to healthcare staff behaviours and the associated emotional turmoil which could result from feeling confused and excluded.

### **Theme 3 – Sympathy for healthcare staff**

Sympathy for healthcare staff evolved during the inductive analysis. One of the educational benefits of facilitated visiting for children in ICU's was an increased appreciation of the work of healthcare staff in caring for the child's family member (Knutsson and Bergbom, 2007b). However, the students in this study demonstrated a wider understanding of the hospital environment and associated challenges.

***Unintentional behaviours*** Although the students in this study described incidents of feeling excluded, unwelcome and intimidated by healthcare staff they acknowledged that these interactions might not have been intentional. There was recognition that NHS hospitals were very busy, hectic places and that healthcare staff were working under pressure which may mean that they are unaware of how they are perceived by visitors:

*I bet some of them don't even notice that they're doing it cos like I know like how rushed they are. If they go into a room and there's a kid sitting there and they walk back out again I bet they probably didn't even notice that they ignored them or give them the look or anything they probably didn't they probably just thinking about what they need to do the tasks they. Probably didn't even acknowledge the fact that they'd ignored them or anything (P-CS42 - FG3 Lines 283 – 288).*

***Too many visitors*** The student's displayed sympathy for both the busy environment and the stresses of this for the healthcare staff. This was reflected in their ideas for improving the experiences of children visiting the hospital. They considered

that there could be too many visitors at times and that this could cause additional stress, such as people having to wait outside:

*...cos then you haven't got too many visitors if they don't like having too many visitors to one bed so then you can have someone else talking to them. Sometimes you can have the problem like when they only want 2 visitors but you've got your Nan, your Mum and your Dad who've turned up and you have to have people waiting (P-CS39 - FG3 Lines 167 – 170).*

Being left waiting outside wondering what was happening was a feature of the MCRN YPAG consultation in the pre-step phase. Knutsson et al (2008) also found that waiting was described as difficult as it led to tension and concern with children often left with nothing to do. The idea of too many visitors seemed to be an additional stressor in deciding whether to visit a relative for some students:

*I think there should be some, like, kind of – not rules but guidelines on how many people can turn up for visiting as well. I never understood that as a kid. I can remember being asked, because my family are the same, they always talk about if anyone's ill or anything, they're not afraid of saying anything, so they'd say, like, 'Well, do you want to come and visit with us?' and I wouldn't really know – like if there was a few other people going, I'd sometimes be like, 'Oh no, I'm okay,' because I thought there's going to be too many people there. So like age ranges who can go and how many people can turn up kind of thing. It goes a bit awkward when you don't know. If you're going in place of someone else, you kind of just sit back and think, 'Oh no, they can go instead.' So it's a bit confusing, like deciding who's going to go, especially if you've got a big family and stuff. (P-CS38 - FG3 Lines 430-440).*



Although a long quote (above), it demonstrates the dilemmas felt by some of the students in relation to the decision to visit. Teenagers often feel great responsibility towards others at times of family illness (Titler et al, 1991) and there was the awareness that there was limited space for visitors and so visiting may prevent someone else in the family from going. This links to the later theme, of what would help, when the students discussed strategies which could support their decision making in these situations.

**To summarise**, the theme sympathy for healthcare staff evolved from the inductive analysis. Students demonstrated an awareness of the pressures and stresses of the hospital environment and how this may impact healthcare staff behaviours. It was accepted that healthcare staff may be unaware of how they are sometimes perceived by visitors due to the busy nature of their role and that at times some may unintentionally appear intimidating. Students were also concerned about situations where there were too many visitors at the hospital, and this concern was incorporated into their own decision making if asked by parents whether they wanted to visit a relative. These issues were the basis for some of the strategies that the students thought would help to improve the support provided to children who have a relative admitted to the hospital, which will be discussed in the next theme.

#### **Theme 4 – What would help**

There was a concern amongst the QN focus groups in Cycle 2 that this study might cause them to have more work for which they did not have time. Some complex ideas were discussed and in the literature there are a number of strategies which would take time and staffing, such as facilitated visiting (Blot et al, 2007; Hanley and Piazza,

2012; Johnstone, 1994; Nicholson et al, 1993; Pierce, 1998; Pinoël, 2015), play facilities (Gremillion, 1980; Matorin, 1985) and resources such as booklets (Davis, 2015; Hanley, 2008; Macpherson and Cooke, 2003). The students involved in this PAR study cycle advocated very simple strategies when discussing what would help when visiting relatives or friends in hospital. These related to actions which would make them feel more welcome and confident, and evolved into the subthemes: information, explanation, communication and acknowledgement to provide confidence.

**Communication:** Improved communication was the greatest change that the students felt would improve their experience of visiting this hospital (FG3 Line 380). This was multifaceted and related to the availability and mode of information delivery, the use of technology and the communications skills of all hospital staff. Patient location and the reasons for moving wards and departments was highlighted as a stressful situation that was often not communicated to relatives well. This included instructions as to the locations of different wards so that relatives could find them easily:

*If there was information on like on the areas because he kept getting moved and it just kept confusing me and my Mum (P-CS41 - FG3 Lines 85 – 86).*

**Information and involvement:** The lack of information about the patient's reason for admission and illness provided by either healthcare staff or family members was deemed not helpful. Children often indicate that at times of family illness they have a desire for more information (Craft and Wyatt, 1986; Craft et al, 1993; Winch, 2001) and in reaction to a lack of information the students described how they would look for information themselves using the internet, but that this was not always helpful:

*I've done my own research on conditions as well, which I think is just even worse. So if you go and see a relative and say, 'Oh yeah, you've got this,' then you go home and you're like, 'Oh, right I'll search it because no one's told me about it.' and it's just like there can be extreme cases that is nowhere near to what your relative's got, and you can just proper scare yourself by thinking, 'Oh god, what else is gonna happen?' but it can be nowhere near that severe. So I think it just makes it more scary for people. (P-CS38 - FG3 Lines 456-461).*

This quote (above) demonstrates how at times there was increased anxiety and stress resulting from searching for information about illnesses and symptoms without adult support. The students identified that often involvement and information from the parent or healthcare staff is more important than being protected from the emotions of the situation. The majority of opinions were that most teenagers would rather be informed and upset than excluded and left wondering or searching for information alone:

*...because I think you don't think you feel like you're in the loop of what's going on cos like if they're speaking to your parents obviously they might like sugar-coat things. Sometimes you just want to know what's going on, like, you're not bothered if its upsets you in a way like it's just like you want to know what's going on. (P-CS42 - FG3 Lines 135 – 141).*

Congruent with the QN nurse focus groups in Cycle 2, the students thought that it would be useful to have information available about visiting rules and guidance. The students considered that both verbal and written information could be beneficial and one idea was that a leaflet could be provided by each patient bed with guidance on what you could or could not do:

*...either telling us or I think they should have something like just like a leaflet or something there on every bed or something that just says what you can and can't do (P-CS43 - FG3 Lines 359 – 360).*

The students' ideas about what information to include linked to the previous subtheme of 'too many visitors' in the empathy for healthcare staff theme. Information about visiting rules, such as how many visitors were allowed in together and the visiting times were considered important. One student explained how they had looked for information in order to plan visiting during a family member's admission, but could not find anything to help:

*I searched for how many people were allowed. When my sister was having a baby, but it didn't really say. Then you don't know until you get there and then you're already there. (P-CS46 - FG3 Lines 453-455).*

**Explanation** In addition to information being provided, it was identified that it needed to be appropriate and that there should be an opportunity to have explanations in some cases to aid understanding. The quality of information given was seen as an important issue. There were examples of teenagers not having any information about what to expect when they visited both at hospitals and hospices:

*You need to know what to expect really...I went go see my Granddad but they didn't actually tell you what to expect from him so it was literally he was just lay there so you couldn't interact with him so it was just like having to entertain yourself around him. So they didn't really talk to me it was just to me Dad.*

*(P-CS41 - FG3 Lines 97– 101).*

Research in ICUs has shown that age appropriate preparation of children prior to visiting a relative improves the experience, with those unprepared reacting with greater levels of shock and fear (Kean, 2010). ICUs are a challenging environment as the patients are all critically ill, possibly receiving ventilator support and requiring input from many healthcare teams (Gibson et al, 2012b). Explanation and support were identified as often absent. The lack of explanation about what was allowed, what to expect and what was happening all contributed to stress and anxiety during visits:

*They need to explain quite a bit more because when I went to see my Niece in Intensive Care we spent the whole half an hour standing there just watching her when we could actually have touched her they just didn't tell us and we didn't dare ask cos they were busy and like things kept beeping and obviously cos she's a tiny little baby its dead like nerve wracking every time something beeped we looked around and no one said anything cos they know its normal but we didn't that was quite bad it was just dead scary (P-CS43 - FG3 Lines 340 – 346).*

In contrast, medical and surgical wards have different challenges, such as lower staff to patient ratios and although the patients who may not have a life-threatening conditions, the ward activity can be frenetic. Facilitated visiting may not be required outside of the ICU and critical care areas, but explanations and support during a visit were still seen as important by the students. The need for explanations from nursing staff when visiting a patient was highlighted and the lack of support in this area was linked to feeling 'not welcome' and excluded. It was identified that nurses often come to a bed space, do something to the patient and then go without any explanation to the visitors or the patient:

*I think it would be useful like to make sure as well that the nurses explain what they are doing not only to the patient but like to the people around them cos I can remember like when I went into my Grandad he was just kind of lying there and the nurses were in and out doing stuff and like messing with like stuff and I didn't know what was going on because they just like walk in do something and walk out. But if they like spoke to someone and said well we're doing this because like because you just don't feel like it's anything to do with you but it is really because it's a relative and you should know what's going on erm cos they just seem to walk in do their thing and it wouldn't really take anything to just say what they were doing as they were doing it kind of thing and just explain what was going on (P-CS38 - FG3 Lines 405 – 414).*

As expected the need for age appropriate information was considered important in helping children to understand information given. Children often use the strategy of 'fishing for information' by positioning themselves where they are able to listen to conversations between adults (Kean, 2010). The following quote illustrates the potential implications of this strategy when the adults use medical jargon or do not acknowledge that a child or teenager is present during medical conversations:

*But maybe if there was like some information that – because I remember going – my Nan had meningitis and she went into one of the wards, my mum was talking to one of the doctors and they were using these really long words and I didn't understand. So maybe if they had some information saying, 'this is what this means. This is what that means.' Maybe that would be easier for children to understand. (P-CS39 - FG3 Lines 442-447).*

**Someone to talk too** Events on the wards were described as sometimes upsetting and stressful, particularly when it involved distressed families or the death of other patients. Experiences involving the deaths of other patients whilst the students were visiting wards were recounted and involved not only older adult patients but also babies in the neonatal unit. Not knowing what was happening caused distress and although there was awareness that due to data protection laws and confidentiality, patient details could not be disclosed to others, the students thought that having some explanation of the events would have helped them to cope:

*There was just this family that was in their own separate room but it was attached to the ward so you could see what was going on and stuff. There was always relatives going in there and crying and coming out and going back in and crying and then they'd come out crying, and they'd be walking past mum all the time and it was like – that was – even though we didn't know them or anything like that, that was still distressing. (P-CS38 - FG3 Lines 546-552).*

In exploring these situations, the students were asked whether the nursing staff asking if they were OK would have helped, and almost all responded that it would have. Having someone to talk to about the experience was considered an important feature that did not occur. Experiences were that the ward activity continued, but that no healthcare staff checked with other visiting families or patients whether they needed to discuss what had happened or if they were OK. The following quotes illustrate the different experiences between adult and neonatal clinical areas, but that the unacknowledged distress is evident in both cases:

*...so we were all sitting there with just been quite traumatic seeing this woman try to kill herself and then they just walked off and we didn't hear anything and we were just – what we'd just seen that was really shocking and there was just*

*no one that we could talk to. That was quite scary, thinking that just almost happened, we saw someone almost die over there and there was no one to talk to. (P-CS39 - FG3 Lines 570-575).*

*When my sister was in hospital obviously there was neonatal where they were really ill, and there were obviously babies dying and everything but the one next to my sister passed away and everyone was aware of it but no one checked if it was alright. Obviously, it wasn't our relative but it doesn't matter. It's still not nice seeing a child pass away right next to you. (P-CS43 - FG3 Lines 577-581).*

Consideration in the literature (Winch, 2001) and from the QN focus groups in Cycle 2 was given to the provision of a specialist practitioner who could liaise with children and young people when visiting the hospital. The students in this study initially did not consider this to be a requirement, as they felt that all nurses and doctors should be able to communicate with people of all ages:

*GF: Do you think there should be a designated Nurse Practitioner for teenagers to talk you through what you're seeing, what you're doing? (P-CT45 – FG3 Lines 264-265)*

*P: No in a way I think they all should have a basic way of how to talk to people of how to describe everything to us. I don't think there should be just one person in general that goes round finding younger people I think it should be everybody (P-CS38 - FG3 Lines 266 – 268).*



When parents have a terminal illness, not all young people want or feel that they require the intervention of services to enable them to make sense of their experiences (Turner, 2017). The students in this study identified a clear need for teenagers to have access if required to someone to speak to other than their own parents or family, reflecting the responsibility felt for other family members (Titler et al, 1991) and an awareness of the possible increased burden on the well adults in the family (Craft et al, 1993; Kean, 2009):

*There isn't really anyone unless you've got other family and friends that understand. So you just either have to deal with it yourself or talk to someone that does understand. If any of my relatives have been in hospital, I don't want to speak to family because they're part of it, and I'm scared of saying – if I say something and bring it up and say, 'What's going to happen?' they might get upset as well. So there should be someone outside of the family who you can speak to... (P-CS38 - FG3 Lines 501-506).*

As the discussion relating to emotional support progressed, the idea of a member of staff supporting young children was revisited. Whereas, they did not feel that a specialist nurse would be required for them (teenagers), a specialist member of staff was considered a possible helpful strategy for younger children for situations when the parents might already be distressed:

*I think if you're a young child as well and you're seeing something quite upsetting like your relative, they look ill or they are ill and you know then because your parents are probably upset about it as well there could be someone there, a member of staff that supports just children for being upset when they go to see their relatives, because your parents can't really support you because they're upset as well (P-CS46 - FG3 Lines 517-521).*

A face-to-face conversation was the preferred option for support rather than the use of a telephone help line or web-based chat:

*I think I'd prefer to speak to somebody more personal (P-CS38 - FG3 Line 509).*

**Acknowledgement to provide confidence:** Personal contact and communication link directly to this subtheme. Although there was not an expectation from the students that the hospital should have a specialist practitioner to provide children with individual support, what was clear was that if staff appeared to be friendly and acknowledged children, then this meant that they would feel welcome and therefore be able to approach that member of staff with any queries or questions that they had:

*...cos when one nurse has come in and acknowledged you then the other one that has come in after has completely ignored you it's like for me if someone comes and speaks to you I might have thought of a question that time and I could have asked her if they acknowledge me walked in and like it takes a lot to think of a question and build confidence to ask and then if ignore you you just kind of think I think they won't answer (P-CS41 - FG3 Lines 269 274).*

The provision of child visitation has been noted previously too often depend upon the individual nurse's ability to build a rapport with a child and family (Clarke, 2000). The findings of this study suggest that the nurse's ability to develop this rapport is also important in providing children with the confidence to ask questions or gain clarity on information gained during a hospital visit. Children are often inquisitive and known to compare things they witness in ICU to things seen in films and on television (Kean, 2010). It is also acknowledged that quiet children who do not ask questions may be

constructing their own meanings to things they see or hear, from their imagination (Gilbert, 1959; Kean, 2010). The students in this study had identified that they have had to look up information on the internet for themselves in the past about family illnesses which had caused them stress and anxiety. Having engagement with healthcare staff was considered important and could address the knowledge gap caused by lack of information or explanation including that from parents:

*It would be better if they spoke to you because you could have questions and if it's through your parents they can't answer the questions for you sometimes (P-CS39 - FG3 Lines 146 – 147).*

In addition to the possibility that parents could not always answer questions, there was an appreciation that information provided by family members was not always interpreted correctly. The opportunity to be involved in conversations with the healthcare staff or to be able to ask them questions was considered an important strategy which could address this issue:

*Obviously if we were told by the nurses or doctors or anything then we'd all understand it (P-CS43 - FG3 Lines 159 – 160).*

Although there was not a need in general for a specialist practitioner for young people, the busy nature of the hospital and the pressure healthcare staff may be working under was highlighted as causing a problem if there was a question or query to be asked. It was considered that being introduced to staff initially and informed who you could approach with questions would help during an admission. There were large signs posted around the hospital identifying what uniform belonged to which grade of staff, but these did not seem to have helped when visitors were on the wards looking for someone to help with a question. Again, this hints to the difference between

information being provided and facilitating an explanation to put the information into context:

*I think they should tell you who to speak to as well, because I know if you do have a question, it's hard because people are rushing around, it's hard to spot someone and try and ask someone before they've gone, so if they introduced someone to you, like say on the first day you were visiting, and just saying, like, 'This is whoever. If you've got any questions, ask them.' Because I think a few times I have been you don't know who to ask. If your relative's asking you to ask something, it's like who do you talk to? You don't know who because not many people know what the uniforms or badges or titles or anything mean, so you just need like a face so you know who to go to (P-CS38 - FG3 Lines 482-489).*

Attitude of healthcare staff was related to communication, exclusion and acknowledging the presence of children. The students thought that the healthcare staff could not just be told to interact with children and teenagers as this may not result in any progress. They considered that attitudes may need to change for positive improvements to be made:

*I think its more people's attitude as well, like staff. Not everyone sort of patronises people but some people do, and I think the way that they look at you and the way they talk to you, not just about interacting with them because everyone could say, 'Right, you've got to start interacting with the children,' but they could interact with you but still treat you wrong, so I think it's about how they actually treat you (P-CS46 - FG3 Lines 425-429).*

This perception from the students is congruent with the concept of the 'silent listener' where staff allow children into the clinical areas, but do not involve them in conversations and in some cases ignore the child (Kean, 2009).

**Improved use of technology:** Linked to communication from relatives was the idea of improving the use of technology. This also linked to the concern about large amounts of visitors, as they thought that by using this technology contact could be maintained without the need for everyone to visit. The use of platforms, such as Skype and Facetime, were considered important strategies that could reduce nurse workload and visitor numbers but also could ensure accurate information was received by families:

*Stuff can be like misunderstood as well because I can remember like when my Grandad was in hospital in .... so like my Auntie was always with him but erm when she come back from visiting like we couldn't visit as often so she'd ring us and tell us but she'd forget most some stuff that had been said (P-CS43 - FG3 Lines 156 – 159).*

**In summary,** the students discussed a number of potential strategies that they considered most important in improving the experiences of children visiting relatives at the hospital. Communication was the main issue which underpinned all the subthemes. Age appropriate information was considered important particularly guidance for visiting to help in planning a visit and knowing what to do during the visit. The need for explanation in some circumstances was highlighted, with experiences demonstrating that written information alone was not always helpful, and that verbal explanation was often also required to consolidate or clarify information. The use of technology to aid contact with the patient was considered important in families having

the correct information, but also thought to be beneficial in reducing visitor numbers. The most important strategy identified by the students in this study was that healthcare staff acknowledged them, so that they would have the confidence to approach them if support was required. Interestingly, the students identified that this may require a change in attitude for staff, as just telling them that they had to let children in would not necessarily improve the experience if the healthcare staff did not acknowledge or include them.

## **Theme 5 – Value of the project**

***Learning from feedback:*** The students felt that the research was important and valuable for them and for healthcare staff. Their perspectives and experiences as provided through their involvement with the study were considered to be important for healthcare staff so that they could learn from different perspectives:

*It does matter cos they obviously they go around asking questions. They need feedback from obviously past experiences and stuff. You never learn anything unless you get feedback from it so... (P-CS42 - FG3 Lines 212 – 214).*

The experience of being involved in the research was deemed valuable to the young people themselves. All were planning for careers in healthcare or teaching and enjoyed the experience of the focus group and research process. One young person stated that in the future “***we could be good role models***” (P-CS38, FG3 Line 618) which was personally a special moment. When considering the impact of the research, this statement made me consider the long term impact of the research. These students could perhaps be inspired to continue to challenge the accepted norms, assumptions and practices, aiming to improve clinical services in the future.

## Personal reflections

Cycle 3 provided an opportunity to consider how my perceptions and views have changed during the PAR study. I had felt strongly that advocating for the students to be able to provide their own informed consent for a topic that they seemed keen to work on was essential during the request to amend the ethical approval. During the focus group, the students stated that they frequently feel patronised and I think that pursuing parental consent in this age group may have been a further reinforcement of this view for them (Jervis, in press). This reflected my changing attitude towards the value of children and young people's viewpoints and perceptions.

The students confirmed some expected perceptions and confirmed that there were still issues with children being excluded or feeling ignored when visiting relatives at the hospital. Children can be considered co-constructors of knowledge related to their understanding of their experiences, having different experiences of a situation than adults (Morrow, 2012). I was surprised by the thought and empathy demonstrated for the healthcare staff that they described as intimidating. Their ability to raise and discuss possible solutions to problems that they experienced demonstrated an awareness of the current challenges for healthcare staff working in busy hospitals and confirmed that children and teenagers should be encouraged to participate in devising solutions to issues that they face (Pain, Francis, Fuller, O'Brien and Williams, 2002).

Facilitating the focus group was a nerve wracking experience. Although I had been invited into the college, the reaction and engagement of the students with the focus group was unknown. It was reassuring to have the two tutors attend as they were well known to the students and their presence proved invaluable in gaining trust. Despite

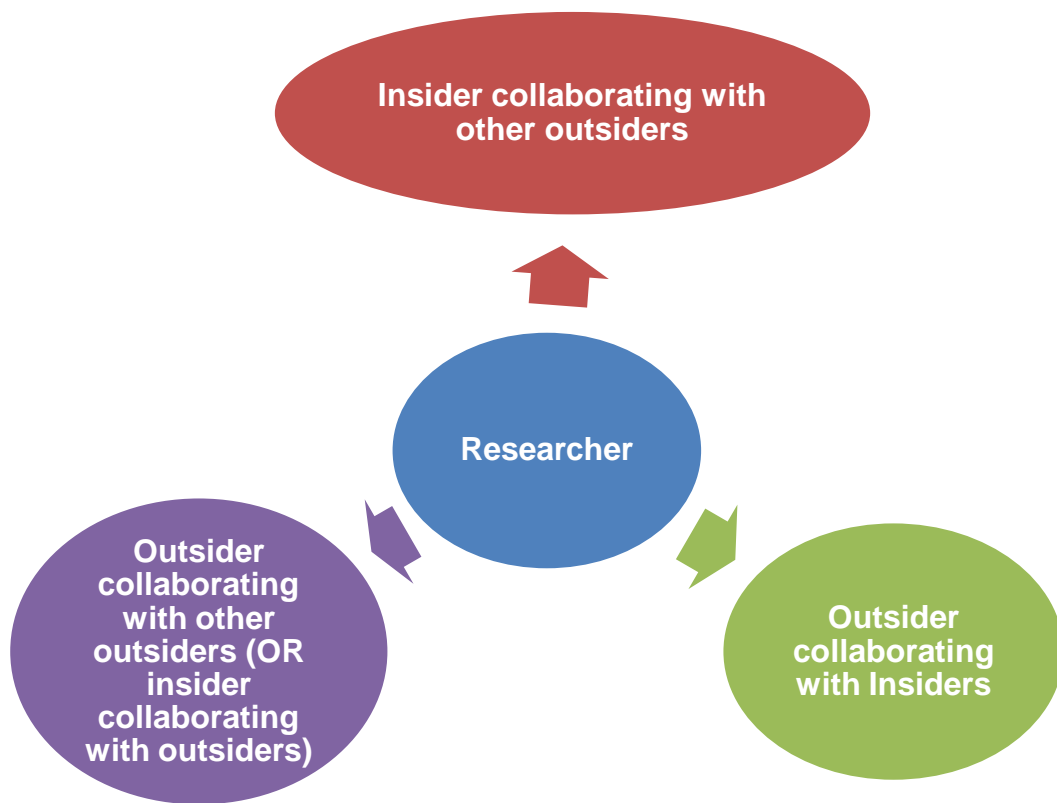
creating what was considered a safe congenial space at the college, providing food and drink to build rapport and conducting the focus group at a convenient time for the students (Groundwater-Smith, Dockett and Bottrell, 2015), there was an initial suspicion evident from the students towards me as the facilitator. They were initially reluctant to engage with the questions and after some time, I shared my thoughts with them, that it was my perception that children were often excluded or ignored when visiting the hospital. Following this, one of the tutors stated that I was there for the truth, which seemed to give the students permission to start sharing their experiences which were predominantly negative. The initial unwillingness to share these experiences could possibly relate to my positionality as the researcher and the power imbalance. I had considered that the tutors' role as gatekeepers to the college students (Stuart et al, 2015) might affect the power balance and the data collection negatively, as students might be reluctant to be honest in front of their tutors who also were instrumental in their course success. However, the support from the tutors was instrumental in the students starting to engage with the focus group discussion.

## **Researcher positionality**

This cycle was very challenging in relation to the implications of my evolving positionalities. As discussed previously it was expected that a reciprocal positionality would predominate the PAR cycles (Figure 4.2, p.120). However, with the developments related to engaging local college students in the study, I was aware that my positionality would change along the research continuum (Herr and Anderson, 2015). It was expected that I would adopt an outsider collaborating with other outsiders' position (Herr and Anderson, 2015). This was a naïve assumption, as the



perceived positionalities were complex and incorporated three different positionalities (Figure 6.3, p.232).



*Figure 6.3 Researcher positionalities Cycle 3*

As indicated, I initially considered my positionality in this cycle to be an outsider collaborating with other outsiders. This was based on the fact that I was an outsider to the college where the students were conducting the plan of designing resources for the hospital. I considered that the students might consider themselves as outsiders, as they were independent of hospital where the study was being conducted and where the work they were doing was for.

As the study progressed and the students requested that they participate in a focus group to share their experiences of the study, I considered that my positionality might

change to that of an outsider collaborating with insiders. This related again to the fact that I was an outsider to the college and would be facilitating the focus group at the college site where I thought the student would consider themselves as insiders. However, the students considered me to be the insider and themselves as the outsiders. This seemed to relate to the origin of the study, and the power imbalance associated with me as the researcher coming in from the hospital and university. Support from the tutors was useful here to try to balance the power. Despite the fact that I felt at a disadvantage facilitating the focus group in the students' space, they appeared genuinely worried about giving me any negative experiences.

## **Summary**

In summary, Cycle 3 represented a cycle within Cycle 2 originating from the planning phase when the need for age appropriate resources for the hospital was discussed. Cycle 3 involved the engagement of local college students to design resources, and subsequently the students requested that they have the opportunity to take part in a focus group to evaluate their role in the study. During the focus group the students shared experiences and perceptions which they felt were important issues in improving the support provided to children visiting the hospital.

All of the students expressed the opinion that they did not feel welcome when visiting hospitals, either as a patient or a visitor. These feelings related to staff attitudes and a lack of communication which left them feeling excluded. They were very perceptive and observant in relation to differences in how they were treated compared to adult visitors and to the perceived protective behaviours of their own parents. They used the term strange to describe healthcare staff behaviours and the associated emotional

turmoil which could result from feeling confused and excluded. Despite many negative experiences, the students demonstrated empathy for healthcare staff which evolved from the inductive analysis. Students demonstrated an awareness of the pressures and stresses of the hospital environment and how this may impact healthcare staff behaviours. It was accepted that healthcare staff may be unaware of how they are sometimes perceived by visitors due to the busy nature of their role and that at times some may unintentionally appear intimidating.

Students were also concerned about situations where there were too many visitors at the hospital, and this concern was incorporated into their own decision making if asked by parents whether they wanted to visit a relative. These issues were the basis for some of the strategies that the students thought would help to improve the support provided to children who have a relative admitted to the hospital, such as the increased use of technology.

Communication was the main issue which underpinned all the themes and subthemes in this cycle. Age appropriate information was considered important, alongside the need for explanation in some circumstances, with experiences demonstrating that written information alone was not always helpful, and that verbal explanation was often also required to consolidate or clarify information. The most important strategy identified by the students in this study was that healthcare staff acknowledged them, so that they would have the confidence to approach them if support was required. Interestingly, the students identified that this may require a change in attitude for staff, as just telling them that they had to let children in would not necessarily improve the experience if the healthcare staff did not acknowledge or include them.

## **Chapter 7**

### **Evaluating actions**

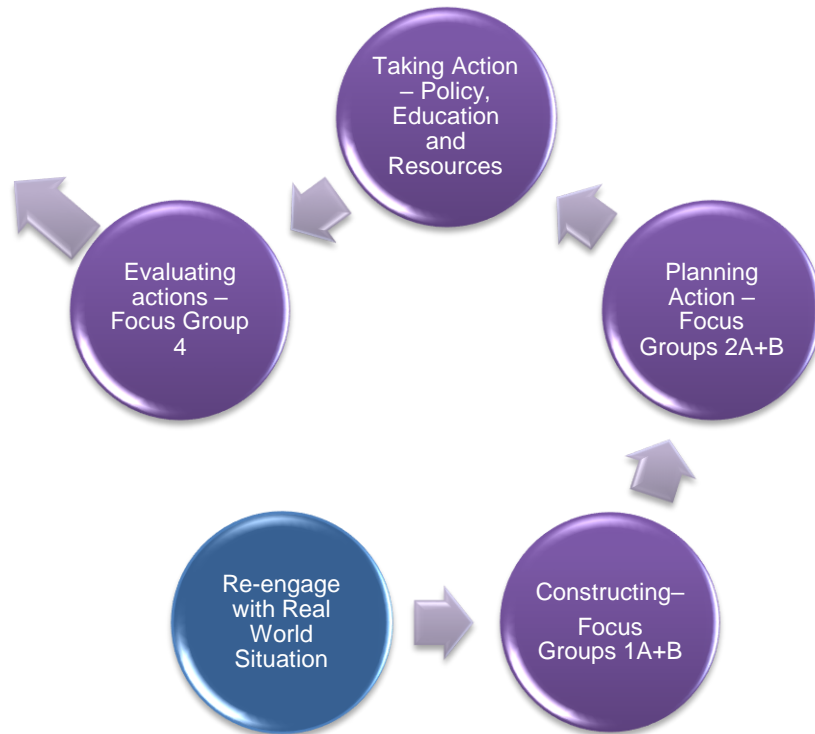
**I keep six honest serving-men  
(They taught me all I knew);  
Their names are What and Why and When  
And How and Where and Who  
(Rudyard Kipling, 1902, cited in Kipling, 1993, p.50)**

This chapter will discuss the PAR study evaluation. First, will be the presentation of the Cycle 2 evaluating action phase. This followed Cycle 3, which was a cycle within Cycle 2, as the ideas and perspectives of the local college students were presented to the QN participants as part of the study cycle. Secondly, discussion of the PAR study will be provided, including personal reflections, issues related to researcher positionality and strengths and limitations of the research approach. Finally, a discussion of the impact of the study will be presented.

#### **Evaluating actions – Cycle 2**

The first three phases of Cycle 2: constructing, planning actions and taking actions were presented in Chapter 5. One of the actions planned was the engagement of local college students in the design of age appropriate resources for the hospital. The findings from this phase (Cycle 3) were presented in Chapter 6. Ideas and perspectives of the local college students were presented to the QN participants.

Following this, the QN participants were invited to the final focus groups to evaluate the PAR study and associated actions planned (Figure 7.1, p. 236)



*Figure 7.1 Cycle 2 Building on lessons learnt*

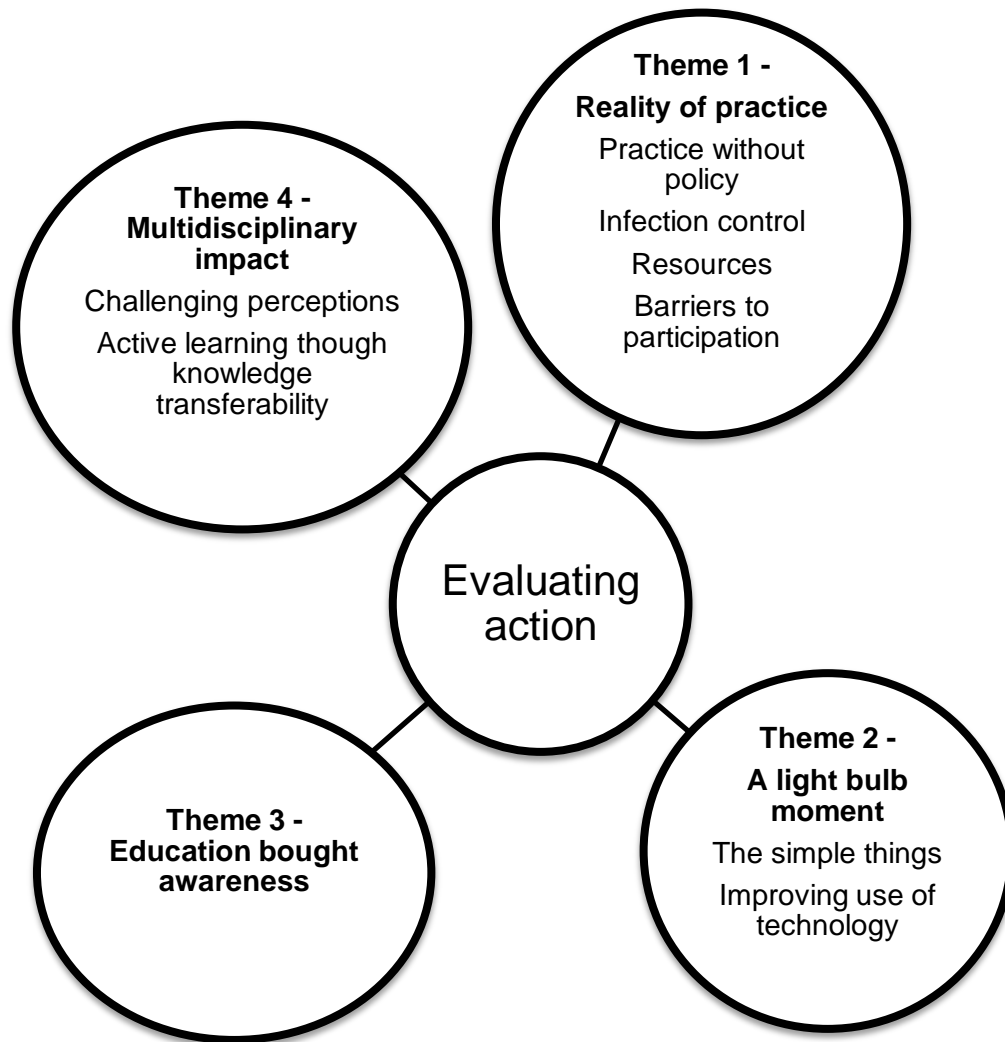
Data analysis followed the same principles as the whole of Cycle 2, combining findings from both deductive and inductive analyses to construct meaningful themes from the descriptive categories. Prior to discussing the themes identified, it is important to note that there were challenges in implementing the evaluating action focus groups. There were delays due to two main factors. Firstly, the co-ordinator of the QN meetings left the organisation and secondly, the new co-ordinator was not made aware of the time slots that had been planned for the research. During the research cycle I had left my ANP role at the hospital to take up a new university role. The change in researcher positionality and organisation contributed to the delays and challenges in making

arrangements for the focus groups. Although, all correspondence relating to the study had been sent to the research email address throughout the study, some meeting dates were sent to my old hospital email address after I had left the hospital. The result was that I did not receive notifications of changes to meetings. I was also unable to access the hospital intranet system which would have enabled me to check meeting details. This was a very frustrating time with me attending rooms to find meetings cancelled and getting messages to check why I had not attended meetings of which I had not been informed.

The evaluation focus group did take place but after a five month delay. Only one focus group was carried out in this phase as ten participants had to leave at the beginning of the group due to service demands on the day. There were twelve participants involved in the evaluation with four of these being new, resulting in a total of eight original participants. The loss of fifteen participants at this stage was disappointing and valuable issues and feedback may have been omitted due to this. Despite this, there was a focused discussion and valuable challenges were raised.

### **Themes from the evaluating action phase**

Four main themes with associated sub-themes were identified in the evaluating actions phase of Cycle 2: 'reality of practice', 'a light bulb moment', 'education bought awareness', 'multidisciplinary impact' (Figure 7.2, p.238). These reflected the themes of the planning action phase of Cycle 2: 'hospital policy', 'in-service education', 'creative problem solving' and 'perceived barriers to creative problem solving' (Figure 5.4, p.178) and will now be explored further.



*Figure 7.2 Themes and Subthemes of the Evaluating Actions Stage Cycle 2*

### **Theme 1 – Reality of practice**

This theme evolved from the subthemes: practice without policy, infection control, resources and barriers to participation. The subthemes related predominantly to perceived barriers and real boundaries that challenged any change in practice,

particularly those planned in the creative problem solving phase of Cycle 2. The power of historical working practices and assumptions was also demonstrated within this theme.

**Practice without policy:** There was clear frustration observed when the issue of **'the policy'** was discussed in all phases of the PAR cycles. Despite clarification that the policy restricting those less than twelve years of age from visiting did not exist at focus groups and meetings over a seventeen month period, it was evident in the final focus group that this restriction still existed in areas of the hospital. There remained no consistency with different age limits being seen in different areas:

*On some of the visits I've been doing I've noticed different ages on the wards still. Some say under 12 and one said under ten and I think there is still some discrepancy on door entrances about children visiting. (P-AN54 - FG 4 Lines 10 -12.)*

Despite the inconsistency, some areas did remove the age restrictions during the period of the PAR study. It was not always clear whether this related directly to action from the participants as is demonstrated in the participant quote below. Although, it seemed that the Consultant decided that the age restriction could be removed, this is one of the ward areas where the original discussions had taken place prior to the formal research process commencing:

*For a long time we weren't allowed to have children under 12 on the ward and then the consultant that implemented that suddenly decided that we could (P-AN28 - FG2A Lines 36-38).*



**Infection control** practices were considered as influential in creating barriers to planned actions to improve patient morale which went beyond the actions planned from this PAR study, but demonstrated that the infection control team were perceived as likely to discourage children visiting:

*Infection control may sound like it's nothing but they'll go mad. Christmas time we weren't even allowed - we wanted to have a little tea party and make a cake and we weren't allowed because, 'You can't give patients that cake.' 'We've made this room look like their living room and they can't have cake in there!' So there are real boundaries for things (P-AN55 - FG4 Lines 395-399).*

**Resources** Participants appeared to have become more aware of children visiting the hospital and a number had noted that children were often in what the participants described as 'hotspot' areas with no facilities. These were all admission areas, such as the Emergency Department and Assessment Units:

*We were looking at the queue, weren't we, in A&E the other day. How many kids are in that queue with relatives? There's no facilities for them. (P-AN55 - FG4 Lines 197-198).*

Again, as had occurred in all the previous Cycle 2 focus groups, it was discussed that there were no spare spaces or members of staff to take on any specialist activities specifically for children visiting. This illustrated the continued concern about service demands:

*Providing that care for that child could be a healthcare that is then taken away from the rest of your patients, because you haven't got that extra person. You just haven't got that facility (P-AN04 - FG4 Lines 194-196).*

**Barriers to participation:** Service demand was also one of the main barriers to participation in the research. The time to participate was one feature of this:

*It's having the time, isn't it, to be able to come. (P-AN04 - FG4 Line 613).*

In addition to the time to participate in the focus groups was the concern about what would be expected of participants:

*People not understanding exactly what you're asking of them being nervous. (P-AN27 - FG4 Line 616).*

This reflected the findings of Cycle 1 when participants were unable to attend focus groups due to service demand and the feedback from a colleague in one department was that staff were afraid of doing anything in case they made work for themselves.

**In summary**, this theme presented the reality of current clinical practice. Some positive outcomes were discussed, alongside frustrations with barriers to actions. There was clear frustration that some clinical areas still had the no visiting for under twelves year olds rule. However, this restriction had been removed from other clinical areas and children were allowed to visit in these. The main challenges to making changes in clinical practice were the infection control teams and a lack of resources, particularly relating to space and a lack of nursing staff.

## Theme 2 – A light bulb moment

***The simple things:*** In contrast to the concerns about service demand and lack of resources, discussions held in the focus groups had had an effect upon participants in clinical practice and encouraged them to consider simple actions when children visit that they would not previously have considered:

*I don't know who spoke about it last time but someone mentioned about a drink of water, offering a child a drink of juice and having facilities for them. Whether it is just somewhere where they can sit quietly where it's not in the middle of the ward, something like that, or a distraction aid or something like that. I found that was a bit of a light bulb... (P-AN20 - FG4 Lines 161-165).*

What were classed as simple actions were now being considered and acted upon by participants in clinical practice. These actions included noticing that children were present and thinking of small things which may make the visit more welcoming:

*I noticed, a lot of kids end up in xxx waiting room because you get a younger generation maybe coming through abdo pains and gynae problems, single mums, and they bring their kids in. And I noticed there one day I was walking through and there was a couple of kids in there and there was no squash. There was nothing. I went and got them a jug of squash, then I went and got them some biscuits because there was nothing to eat there and I thought, 'We haven't really got many facilities, have we, for kids in that situation waiting for mum to come out.' (P-AN55 - FG4 Lines 166-175).*

A particularly encouraging finding was that there was also awareness from participants in the evaluation focus group of acknowledging children and young people and giving them an opportunity to ask questions:

*It's probably just a matter of saying, 'Have you got any questions? Are you all right?' [37:48 - participants talking over each other]*

*It may be the first time they've been in a hospital, I don't know. So I would obviously say, 'Are you all right? Is everything okay?' (P-CN21 - FG4 Lines 516-519).*

This was the main strategy that the college students in Cycle 3 had identified as crucial to providing children with the confidence and opportunity to ask questions or gain an explanation to aid understanding of the situation.

The difference in the original and new participants was evident in some areas of the discussion, and this was one such example. During this conversation one of the new participants gave a contrasting comment, that normally they would not ask teenagers if they had any questions:

*...but normally if there is a teenage person sitting with a patient you don't really go and ask them, 'Have you got any questions?' (P-AN56 - FG4 Lines 520-521).*

**Improving use of technology:** Although no actions were achieved in relation to getting information onto the internet, there was some progress with the use of the

Wi-Fi for communication. There were talks with the IT departments about accessing Wi-Fi for patients raised in the first focus groups during the constructing phase:

*Xxx having a chat with them to try and get it done as part of it, to try and get Wi-Fi here for the patients. (P-AN26 - FG1B Lines 582-583).*

In the evaluation focus group there was an example of Skype being used by a patient and their family:

*We had someone Skyping the other night. Skyping Australia. (P-AN04 - FG4 Line 560).*

**To summarise**, this theme illustrated that the PAR process had, for some participants, resulted in ‘a light bulb moment’ in clinical practice. This is defined as ‘a moment of sudden realisation, enlightenment, or inspiration’ (Oxford Dictionaries, accessed May 2018), and the quotes provided illustrate how participants had implemented some simple changes to their own clinical practice. These were simple actions that they would not have considered previously, such as asking a child visiting if they were okay. In addition, some clinical areas had liaised with the IT department regarding accessing Wi-Fi for patients, and there was an example of Skype being used by one family. It was also highlighted that the participants now had an awareness of children when they were present.

### **Theme 3 – Education brought awareness**

When the education component was evaluated there were three main points made relating to general updating, the formal teaching session provided by the hospice

educator from the local children's hospice and educating student nurses. This theme was discussed primarily by 3 participants, 2 of which were children's nurse who had attended the hospice training. Following discussion in the evaluation focus group 1 new participant stated that more sessions on key issues would be useful and could encourage the implementation of simple and quick changes. This was based upon the discussion and information she had received during the evaluation rather than throughout the process:

*I think it would be good for you to do a session of some of the key things that we could change and those things that we discussed today quite quickly. [46:58 - participants talking over each other] Some quick things we could change like taking those notices down at entrances to wards like no under 12s. (P-AN54 - FG4 Lines 628-631).*

The training session delivered by a hospice educator from the local children's hospice was considered to be beneficial in changing the mind-set and encouraging the consideration of the family. The participants recommended this training for all other registered nurses and student nurses. The children's nurses who had attended with the adult nurses provided an insight into the observed benefits of the hospice training to the adult nurses;

*The atmosphere in the room, they all loved it, they all couldn't believe it. (P-CN23 - FG4 Line 250).*

*And I think she helped them to realise that it isn't a one-dimensional thing. (P-CN32 - FG4 Lines 255).*

***In summary***, education was considered an important element in improving the confidence of the participants to engage with child visitors. The training session provided by a hospice educator from the local children's hospice had provided an overview of child development, children's needs during a crisis or bereavement and simple age appropriate strategies that could be used by nursing staff at the hospital. This session evaluated well and was recommended for all adult registered and student nurses. In addition, short update sessions for the QN's, was recommended to encourage future implementation of simple measures.

#### **Theme 4 – Multidisciplinary impact**

***Challenging perceptions:*** Observation of the focus groups had shown that there was a balanced and challenging discussion when they contained a mixed group of participants of both adult and children's nurses. This had been noted in my research journal from the focus groups of the constructing phase (FG1A and 1B), but became increasingly evident in the planning action (FG 2A and 2B) and evaluating action focus group (FG4). Towards the end of focus group four one adult nurse participant reflected that having the child health team involved had encouraged the challenging of perceptions and clinical decisions.

I was interested in whether the focus group method used had been the best way of conducting the research for the participants. There were no negative comments about this method. The main comments related to the inter-professional discussions which had taken place. The sharing of clinical knowledge and practices had appeared to have created an environment for critical reflection as demonstrated by the dialogue below:

*P: It makes you just - it makes turn your mind-set around things think about it in a different way. And having the girls from paediatrics here has definitely... (P-AN55)*

*GF: That was my next question. I wondered was working across the Trust, so we had child health with adult health, do you think that was a beneficial way...?*

*P: For me, yes. (P-AN55)*

*P: I think it's good to challenge some of our thinking. (P-AN54)*

*P: Yeah, which is good. I think so. (P-AN27)*

*P: Because if we were just adult nurses we'd all sat here and agreed with each other (P-AN54)*

*(FG4 Lines 588-595).*

This multidisciplinary challenge to clinical practice and decision making had resulted in three main in-depth discussions that occurred throughout all the focus groups in Cycle 2 which demonstrated a challenge to perceptions and clinical assumptions. These related to holistic assessment, child protection and parental capability. There was a demonstration of **active learning through the transfer of knowledge** between participant groups. This was particularly evident as the participants from child health shared both clinical practices and knowledge from experience:

*P-AN55 - Which is why we need to change the way we think about kids coming in to visit as well because we've never thought of that really, have we? Other than, 'That baby's going to pick something up.' [22:50 - participants talking over each other]*



*P-CN21 We would think that from the paed's point as well. If someone says, 'Can I bring a six-week-old baby?' we would always say, 'It's probably not wise but you can. We don't stop you (FG4 Lines 305-310)*

The assessment process was discussed in the constructing phase by the child health team and was regularly re-emphasised by these participants when discussing strategies to support families. In the evaluating action focus group, holistic assessment and care continued to be discussed between the adult and child health team participants. Holistic assessment was considered extremely valuable in child health:

*That's one of the things we are told not to do. That is not the condition. That is not the condition. That's not the disabled kid. That's not the Down's syndrome kid. That's Amy, that's Peter or that's Paul. It's the individual person and you look at it holistically. And to provide that is massive. (P-CN23 - FG4 Lines 185-189).*

In contrast, the adult nurse participants described how the holistic elements of assessment and care planning in their areas did not often include family details. There is a hint within this quote that thinking of the whole family and the effect of an illness or surgery was a new but interesting concept:

*We don't necessarily look at the whole picture. If an adult comes in they are that condition especially in surgery. [19:28 - participants talking over each other] It's a case of you come in with that, you go to theatre, we make you better and off you go. We don't necessarily know that you've got three, four, five kids at home the neighbour's looking after unless you tell us that. It's not something we'll ever ask. So I think in terms of you only know when people*

*come trotting in in theatre but you don't even necessarily know who they are to that person. They've got visitors but is that the neighbour? Is that the husband? You don't necessarily always know unless somebody's there for a significant amount of time. So I think in terms of trying to fully understand that person was quite interesting as to how the knock-on effect to that whole family (P-AN04 - FG4 Lines 257-267).*

At times, some of the discussions were very challenging and the different speciality groups did allow their assumptions about other areas to be challenged when this occurred. One such assumption was that in child health, the adult accompanying the visiting sibling is always capable of supporting that child:

*I think what you've got to understand as children's nurses is that the adult that's with that poorly child or the sibling of that poorly child is a capable person but if that parent is actually in a bed poorly, can't move, connected to drips, then that's a different [30:43 - participants talking over each other] ... (P-AN04 - FG4 Lines 414-417).*

This assumption was challenged by the child health participants who explained that well parents are not always able to support their children:

*If you've got a parent of a very, very ill child you would argue if there's a sibling there they're not in a fit state to look after the sibling at all, are they, anyway. Just because they're not ill they're not capable at that point, are they, of being a responsible parent at that point. (P-AN55 - FG4 Lines 428-431).*

This was a complex discussion which referred back to the adult nurse participant's fears about responsibility and abandonment. As in previous focus groups knowledge of child protection procedures and strategies to support the adults were shared.

*In summary*, this theme discussed the multidisciplinary impact of the PAR study. It was observed during the focus groups that there was active learning between participants when the groups were heterogeneous. The child health participants often challenged the assumptions and practices of the adult nurse participants, and this was noted to have been beneficial for the adult nurses. It was perceived by adult nurse participants that if the focus groups had remained homogenous, then challenges would not have occurred as they would likely have all agreed with each other, limiting any progress.

### **Summary of the themes from evaluating action stage**

The evaluation was limited due the reduced number of participants who were able to attend the final focus group. It was identified that there remained barriers, both real and perceived to the actions discussed in the planning action phase. It had been clarified that there was no policy which restricted children visitors to those over twelve years of age. Although some clinical areas had removed the age restrictions, others still had restrictions in place. There was no consistency in the age limits however, with some using the age twelve and others the age of ten. Although no progress was made in developing information on the hospital internet website, some progress had been made with the use of technology to aid communication with families. Wi-Fi access for patients was being discussed with the IT department and Skype had been used to contact family members.

Infection control procedures and service demand remained perceived barriers to providing support and resources to children visiting. However, there was an increased awareness of the presence of children, and participants were using simple measures to include them in conversations or make them feel more comfortable. These may be a reflection of both the formal education sessions and the process of active learning through knowledge transferability of having both adult nurses and the child health team working together on the PAR study.

### **Strengths and limitations of the research approach**

This study, as with most nursing research questions, was never context free. It had arisen from critical reflection, informed by perspectives consistent with distinct professional knowledge and, had the aim of improving and supporting the health of a specific population (Thorne, Stephens and Truant, 2015). This population was children visiting adult relatives at the hospital and their families. The strength of PAR approaches is that they are context bound and address real life problems (Kindon et al, 2010), congruent with the research question and aims. However, this means that empirical transferability cannot be assumed. The aim of PAR is not to generate “generalisations” but to “help people to understand and to transform ‘the way we do things around here’” (Klemmis, McTaggart and Nixon, 2014, p.67). This was achieved as the focus of the PAR remained upon the issues related to child visitation at the hospital which was the study location.

However, if considering transferability as the “degree of relating to other contexts” (O’Reilly and Kiyimba, 2015), then it is proposed that that the study did achieve transferability in two ways. Firstly, there was the potential of transferability of

knowledge amongst the participants. The participants worked throughout the hospital in both emergency and elective clinical areas, and included both adult and children's nurses. The main strength of the PAR approach was the cyclical process which encouraged reflection and provided the opportunity of time and space for trust to develop between these different groups. This produced a situation where specific knowledge was gained through reflection-on-action and multidisciplinary active learning. Participants were therefore able to extract what information they wished from the focus groups and apply them to their own practice areas. Secondly, some findings were congruent with previous national and international research in ICU's, suggesting that some assumptions and challenges are not specific to one particular area. The inductive analysis from this study may therefore provide some new concepts to the knowledge base which may be applicable to other localities.

For readers to make a critical judgement on transferability to their own clinical area requires a detailed account of the research process (Koch and Kralik, 2006) and the participant sample (Elliott, Fischer and Rennie, 1999). The systematic collection of demographic data from participants, including general characteristics such as age, sex, and gender aid the reader to these judgements (Huxley, Clarke and Halliwell, 2015). It is also acknowledged that when facilitated well, focus groups can allow the investigation of how understandings differ by social groups, such as gender, age and social class (Conradson, 2005). In order to protect confidentiality and anonymity of the participant's this demographic data was not collected. In addition to issues relating to transferability judgements, a limitation of this on reflection was that this data may have provided information relating to any association with the values/assumptions held, or the effect of experience. I had assumed that more experienced, mature nurses would have been more rigid in the use of the perceived hospital policy, given that it appeared to be a historical practice. However, it was observed in the focus groups and

noted in my journal that some newly qualified nurses were more adamant that the age restriction should be enforced. This perhaps relates to experience and confidence in one's own decision making. It was difficult to assess this within the focus groups as participants may have been reluctant to share such insights. Individual interviews in addition to the focus groups may have been more appropriate in exploring these types of feelings and emotions (Krueger and Casey, 2015).

PAR is a collaborative approach to research and is driven by the participants, guided by the researcher. One of the challenging tasks in facilitating the focus groups in this study was to trust the PAR process and allow the participant's to decide the direction of the conversations in the focus groups (Day, Higgins and Koch, 2009). This was both a strength and limitation of the approach, as although it resulted in some repetition of discussions it did allow the participant's to explore perceptions and ideas that would not have been identified if there had been a fixed focus group schedule.

The need for nursing staff to explore and challenge their own beliefs and attitudes related to family centered care and child visitation was recommended in previous research studies (Clarke, 2000; Clarke and Harrison, 2001). The cyclical nature of the PAR approach encouraged the reconstruction of past professional and personal experiences amongst the participants. It also enabled reflection and active learning to take place amongst the participants in Cycle 2; the adult and children's nurse participants. In this study, the PAR process and use of focus groups seemed to encourage the participants to challenge their own and each other's assumptions. The differing viewpoints acted as a trigger for further reflection which was important for discovering new ways of seeing and providing insight into what was underpinning their

understanding of child visitation, this in turn can create effective and informed transformation of practice (Cook, 2009).

“The hallmark of focus groups is their explicit use of group interaction to produce data and insights that would be less accessible without the interaction in a group” (Morgan, 1997, p.2). This is congruent with the PAR approach to explore the experiences and views of the nurses as a collective group and for any actions to be initiated by the participants. In this PAR study exploring the differing assumptions, experiences and understandings of the phenomena included how these vary between different nursing staff by speciality or experience. The focus groups were both homogenous and heterogeneous. To explore the potential differences between those who may hold differing professional values two focus groups consisted of adult nurses only, while two comprised both adult and children’s nurses.

On facilitating the focus groups, I was surprised at the extent to which the dynamics of the groups changed when they were heterogeneous. The focus groups that involved both adult nurse and children’s nurse participants felt much more positive and vibrant. Although there were discussions which confronted assumptions and speciality boundaries, these had resulted in debate and challenges from both professional groups. There always appeared to be a greater understanding of each other’s clinical demands as strategies and barriers were debated, as though the process had stimulated “new directions to emerge; to enable diversity and multiplicity to work together to challenge the given, to recognise the nearly known and to support the creation of trustworthy, transformational knowing” (Cook, 2009, p.289).

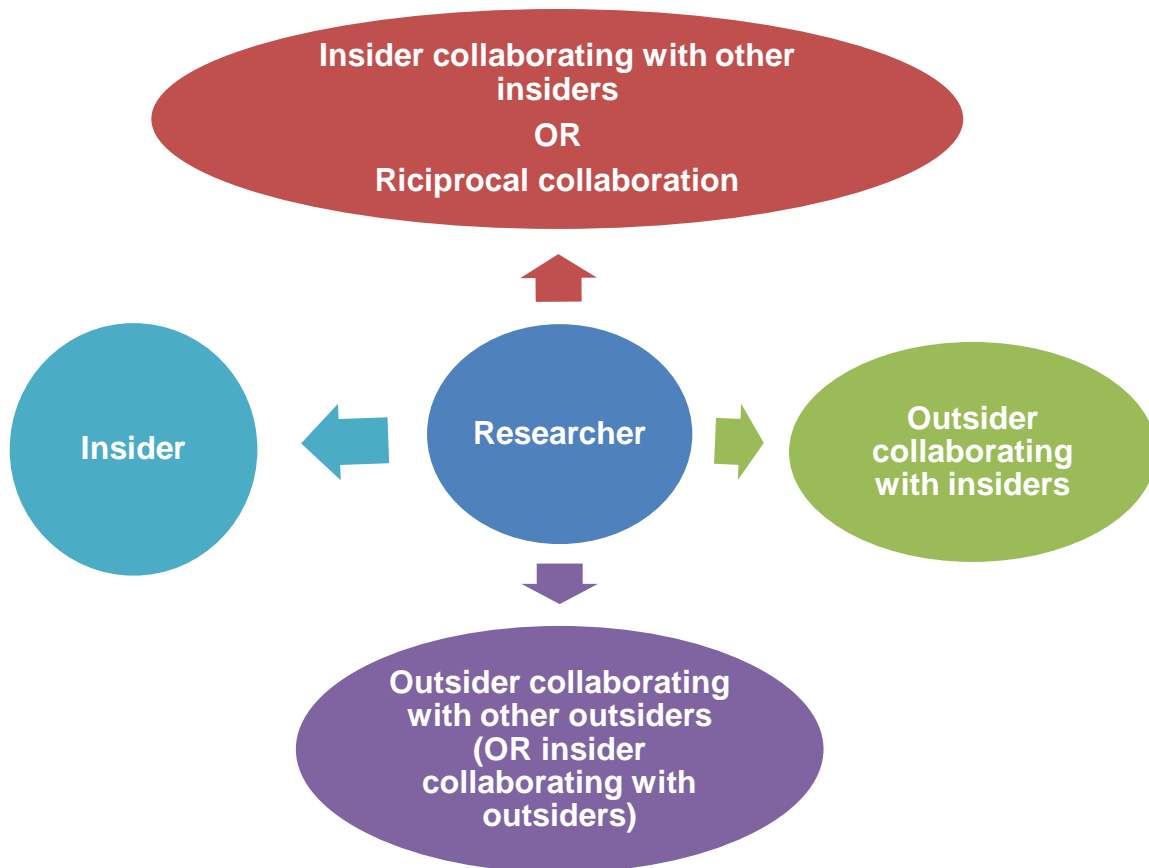
The challenges to each other's perspectives and assumptions appeared to encourage creative ideas to solve problems in addition to knowledge transferability as we all actively learned from each other. The PAR process provided a space for reflection-on-action, challenged by others and so had the potential to influence future action (Schön, 1992). In the evaluating phase of Cycle 2, participants reflected that if the group had only consisted of adult nurses, then they would have all agreed with each other and so little would have changed. But, by reflecting-on-actions with the children's nurse participants, a change in mind-set had occurred. The participants discussed their own changing assumptions and different perspectives as the PAR cycle progressed. At the start of the research I had strong opinions relating to family centred care as in my clinical experience this seemed to only occur for the adult family members over eighteen years of age. During transcription and data analysis, the discussions about family structure and family roles, particularly about grandparents as surrogates caused me to start considering another hidden group of children, those that care for their parents.

### **Researcher positionality**

One of the central challenges of PAR is reframing one's own self-understanding (Lykes, 1997). It is important to be aware that the community or population involved in the PAR study may see you differently than you see yourself in relation to positionality (Smith, Bratini, Chambers, Jensen and Romero, 2010). Attention to positionality is a component of reflexivity, contributing to the demonstration of validity and trustworthiness (Herr and Anderson, 2015). "The human science researcher is not just a writer, someone who writes up the research report...but...rather an author who writes from the midst of life experience where meanings resonate and reverberate with reflective being" (van Manen, 1996, p.64). Writing up this thesis, represents a life



experience for me as the researcher, in addition to that of the participants. Throughout the PAR study, my researcher positionality has been influenced by both my personal professional circumstances but also by the viewpoints of the different participant's, and so has changed frequently throughout the study (Figure 7.3, p.256).



*Figure 7.3 Whole Study Researcher Positionalities*

On planning and beginning this study, I was working in the clinical environment where it was to be conducted and as such could consider using the insider model. The insider position involved reflecting upon my own practice (Herr and Anderson, 2015), which was pivotal in the proposal of the study and continued throughout the process. In addition to my ANP role, being well informed from the literature provided me with a

strong knowledgeable position and a conscious decision was made to share this knowledge if invited by the participants (Day et al, 2009). It was important to acknowledge this from the planning of the focus groups in order to consider any personal contribution to the PAR study during analysis.

As the PAR study began, an insider collaborating with other insiders (Herr and Anderson, 2015) emerged, as the issues and study idea was discussed with interested colleagues. It was expected that a reciprocal positionality (Herr and Anderson, 2015) would predominate the PAR cycles. The participant's in Cycle 1 were colleagues interested in the study and who had been involved in discussions with me prior to the proposed study. There was the potential for power relations to affect the planned democratic PAR group, as I was a senior nurse and some colleagues were more junior. However, the PAR approach encourages collaborative working through all aspects of the research process and so a reciprocal positionality was the gold standard objective.

Due to the challenges encountered in Cycle 1 and the loss of the original participants, Cycle 2 involved active recruitment. This involved recruitment of nursing staff who were unknown to me and so although still an insider working as an ANP in the hospital, I could be seen as an outsider collaborating with other insiders (Herr and Anderson, 2015) by other more junior nurses who were being recruited at a set mandatory meeting day. Although nursing staff did not have to participate in the study, there was awareness that there had been a shift in the power relationship, as some may have felt obliged to participate. It was hoped that by adopting the PAR approach whereby the research is designed by 'all participants' (Searson, 2001, p.85) greater collaboration would be achieved. This was however, very nerve wracking as well as

exciting, as it is impossible to write a clear research design before embarking on the voyage of discovery with the clinical team.

During Cycle 2 my positionality within the research project changed and evolved. I had moved from an insider researcher collaborating with other insiders to that of outsider collaborating with insiders as I left the hospital and my role as ANP to take up a role as a University Lecturer in Nursing. This was a challenging time which demonstrated how positionality could affect the ability to access participants. When I moved to the University the majority of the participants still seemed to consider me an insider. However, I was aware that some participants who were new to the hospital might think of me as an outsider. This was a challenging time after over twenty years of experience in the organisation. In the position of now being an outsider collaborating with other insiders (Herr and Anderson, 2015), more difficulties were encountered in terms of access. It was difficult to arrange the focus groups, with emails being sent to my now redundant NHS email account rather than the University research email. Barriers to collaboration in clinical practice emerged, due to the lack of easy access to colleagues.

Cycle 3 was also very challenging in relation to the implications of my evolving positionalities. As discussed previously it was expected that a reciprocal positionality would predominate the PAR cycles (Figure 4.2, p.120). However, in engaging local college students, there was an awareness that positionality would again change along the research continuum (Herr and Anderson, 2015) from Cycle 2's outsider collaborating with insiders to an outsider collaborating with other outsider's position (Herr and Anderson, 2015). This was a naïve assumption, based on my perception that both were outsiders, not being members of the hospital. The resultant three

positionalities involved in this cycle were complex and related to the differing perceptions of the researcher and the communities (Smith et al, 2010).

As Cycle 3 progressed, the students requested that they did a focus group to share their experiences of the study. I considered that my positionality may change to that of an outsider collaborating with insiders (Herr and Anderson, 2015) based on this development. This related to my position as an outsider to the college facilitating the focus group at the college, where I thought the students would consider themselves as insiders. However, the students considered me to be the insider and themselves as the outsiders. This seemed to relate to the origin of the study, and the power imbalance associated with me as the researcher coming in from the hospital and university. Support from the college tutors was useful here to try to balance the power. Despite the fact that I felt at a disadvantage facilitating the focus group in the student's space, they appeared genuinely worried about giving me any negative experiences.

## **Impact**

The social purpose of this PAR study, underpinned by the UN CRC (1989), was to achieve an improvement in the support provided to children who visited adult patients at the hospital. The social purpose of this research therefore aligned to the position of "dismantling the ideas and practices of the deliberate exclusion and alienation of persons" [the children] and encouraging "others [the staff] to interrogate their own assumptions, and the normative assumptions of their cultures, in search for more inclusive and relational ways of living" (Whitehead and McNiff, 2006, p.25) and working.

The evaluating action phase of Cycle 2 indicated that some actions had been successful, but it was difficult to measure the impact. It had been clarified that there was no hospital policy restricting visiting to only those aged over twelve years, and this had resulted in a number of wards removing signs to this affect. The education sessions provided by the children's hospice had been evaluated well by the participants who feedback that it would be useful for all nursing staff and student nurses. This was reported to the SNT, but as I left the study it was not possible to evaluate the long term plans in relation to education.

One strategy used in PAR is to "accept small wins" as "tempered radicalism offers the options of small steps leading in the desired direction" (Hilsen, 2006, p.34). The use of PAR provided a space for adult and children's nurse participant's to challenge each other's views, assumptions and clinical practices related to children visiting adult areas. It allowed the development of active learning through knowledge transferability for all participant's and for me as the researcher, as clinical expertise was shared in response to reflection-on-actions and clinical dilemmas. By allowing participant's to control the flow of conversations throughout the focus groups, this tempered radicalism ensured that the study worked for change from within opposing structures rather than confronting and provoking defensive reactions or open conflict (Meyerson and Scully, 1995).

It can be difficult to attribute meaningful change to a specific intervention in PAR. Causality is often expressed simply as linear, but this excludes consideration of societal complexity and the nature of human ethics and responsibility (Chevalier and Buckles, 2013). The underpinning reasons provided for the restriction of child visitation were complex and ingrained in personal and societal values and perspectives. In the

evaluation phase of Cycle 2 adult nurse participant's feedback incidents where they had adopted some of the simple measures suggested during the study, such as offering a drink or asking a child if they were OK. Some identified that they would never have even thought to notice the children. These small incidents indicate a change in thinking, which led to a personal need to change practice, rather than the change being externally driven when the basis for the change may not have been understood or well received (Cook, 2009). By engaging in self transformation, these participant's may encourage transformation in others (Torbet, 2001) leading to more widespread practice development.

The college student participants in Cycle 3 may also contribute to long term improvements which are beyond the scope of this study to evaluate. One participant said that perhaps they could be the role models of the future, and as they all hoped to go into healthcare careers this was possible. The college was interested in further collaborative work with the hospital and were linked to specific teams who hoped to engage them in developmental work.

On a personal level, by engaging in self-transformation myself I hope to continue to transform clinical practice of the future in others. My teaching has progressed to include sessions for both student and registered nurses facilitating critical thinking and reflection-on-action. The findings have also been disseminated; locally and regionally (Appendix 18, p.438); nationally and internationally (Appendix 19, p.440). Colleagues from other hospitals have reflected during these sessions that consideration had not been given to children visiting and how best to support staff in providing appropriate family care. Other colleagues, who engage young people in hospital user engagement

groups, have commented that they ask for opinions of specific hospital services, but never ask them what it is like to walk into a hospital as a child or young person.

## Chapter 8

### Looking back for the future

#### **The best way to understand something is to try to change it**

(Kurt Lewin cited in Greenwood and Levin, 1998, p.19)

The aim of this PAR study was to identify and critically explore the issues surrounding children visiting adult relatives on any ward in one large teaching hospital in the UK in order to improve the support provided. The study had originated from reflecting upon incidents in clinical practice, and a subsequent comprehensive literature review had demonstrated that there was a long history of evidence that facilitating visiting for children has positive effects (Craft et al, 1993; Gibson et al, 2012b; Knutsson et al, 2008). Despite, this there was little evidence that it was being applied in clinical practice with children often been restricted from visiting. Together with consideration of the UN CRC (1989), the social purpose of this PAR study was to achieve equity and an improvement in the support provided to children who visited adult patients in the hospital. This chapter will provide a conclusion of the main findings of this PAR study, followed by recommendations for clinical practice, nurse education and future research.

#### **What this PAR study added to the knowledge base**

*The deductive analysis* of this PAR study found themes congruent with the findings in the literature review. These findings confirmed that although there was a strong evidence base that children visiting hospitals had beneficial outcomes (Gilbert, 1959) and that there were strategies shown to support the practice, there remained a



variation in visiting practices throughout the hospital. There was a clear distinction between the adult and paediatric clinical areas, with a culture of open visiting and no age restrictions on siblings visiting in child health. A number of adult clinical areas had an age restriction of twelve years for visitors. This was attributed by the adult nurse participants as being the result of following the hospital policy, although no policy could be located. Evidence in local historical records suggested that fourteen years of age was the age restriction used in the regional area of this study in the past (Goodall, 1982; *The Staffordshire Sentinel*, 1912), although internationally twelve years was the most common age restriction documented in the literature (Anzoletti et al, 2008; Morgan, 2012).

It was also identified in this study that there was a lack of information available for both staff and visitors relating to child visitation at the hospital. The lack of written policy or guidelines for children visiting was also a feature of previous research (Knutsson, Otterberg and Bergbom, 2004; Vint, 2005b) particularly in ICUs. Where policies did exist, adherence and consistency with them was variable, dependent upon the attitudes of individual nurses, who often used their own clinical reasoning to decide whether to admit a child visitor or not (Anzoletti et al, 2008; Clarke, 2000; Simon et al, 1997). This was also evident in this PAR study where participants discussed adapting the perceived policy depending upon individual patient circumstances.

A number of the reasons for excluding children from visiting adult patients provided in this study were consistent with the literature. These included perceived infection risks (Gremillion, 1980; Lindsay, 2009; Mclvor, 1998; Moore, 2006; Morgan, 2012; Vint, 2005a; Vint, 2005b), protecting the children from harm (Clarke, 2000; Morgan, 2012; Vint, 2005a; Vint, 2005b), it being too upsetting for the child (Clarke, 2000; Knutsson

and Bergbom, 2007a; Knutsson, Otterberg and Bergbom, 2004; McIvor, 1998; Morgan, 2012; Vint, 2005a; Vint, 2005b), children would disrupt the clinical areas (Bates, 2010; Knutsson, Otterberg and Bergbom, 2004; Morgan, 2012; Vint, 2005a; Vint, 2005b), and protecting the family or nursing staff (Clarke, 2000).

The protection of nursing staff from emotional trauma has been identified as a reason for restricting child visitation and this related to some visits being described as emotionally demanding and distressing (Clarke, 2000). Adult nurse participants in this study also provided examples of situations which were emotionally demanding and caused an element of distress, but these had ultimately been considered positive experiences. The demands related to the emotional experiences of dealing with families of dying patients, but were also associated with a feeling of role conflict. Frustration was felt in relation to service demands and that children would further exacerbate the work load, due to extra requests or disruptive behaviour. Families transferring responsibility for decision making to nursing staff was also stressful, with adult nurse participants worrying whether they had provided the correct advice.

Previous literature had identified that there was a deficit in the education and resources required to support staff in the area of child visitation to ICUs (Gibson et al, 2012). A lack of resources was also identified in this study and included; written information and guidelines for visitors and healthcare staff, space for conversations and visiting, and activities for children who did visit. A lack of education was also identified by the adult nurse participants as contributing to their lack of confidence in dealing with children visiting.

In Cycle 3, the deductive analysis revealed that the college students often did not feel welcome at the hospital. This often related to a lack of communication or feeling excluded. This was consistent with the Pre-step consultation focus groups, where the MCRN YPAG described similar experiences and with the literature where being left waiting was described as leading to tension in children (Knutsson et al, 2008). Kean (2009) had also reported that children were often assigned the role of the 'silent listener', where children who were permitted to visit were often not involved in conversations leading to them feeling ignored.

The college student participants also described a need for information and discussed experiences where neither healthcare staff nor family members had provided adequate information. This was again congruent with the MCRN YPAG consultation focus group findings. Knutsson and Bergbom (2007b) also found that families did not always communicate with children about a family illness after a visit to ICU. Parental distress had been identified as resulting in them not always able to reassure or support their children during a family illness (Winch, 2001), or being unaware of their children's needs (McIvor, 1998). In both these instances, it is recognised that parents may require support from healthcare staff in order to provide the appropriate care for their children. The college students in this study discussed the difficulty of not been provided with appropriate information or support. This included from parents and family members, but also healthcare staff. This was particularly relevant if an incident occurred when visiting a hospital, such as the death of another patient. The college students also recognised that adults often tried to protect them by trying to manage the content and flow of information giving to them (Kean, 2009), but at times this seemed to cause increased levels of stress.

During the evaluation phase of Cycle 2, one of the main subjects was the differences in assessment processes between child health and adult clinical areas. The adult nurse participants reflected in the evaluation phase that the holistic elements of assessment and care planning in their clinical areas did not include detailed family information when compared with the admission assessment completed by the child health team. In child health it was clear that great value was placed on gaining a holistic assessment as soon as possible on admission of a child, which included details of all family members and responsibilities. Winch (2001), a Paediatric CNS highlighted that child visitation can provide an opportunity to discuss the patients role in the family and provide information about the whole family, making education and discharge planning more effective. There were indications in the evaluating phase of Cycle 2 that consideration was being given by the adult nurse participants to the value of the child health model of assessment, particularly in relation to fully understanding a patients home and social situation.

*The inductive analysis* did yield new challenges and perspectives to the concept of child visitation from both the nurse and college student participants. In addition to the deductive reasons for restricting children from visiting adult relatives, two new justifications were identified in this study. These related to concerns from the adult nurse participants about responsibility and abandonment. There was an assumption that the nursing staff had responsibility for the care of any child visiting, including providing food and ensuring good behaviour. This was a major concern and in some cases was a reason for restricting visiting. In addition to the care of the child, there was some concern about responsibility for providing correct advice or information. This was congruent with research findings published after the initial data analysis (Golsäter, Henricson, Enskär and Knutsson, 2016), where feelings of

responsibility were attributed to a lack of education and awareness of the needs of children and families.

Fear of child abandonment was another theme identified which related to restricting or excluding visits. This was closely linked with the issues of responsibility and liability, featured in the experiences shared in the Cycle 2 focus groups. Evidence from these experiences demonstrated that children may be left at the hospital without parental or guardian supervision for a number of reasons and had included being abandoned by other family members. Although these incidents were rare, they had resulted in established anxieties reinforcing the perceived policy that no children under twelve years of age should visit.

Fear of liability was only noted by one author in the literature. Gremillion (1980) highlighted the risk of liability from negligence related to causing harm to visitors, suggesting that it may be possible to prove negligence if an incident occurred due to failure in enforced visitor restrictions. Child visitors could therefore be viewed as a serious legal liability due to the difficulty in ensuring absolute enforcement of the visitation rules. This paper however, is thirty eight years old and was based on clinical practice in the USA which has a different healthcare system to the UK (Boslaugh, 2013). Fear of liability did not appear to be the underlying concern of the adult nurse participant's in this study. The concern was more closely linked to the fear of doing something wrong or giving the wrong advice, thereby not helping the family or the children.

During the Cycle 2 focus groups, the children's nurse participants were able to discuss the legal position and procedures required in circumstances of child abandonment and responsibility. These ranged from informing the accompanying parents and guardians that they were responsible for the visiting child, including care and monitoring behaviour, through to the policy for cases of child abandonment and child protection. This active learning through knowledge transferability from the child health team to the adult nurse participants was evident throughout all phases of Cycle 2.

Another theme closely linked to the issue of responsibility was that of role conflict (Murray, 1983). Conflicting priorities due to service demand and role boundaries resulted in increased stress related to children visiting. The perceived responsibility for any child that visited alongside the potential extra demands for support or resources was seen as competing with direct patient care. With the patient seen as the sole focus of care, some participants initially did not consider that they had any role in providing support to visitors, particularly children.

Identity also caused role conflict in relation to children visiting. Nurses derive their self-concept and professional identity from their public image, work environment, work values, education and traditional social and cultural values (Ten Hoeve et al, 2014). Personal and professional role boundaries blurred in some situations resulting in anxiety and concern about behaving in appropriate ways. It was identified that dilemmas can arise for nurses who are also parents, as they can project their own beliefs onto a situation involving children, or have restricted children visiting when they would wish their own children to be allowed access if they themselves were the patient. There was also recognition from the adult nurse participants that feelings and responses as a professional nurse were often different than the responses they would

give in the community. This perception of professional behaviour and acceptability is consistent with the role of public image in nurse identity. There was evidence of a perception that the public may not find some socially accepted behaviour such as admiring a baby, acceptable from a professional nurse in a clinical environment.

Craft et al (1993) recommended further research into both the long and short term effects of visiting or not visiting on children. Although not the focus of this study, discussions in the Cycle 2 focus groups included childhood experiences. Often in clinical practice, children under twelve years of age are only permitted to visit an adult relative if the patient is dying (Morgan, 2012). A number of participants associated childhood visits to the hospital as the cause of hospital phobia in adulthood in members of their own families. They described how siblings and spouses associated hospitals with death which were attributed to them only being allowed to visit a relative in hospital when they were dying. This impression provides some evidence that bad memories and associated psychological effects such as hospital phobias may result from policies which only allow visitation to dying patients.

Acknowledgement for confidence evolved as a theme from the college student focus group in Cycle 3. Previous evidence has demonstrated the need for children to have preparation prior to visiting adult relatives on ICU's and that those frightened by the experience were the ones who had not received any (Craft et al, 1993; Kean, 2010). Many research studies findings (Craft et al, 1993; Kean, 2010; Knutsson et al, 2008) echoed theories about children's perceptions and experiences surrounding illness and death, that "bereaved children need help in four main areas: information, reassurance, the expression of feeling and an opportunity to be involved in what is happening" (Monroe, 1995, p.89), reflecting the needs of the adult population. In this study, the

college students also highlighted the need for information, explanation and good communication. The most important requirement was communication and acknowledgement by healthcare staff. Being acknowledged when visiting relatives was seen as crucial in making them feel welcome and in giving children the confidence to approach a member of the healthcare team if they had any questions.

Sympathy for healthcare staff and a broad understanding of the current NHS situation from the college students was an unexpected finding in Cycle 3. Although, they described feeling excluded, unwelcome and intimidated by healthcare staff, they did acknowledge that these interactions may not have been intentional. When discussing 'the look' which was often perceived as an intimidating action from healthcare staff, the college students acknowledged that they did not think the staff were always aware that they were doing this.

The college students also displayed sympathy for healthcare staff working in the contemporary busy hospital environment when considering what resources or support would improve the experience of visiting adult relatives for children. These ideas included improved use of technology, such as Facetime and Skype, to improve communication with all relatives with the added benefit of reducing visitor numbers. Although it was known from the literature that teenagers often feel great responsibility towards others at times of family illness (Titler et al, 1991), making the decision to visit was found to be stressful at times related to the unexpected concept of concern about visitor numbers and that they may be stopping someone else from visiting.



In conclusion, there is a need for consistency in clinical practice in relation to visiting practices. Conflicting actions and information were stressful and confusing for children, but also caused stress and conflict between different staff. Although there was a clear aversion to having a policy, due to the likelihood that it would never be read, there was a keenness to have guidelines for visiting available for healthcare staff and visitors. Linked to the concern that a policy may rarely be accessed, of personal concern was the theme 'practice without policy'. Results from Cycle 2 consistently demonstrated that policy was used as a reason for restricting visiting by children and young people despite the policy not existing. This has implications for any change process related to historical or current policy and procedures. The findings raised two further questions. Firstly, was there a lack of up-to-date policy knowledge causing adherence to long out of date policies in current practice. Or, was the reliance on an out of date policy known and used by staff to avoid having to deal with what was perceived as a complex and stressful encounter: children visiting the wards?

One of the strengths of this PAR study was that the multiple participants provided multiple perspectives and experiences which were of benefit to both the participants' and to me as the researcher. Reflecting upon the focus groups during the data analysis, particularly in relation to the theme of family structure, I realised that children who have carer responsibilities had not been considered. Young carers are those aged under eighteen years of age who provide on-going care to a relative with a physical or mental illness, disability or addiction. The 2011 Census of England and Wales identified 178 000 young carers ,which was an 83% increase in those aged between five and seven years and a 55% increase in those aged between eight and nine years (Barnardos, 2018). Although, not a theme directly quoted from the focus group transcripts, this was an important inductive theme which requires further research and investigation.

Throughout the PAR process both adult nurse participants and children nurse participants had an opportunity to share knowledge, but also to challenge assumptions held about each other's practices. This led to some creative problem solving approaches and inter-professional learning, such as processes to follow in child abandonment. Bringing the different speciality groups together encouraged the exploration of potential solutions, the sharing of ideas and of current practices. It also highlighted the need to consider the concept of holistic and family centred care in adult nurse education. Patients are part of a larger network of family and friends. However, when teaching student nurses in the adult field, is there enough emphasis on this? Consideration should be given as to how dealing with children could be included within the curriculum. Internationally, not all pre-registration nurse education has separate specialist training, such as adult or child branch. Australia is one such example, where pre-registration training is as a general nurse and includes some child assessment (Copnall, 2018). In UK, where student nurses are separated into branches of training, consideration needs to be given into how to include content applicable to childhood developmental needs and child visitation.

Gibson et al (2012b) highlighted the importance of including visiting needs in both pre and post registration education curricula. Higher Educational Institutions have been called upon to more intensively address the importance of visiting policies and to facilitate the development of higher reflexive competencies (Juchems, Mayer and Zegelin, 2008, cited in Gibson et al, 2012b). Student nurses need to be encouraged and empowered to challenge not only their own values and assumptions, but also those of others, including colleagues, patients and relatives. Exploring others assumptions, reactions, actions could lead to a more exploratory mind-set rather than a judgemental one.

## **Respecting the voices of children and young people in the organisation**

Great importance is placed upon children's participation in healthcare research (Fleming and Boeck, 2012) and engagement with both the college student participants within the PAR study and the MCRN YPAG during the consultation phase in the Pre-step provided detailed perspectives that were relevant to their experiences. Young people involved in the research process 'can offer a different perspective' (Kirby, 2004) which was evident in this PAR study. The MCRN YPAG provided confirmation that the research question was valid as there continued to be issues within clinical practice when they visited. They also provided valuable opinions on the research design, particularly in relation to including children in the study.

"Children are a part of the social world and without their perceptions and experience's being documented, we gain a partial view and an inaccurate perspective" (Butler, 2012, p.72). Although children are included in medical research through organizations such as the MCRN, greater consultation and collaboration with children and young person's groups in other areas of healthcare would further enhance the service delivered to the whole population. Many hospitals have groups, such as The Health Societies, which engage children in reviewing resources in child health. These groups could be further engaged into working collaboratively with healthcare staff on projects which are hospital wide.

## **Recommendations for clinical practice**

- A structured approach to child visitation should be established and implemented in all clinical settings.
- Early identification of patient circumstances, including any children who may wish to visit, should be implemented through the use of appropriate family-centred assessment strategies.
- Nurses need to question and challenge their own personal and others assumptions and values in relation to child visitation and family centred care.
- Consistency is required in the implementation of visiting practices and policies.
- Policies and practices must be reviewed regularly to ensure up-to-date evidence based practice.
- Greater opportunities for inter-professional learning and multidisciplinary working should be established across adult and child health teams.

## **Recommendations for nurse education**

- Child developmental needs in relation to family illness should be included in all nurse education curricula, both pre and post registration.
- Experiential and clinical practice orientated learning should be encouraged and include issues such as, child visitation and family centred care.
- Student nurses should be empowered to challenge values and assumptions related to clinical practice.

## **Recommendations for research**

- Cultural studies are required to explore the relationships between child visitation, cultural norms, values and assumptions.

- Research is needed to explore the experiences of young carers visiting hospitals.
- Further research to examine the long term effects of visiting practices and restrictions is needed.

## **Researcher's concluding reflections**

This PAR study and PhD thesis has been a challenging journey, full of both positive and frustrating moments. The use of the PAR approach has been invaluable in developing my research knowledge and skills. My intention was to research on clinical practice whilst trying to make concrete improvements. Although some positive clinical improvements were made, there are many yet to come to fruition. I think that at the start of this journey, this would have been a disappointment, but using the PAR approach I have gained an understanding into how the impact of research can take time to develop. I have learned to enjoy the 'small wins' (Hilsen, 2006), and embrace the mess (Cook, 2009) as a beginning for practice transformation, rather than expect to fully solve all problems with one study. In addition, as an adult nurse, the PAR process provided an opportunity to engage with children and young people. This proved enlightening, in both their willingness to participate in the research, but also in relation to their perspectives and perceptions of the world they encounter. In concluding, I would therefore like to thank all the participants who took time to share experiences and challenge assumptions, both within the focus groups and also in continuing to do so in clinical practice.

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# Appendices



# **Appendix 1**

## **Data Extraction Table**

AUTHOR	STUDY METHODOLOGY OR PAPER TYPE	CHARACTERISTICS OF THE PARTICIPANTS	DETAILS OF ANY INTERVENTION	OUTCOME MEASURES/RESULTS	STUDY RECOMMENDATIONS
Gilbert, 1959, UK	Article (opinion) from hospital administrator			<p>Discusses the question of allowing children to visit mothers admitted to hospital. Need to mitigate the damage to the 'deserted' child.</p> <p>Identifies 4 separate sections to be considered for 2 angles – patient, child and staff.</p> <p>1 - Infectious illness such as TB (absence may be up to 2 years) arrangements should be made for visiting while taking precautions to stop child becoming infected. Open air meetings best. Every effort to ensure weekly or preferably twice weekly visiting takes place.</p> <p>2. Accident – mother may be suffering</p>	

				<p>shock and need absolute quiet and freedom from worry. May want freedom from the children. Hospital need to ensure no introduction of infection (burns or scalding). Child – may be better to stay away until bandages, disfigurement dealt with.</p> <p>3. Surgical/Medical Care – short stay (10-14 days) mother and staff may think the child does not need to visit as will be home soon. From child’s perspective – may worry that mother has gone for good. Discusses possibility of stories in school ground of mothers who have disappeared could do damage. May not feel able to ask the question. Gives example of child who began to object to going to school on Monday which resolves once new baby born – later disclosed that school friend had told her she had read in a story book of a Mummy who died when she had a baby – child afraid to mention it and so not received any comfort or reassurance.</p> <p>4. Confinement Care Maternity. Important to consider child visiting as</p>	
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				<p>mother will return home with a new baby who will occupy mothers time etc. Gives example of a worried child being taken to visit mother in maternity ward and seeing new baby in crib – becoming happy again. 3 London hospitals maternity units allowed some visiting by a child, Highlights need to be careful of introducing infections and that not possible on an open ward,</p>	
Berlow, 1960, USA	Article (USAF Major)	400 bed USAF Hospital, Wright Patterson Air Force Base, Ohio and 45 bed USAF Hospital, Whiteman Air Force Base, Missouri.	Unrestricted visiting for children of any age to parents between 10am and 8pm.	<p>Other patients eagerly await arrival of children – makes them feel more at home.</p> <p>No children have been upset.</p> <p>Gained knowledge of the hospital and lose groundless fears.</p> <p>Minor incidents – careless parenting (no details provided)</p>	<p>Not seen as appropriate in obstetrics, paediatrics or closed psychiatric wards.</p> <p>Not where there are contagious diseases.</p>
Chaloner, 1972, UK	Article		Advocates visits to parents and grandparents who are patients.		<p>Recommends that parents consult ward sister in advance to plan visit and must keep children in order.</p> <p>Instructions should be in printed</p>

					<p>form in the entrances to the hospitals.</p> <p>Recognise the relationship with grandparents – beneficial for all for children to visit- linked to plans for elderly care.</p>
Gremillion, 1980, USA				<p>Discusses reasons for exclusion –</p> <p>Risk of infection. Refers to Watkins, Frey, Eton works which show no increase. Dialysis and oncology among special risks – documentation lacking. 1 instance 20 cases of varicella on pediatric oncology unit with open visiting. Should screen during community outbreaks.</p> <p>Reports that no increased infection found when simple screening and precautions observed in oncology and transplant services.</p> <p>Fear of liability – in event of visitor incident. Also may be held liable for real or perceived injury to prohibition of possible beneficial techniques such as</p>	

				<p>Lamaze childbirth method.</p> <p>Prevent confusion, noise and disruption to hospital routine so that convalescent and restful atmosphere is maintained for patients.</p> <p>Some hospitals have provided play facilities staffed by volunteers (Williams and St Vincent) – although convenient to visiting adults do not address the fundamental question of whether children have a right to visit a family member,</p> <p>Knowledge from hospice seems to support positive influence of children (McIntier).</p> <p>Refers to Buckley – devastating effect on children of serious or prolonged parental illness – sharp increase in children’s behavioral disorders.</p>	
Goodall, 1982, UK Stoke-on-	Opinion	Consultant paediatrician	Reflecting upon experiences in paediatrics and in dealing with a mother	2 year old child attending paediatric outpatient with mother – who was due admission in next few days. Mother was worried as to how child would cope as	The younger the child the more important it is that hospitals allow the child to visit.

Trent			who was to be admitted	<p>children not allowed to visit the ward. Note to ward sister and consultant solved this but mother reported back that the other mothers were jealous about her child's special arrangements.</p> <p>Discusses reasons for refusing entry – might upset the child, distress the patient or annoy other patients.</p> <p>But children more upset by not knowing what is going on than by being included. Discussed separation literature and age related reactions.</p>	Explain to parents and professionals the effect of protecting children from all unpleasantness. – Delay or damage emotional development.
Jones, 1984, UK	Case study	Patient – hysterectomy aged 35. SRN. 2 children aged 3 and 5. No local family. Husband had to have time off to look after the children. Utmost importance that they were allowed to visit. Knew that children could develop fantasies about mother dying or that something was		<p>Ombudsman's findings – Consultant not prepared to interfere with policy of visiting hours. In his opinion he did not think the ward suitable for children to visit due to busy theatre lists, patients have major operations or terminations. Thought the wife was being selfish.</p> <p>Second sister of the ward – agreed children may be permitted for special circumstances, Had not found the restriction a problem.</p>	

		<p>very wrong if not reassured occasionally. Dismayed when info letter stated that children under 12 could visit only on a Sunday afternoon. Checked with ward sister who confirmed the policy and said that well patients were permitted to see their children off the ward. Contacted local community health council and meeting was held with the nursing officer and ward sister – feeling of hostility. Could see them in the corridor 48 hours after major surgery, Dayroom was not used – ambulant patients only. Surgery went ahead – children visited in the corridor and on a Sunday. Later</p>		<p>The commissioner did not uphold the complaint that the ward visiting was unduly restrictive.</p>	
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		complaint investigated by the ombudsman,			
Matorin, 1985, USA.	Personal experience	Social worker in psychiatric setting.	Reflecting upon personal experience with hospitalization for emergency cancer surgery.	<p>Encountered persisting mythology shrouding child visitation in medical setting.</p> <p>These were potential for increased infection and disruption of harried staff routines and procedures.</p> <p>Refers to playroom for visiting children (St Vincent) and Air Force relaxing restrictive riles for children (Berlow 1960 and Gremillion 1980).</p> <p>Authors experience – brief separation imposed by the hospital for surgery increased stress of possibility of metastatic cancer, terror of prognosis and ultimate separation from 5 month old child. Aggravated by confrontation with traditional administrative bureaucracy when request that child allowed to visit her room was refused.</p> <p>A compromised 'visit' in a noisy, drafty hospital lobby left this vulnerable patient</p>	Author urges hospital administrators to creatively reexamine policies about children's rights to visit.

				and her overwhelmed baby so frustrated and totally unable to connect emotionally amidst wheelchairs, an attending private nurse, the father and housekeeper and an intrusive stream of other visitors and staff. Ultimately a visit was allowed – medical social worker advocated.	
Dopson, 1989, UK		Describes a programme of children from local schools visiting elderly patients at Abbots Langley Hospital (branch of Watford General) – elderly/long-stay unit.		Author spoke to 4 children visiting the unit as part of a bible study class. Found that only 1 out of the 4 children had visited a relative in a geriatric ward. Others had not been inside a hospital.	
Anon, 1991, USA	Infection Control Policy discussion			CDC has no official infection control guidelines on hospital visitor policies. However infection control practitioners adopted strategies to prevent nosocomial outbreaks particularly linked to children visitors.  Request practice is to prohibit children from patient areas expect for special circumstances such as sibling visitation. When allowed to visit strict screening for	

				<p>infectious diseases in often in place.</p> <p>Roberta Mirenberg (nurse epidemiologist in New York) says many youngsters are non-compliant with hospital policy – 14/15 year old will try to pass off as 16. Concerns about measles outbreaks – but no documented cases of nosocomial measles related to visitors (children and youth prohibited). Athens (GA) Regional Medical Centre children under 12 year prohibited except for sibling visiting Then must have special pass from information desk.</p> <p>Is a play area near the information desk and staff will watch children while parents visit</p>	
Lewandowski, 1992, USA	Article	Considering the psychological and emotional care needs of well children in families of a patient in critical care.		<p>Well children may feel loss of both parents – time spent visiting hospital by the well parent.</p> <p>Perceived abandonment and inability of the child to cope may result in behavioural problems.</p> <p>Well parents may feel overburdened and</p>	<p>Critical care nurses vital in helping parents and well children communicate and manage complex family issues.</p> <p>Consider 'family time' – enable nurses to have time to carry out family assessments/interventions.</p>

				<p>unable to support the children.</p> <p>Response of well child to ill sibling may be guilt, helplessness, loneliness, fear for own health.</p>	<p>Consult with pediatric clinical specialists.</p> <p>Challenge is dispelling myth that children are too young to understand or be affected by critical illness.</p>
<p>Craft, Cohen, Titler and DeHamer, 1993, USA</p>	<p>Phenomenology .</p> <p>Interviews with children.</p> <p>Open-ended audiotaped interviews conducted by a trained interviewer who had critical care experience and was a pediatric nurse.</p> <p>Conducted at</p>	<p>11 children of 9 parents hospitalized in a large Midwestern hospital.</p> <p>Criteria – their parent was admitted to an adult medical or cardiac critical care unit, spoke English, and aged between 5-18 years.</p> <p>All were male.</p> <p>7 had older siblings, 2 had younger siblings and 2 had none.</p> <p>Patients aged 36-53 years. Mean age 37.8 years.</p>		<p>Emotional turmoil. - Shock, anxiety, fear, confusion, frustration, uncertainty.</p> <p>6 who visited critical care unit for the first time without preparation said they found the equipment frightening.</p> <p>Those that had been before or who had been told in advance what to expect did not seem frightened.</p> <p>Primary concern was the parent's ill health – all suffered fear of a parent's death and felt anxious about the uncertainty of the parent's recovery – this lessened their ability to cope with day-to-day stress.</p> <p>5 indicated confusion about the illness or a desire to be more informed.</p>	<p>Practice –</p> <p>Important to encourage children to visit and adequately prepare them using developmentally appropriate strategies.</p> <p>Nursing interventions to increase communication between children and nurses and children and family need to be implemented.</p> <p>Baker et al – advocated information based on developmental status.</p> <p>Nicolson – Child Visitation intervention.</p> <p>Notification to school nurse.</p>

	<p>the hospital in private conference rooms adjacent to the ICU areas.</p> <p>Averaged 1 hour.</p> <p>Questions are detailed in the paper– revolve around perceptions of the impact the event had for them, the family unit, other members in the family, what was helpful for them and their families.</p> <p>Appropriate probes used to elicit views</p>	<p>7 patients were male and 2 female.</p> <p>3 patients were unemployed. Employed patients were an insurance adjuster, a maintenance worker, a rail road supervisor, a nurse's aide and 2 clerks.</p> <p>Admitted due to – severe coronary artery disease, myocardial infarctions, respiratory failure and sepsis following bone marrow transplant, status asthmaticus, pneumonia, renal failure, lymphoma, cardiac arrest, respiratory arrest and multisystem failure,</p>		<p>Family disruption –</p> <p>8 taking more responsibilities at home some found this burdensome whilst others welcomed the opportunity to help in a time of crisis.</p> <p>All noted loss of family unity and communication – no longer eating together, more arguing.</p> <p>5 described a change in relationship with the well parent – more leniency or strictness. All noted the well parent was irritable, tired or depressed.</p> <p>All but 1 reported feelings of loneliness and missing both parents (the exception = ill parent was a substance misuser). These were intensified in those staying with relatives or friends.</p> <p>All but 1 spontaneously emphasized that it was important to them to be able to visit the hospitalized parent (same 1 did not).</p> <p>Need for support – emotional support</p>	<p>Research –</p> <p>Determine how parents decide whether their children should visit and what factors influence this.</p> <p>Short and long term effects of children visiting or not visiting their parents in critical care.</p> <p>Nursing to develop and test interventions that will assist children to cope adaptively by meeting their informational and support needs.</p>
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	<p>without suggesting new ideas (examples given in the paper).</p> <p>Potential participants identified every 24 hours – reviewing patient charts and asking nurses who had children.</p>			<p>from family and friends. All cited instances of feeling cared for by others.</p> <p>Some focused on help day-to-day such as teachers reducing the amount of homework or friends bringing food.</p> <p>7 noted the importance of being able to talk with someone about the experience. Of these 4 relied on the well parent, 4 able to talk to an adult outside the immediate family (grandparent or family friend). 3 talked to friends their own age in addition to an adult.</p> <p>3 stated frustration with the 'pity' of strangers and acquaintances and seemed to find it intrusive.</p> <p>Illness – 6 experienced a minor illness during the study (colds, flu).</p> <p>Interview seemed to have been viewed as therapeutic – several parents and a few children expressed appreciation to the investigator for the opportunity to talk.</p>	
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				<p>Themes similar to previous work of 120 siblings whose brothers or sisters were hospitalized.</p> <p>Results suggest that isolating children by keeping them away from hospital with little information is not an effective way to help children to cope.</p>	
<p>Nicholson, Titler, Montgomery, Kleiber, Craft, Halm, Buckwalter and Johnson, 1993, USA</p>	<p>Quasi-experimental, post treatment design.</p> <p>Aim to examine the behavioural and emotional responses of child and non-hospitalized adult family member to facilitated child visitation in adult surgical ICU.</p> <p>Compared 2 groups –</p>	<p>Inclusion criteria were –</p> <ul style="list-style-type: none"> <li>▪ The family had a adult family member in the SICU</li> <li>▪ Had a NHAFM and a child from 5-17 years</li> <li>▪ The child had not visited the patient</li> <li>▪ Both NHAFM and child were available to participate.</li> </ul> <p>NHAFM's were parents or grandparents.</p> <p>Exclusions were</p>	<p>Child Visitation Intervention – systematic facilitation and supervision of child visiting an adult family member in ICU. Provision of emotional support before, during and after the visit.</p> <p>Developed by CNS's – incorporates coping behaviours and age appropriate developmental tasks based on work of Piaget and Pidgeon, such as use of</p>	<p>Child –</p> <p>Manifest Anxiety Scale (anxiety) and Perceived Change Scale (behavioural and emotional changes). Children in the facilitated visitation group had a greater reduction in negative behavioural and emotional changes, but had more perceived life event changes.</p> <p>NHAFM – State-Trait Anxiety Inventory (anxiety) and Mood Adjective Check List (mood) – no significant differences were found between the 2 groups (but requires larger sample)</p> <p>Extraneous variables – Feetham Family Functioning Survey (family functioning) and Life Event Scale (life event</p>	<p>Facilitated child visitation has appositive benefit for children.</p> <p>At time of press study was being replicated with a larger sample size.</p> <p>Recommend replication of the study in community hospitals and in other critical care settings, such as medical, cardiovascular and pediatric units in small and large hospitals. Also on a more heterogeneous sample from varied cultures, races and socioeconomic status</p> <p>Add post treatment measures on the restricted child visitation group</p>

	<p>facilitated visitation and restricted visitation.</p> <p>Convenience sampling -2 stage sampling technique. 10 families assigned to control group (restricted visiting). After 2 weeks another 10 families were enrolled into the experimental group – measures were then collected within 48 hours of the child visiting the ICU.</p> <p>Outcome measures using scales – data</p>	<ul style="list-style-type: none"> <li>▪ Families experiencing extreme psychological/emotional upset</li> <li>▪ Unable to read, write or speak English</li> <li>▪ Did not meet health screening criteria.</li> </ul> <p>Total 20 – 10 in each group.</p> <p>All were white.</p> <p>Children aged 6-16 years</p> <p>NHAFM's aged 30-64 years,</p>	<p>pictures</p>	<p>changes).</p>	<p>and pre-treatment on the facilitated group. Also child visitation on a minimum of 2 visits.</p> <p>Comparison of patient illnesses, postoperative day, acuity level, length of illness and length of hospitalization on behavioural and emotional responses of family members.</p> <p>Follow-up study on the psychological effects of visitation to determine the long-term effects of the intervention.</p> <p>Epidemiologic effects of effects – children thought to pose an increased risk of exposing patients to infection</p>
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	<p>analysis done using Macintosh StatView II and SuperANOVA. Two-tailed <math>t</math> tests used to analyze differences in the means of the dependent and extraneous variables.</p> <p>Frequency data and chi-square tests used to analyze nominal level extraneous variables.</p> <p>Analysis of covariance procedures used to examine interaction effects.</p>				
Johnson, 1994a,			Describes detailed strategy for child		Most important aspects are prepare the child with age-

USA			visitation to adult ICU's – age-related preparations and nursing actions, patient preparation, assisting the grieving child, post visit stress reduction		<p>appropriate information and providing the nurses with pediatric assessment and teaching skills.</p> <p>Research questions –</p> <p>What are the psychological and emotional effects on the patient and the child</p> <p>Do prepared children cope differently than those who are not?</p> <p>Which preparation strategies are most important/effective</p> <p>What criteria should be used to ensure effective preparation</p>
Johnson, 1994b, USA	Opinion paper – 6 different viewpoints	ICU staff nurses, family member, ICU clinical, nurse epidemiologist	Visiting ICU	<p>Various opinions.</p> <p>Those that opposed children visiting ICU – had allowed children to visit in special circumstances and found the experiences positive.</p> <p>One that did agree – described positive experiences, but also one stressful</p>	<p>Visiting should be planned.</p> <p>Should be a printed copy of the childrens visiting policy</p> <p>Should be determined on an individual basis.</p> <p>Should be verbally screened for</p>

				<p>experience following the death of a patient – children hysterical and screaming – acknowledges that staff need to understand that children have emotional needs – to be seen as people.</p> <p>Family member – dad on ICU for a month before visiting allowed. Children asked every doctor and nurse who came out of ICU if they could see him – needed to know he was actually behind the closed doors. Were curious when visited.</p>	<p>communicable diseases and immunisation status.</p> <p>All under 12's should be restricted during seasonal outbreaks.</p> <p>Children should not be coerced.</p> <p>Child developmental levels – should be the basis for the approach to visiting.</p> <p>Teaching tools – books, medical play, videos</p> <p>Provides suggested answers to questions from children and post-visit stress reduction techniques.</p>
Johnstone , 1994, Scotland UK	<p>Literature review – children visiting members of their family in ICU's.</p> <p>No conclusive proof that children interfere</p>				<p>Parents should make the final decision as to whether their child visits.</p> <p>Nurses and doctors should be able to discuss relevant research with the parent to enable them to make an informed decision.</p> <p>Nurses should be more aware of</p>

	with the ICU. Introduce or catch infections or are more worried about the surroundings than adults.				children, physical and psychological growth and how to support parents to support their children when a member of the family is in hospital.
Whitis, 1994, USA	Questionnaire visiting policies	Acute hospital units and ICU.  Questionnaires sent to 125 approved hospitals in 10 US states.  Randomly selected and stratified (by hospital size).	Questions – what are current visiting policies and provisions for families? How are nurses implementing the policies?	50 hospitals responded = 40% return rate.  Limitations due to policy (age, children, number of visitors) and nursing judgement (visitor illness, length of visit).  64% had a policy regarding visiting children. Those under 12-14 years were not allowed to visit.	
Norman, 1995, USA	Critical questions	Intensive care unit – soon allowing children under 12 to visit – what can do to help things go smoothly.		Preparation important  Printed copy of visiting policy for children should be given to staff and patients families – how visits are arranged, visitation hours, importance of screening for communicable diseases, rules for the visit, potential benefits.	

				<p>Patient's primary nurse works with family to prepare the child – often using picture books, videotape or slides.</p> <p>Child should want to visit. Should not be coerced.</p> <p>Plan the length of visits – short.</p> <p>Child to be accompanied by responsible adult.</p> <p>Patient bed position – low.</p> <p>Patients who are intubated etc. will need help communicating.</p>	
Simon, et al, 1997, USA	<p>Descriptive exploratory design – gather both quantitative and qualitative data.</p> <p>14 sets of questions – current visitation practices, nurses</p>	<p>Distributed to mailboxes of staff nurses working in critical care in 5 area hospitals.</p> <p>Return rate 33.5%</p> <p>201 nurses completed</p> <p>90% female.</p>		<p>Majority of day shift and full time staff preferred visits by children by restricted.</p> <p>Significant number of nurses in combined ICU preferred visiting restrictions across all variables including children.</p> <p>Nurses reported that they evaluated the age of children when making decisions regarding their visitation.</p>	<p>Hospital and unit visitation policies should be reviewed and revised to ensure opportunities for nurses to individualize visitation to meet the needs of the patient, family and nurse, Allow the nurse to use judgement in decision making.</p> <p>Change practice to reflect research-based standards of</p>

	<p>perceptions of effects of their institutions policy on visitation, how nurses viewed policies that govern practice.</p> <p>Nurse's perceptions rated on a 5-point Likert scale.</p> <p>Pilot was completed.</p>	<p>25% under 30 years</p> <p>29% 31-36 years</p> <p>36% 37-44 years</p> <p>10% older than 44</p> <p>65% BSc</p> <p>17% Associate degree in nursing</p> <p>9% diploma</p> <p>4% MSc in nursing</p> <p>Clinical experience in CCU-</p> <p>46% 0-5 years</p> <p>29% 6-10 years</p> <p>15% 11-15 years</p> <p>10% more than 15 years</p>		<p>Examples of when official visitation was enforced included when children were unsupervised.</p>	<p>care.</p> <p>A change in policy should not drive practice</p> <p>Education relating to cultural beliefs and behaviours.</p> <p>Research –</p> <p>Focus on implementation of creative strategies for family visitation that meet the needs of patients, families, healthcare providers.</p> <p>Replicate to examine nurse's perceptions further and add studies related to patients and families perceptions.</p>
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		<p>Combined ICU 23%</p> <p>Cardio ICU 21%</p> <p>Coronary Care 20%</p>			
Pierce, 1998, USA	Practice development		<p>Trauma ICU.</p> <p>Facilitated visit packet developed for nurses, parents and children to help make decisions about a visit – included colouring book about the hospital and patients care, information sheet for nurses and parents that included age-specific tips for effective interactions (developed in conjunction with pediatric colleagues), brochure 'Helping Children Cope with Trauma' which offers</p>		

			suggestions for support and answers to frequently asked questions.		
Mclvor, 1998, UK	Literature Review – children visiting ICU – reasons given for policies excluding children, consider who should decide whether a child could visit.			<p>Reasons for restrictions – Clear that it is usual for children to have visiting restrictions for adult ICU's. Age often justification. Cites Biley et al (1993), Plowright (1996). Literature revealed little evidence to support restriction due to age. Other reasons – only if wish of the parents, risk of infection and environment is too distressing (Biley, Plowright plus Fairburn, 1994).</p> <p>Who should decide? – Nurse in charge (Biley et al 93 and Plowright 96). Johnstone (94) suggests should be visiting child's parents, recommend nursing and medical staff should be available to discuss relevant research with parents so can make an informed choice.</p> <p>Information and understanding – Cite Baker et al (1988), Craft and Craft (1989) Lewandowski (1992), Craft (1993)</p>	<p>No conclusive evidence to support restricting visiting.</p> <p>Suggests that majority of children should be allowed to visit if they wish, but with involvement of parents and adequate/age appropriate preparation and support during and after visit.</p> <p>Some evidence to restrict very young (under 9 months) due to establishment of humoral immunity and so possible increased risk of nosocomial infections. _ Needs to be discussed with experts.</p> <p>Need to establish whether infectious disease screening could protect patients vulnerable to infections (such as neutropenic patients) – and whether should</p>



				<p>children need information. However Titter et al (91) some spouses felt helpless in knowing how to communicate with their children in these situations – many parents believed their children too young and attempted to protect them from anxiety inducing information – but the children seemed to have some understanding. Lewandowski (92) warns that children may not ask questions for fear of unsettling the parent etc. Baker et al (1988) patient and spouse may be overwhelmed with life threatening event and so may not consider how crisis may affect the children. Craft (93) when parents unable to meet the informational needs then nurse must intervene directly. Shonkwiler (1985) warns that child’s imagination can create unrealistic fantasies which may be more overwhelming than seeing the sick relative. Discuss different approaches employed by other studies including facilitated visits.</p> <p>Is it a good thing? – Predominantly relates to visiting in paediatric areas.</p>	<p>only be restricted to children.</p> <p>Nurses must recognize that children are affected by admission of relatives and have a right to receive information. Those parents may not always be aware of their child needs and may need support themselves.</p> <p>Nurses need appropriate knowledge – training in child development – major concerns, considerations, needs.</p> <p>Suggests simple statement</p> <p>“Children may visit the ICU. However, to ensure that this is beneficial to the patient and the child, it is advisable to discuss this with the nursing staff caring for your relative before any visit”.</p>
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				<p>Nicholson et al (93) small sample size, but children prepared for and allowed to visit had fewer self-perceived negative changes in behavior and emotions than in the control group.</p> <p>Risk of infection – predominate literature related to visits to paediatric or neonatal areas. No evidence to show increased risk. This included when open visiting introduced. Discusses adult ICU areas which have screening prior to visits (Nicolson et al, 1993).</p>	
<p>Clarke, 2000, England UK</p>	<p>Exploratory pilot study.</p> <p>Qualitative research approach – in-depth focused interviews.</p> <p>Thematic content analysis used.</p> <p>Aim to examine</p>	<p>12 trained nurses who worked on adult ICU in a District General Hospital.</p>		<p>4 categories –</p> <p>Bending the Rules (inconsistencies between official and unofficial visiting policies).</p> <p>Building a Rapport (child visitation appeared to depend upon the nurse’s ability to establish a rapport with adult and child involved).</p> <p>Protecting and Shielding (desire of well family members to protect and shield the child from the ICU environment, nurses</p>	<p>Implications for practice –</p> <p>Explore and challenge beliefs and attitudes of nursing staff before trying to change practice/policy.</p> <p>Provide education and training on how to communicate with children based on growth and developmental theories,</p> <p>Collaborative team approach – communicate and proactively seek assistance from Pediatric</p>

	<p>and describe the experiences and perceptions of trained nurses towards children visiting adult ICU.</p> <p>Purposive sampling.</p>			<p>desire to protect the patient, attempt by nurse to protect themselves from additional emotional trauma, protect patient and child from risk of infection.</p> <p>Coping and Collaboration (personal experiences – nurses, parents and child’s ability to cope.</p>	<p>Unit, Chaplains and Social Workers to develop protocol</p> <p>Information from different sources of expertise should be made available on the ICU.</p> <p>Research –</p> <p>Concept of family-centered care in the UK needs defining and development within the adult ICU.</p> <p>Comparative study of the nurses and parents perceptions and experiences towards children visiting ICU using qualitative research approach</p>
Pengelly, 2000, UK	<p>Commentary to Clarke 2000 (above)</p>			<p>Importance of taking well child’s needs into consideration when visiting a sick adult not fully recognized. Discusses Plowright (1996) and Craft et al (1993).</p> <p>Noted interesting that although large amount of evidence regarding children’s understanding, myths concerning needs persist – need to protect from difficult</p>	<p>Needs more research.</p> <p>Identifies lack of collaboration between nurses - adult nurses did not think to get advice from those who work with children.</p>

				situations.	
Granaas-Elmiger, 2000, Austria  Required translation	Case studies	Psychologist – hospice  2 cases detailing children wanting to visit 1 - neighbour and 2 - grandfather.		Suggests own insecurities about illness and death responsible for parents being over protective – children notice when parents deal with a grave problem, feelings of parents change suddenly, parents hide things from them.  Provides strategies for the care team – individual information using books, etc., direct individual advice for the children with the help of parents, help support the parents, encourage children to show emotions, recognize emotions.	Strategies to be tailored to the age of the children and in agreement with the parents and patients.  Marginalization of ill or dying people in society should not happen.
Clarke and Harrison, 2001, England UK	Literature review – needs of children visiting on adult ICU  English language studies.  Literature supports children visiting	.			Implications for practice –  Explore and challenge previously held beliefs, attitudes and assumptions towards children visiting this environment.  Provide education and training about how to communicate with children.  Develop and test planned

	critically ill family members in ICU and identifies it as a positive intervention to help them to cope. Important to talk to them based on growth and developmental theories.				<p>systematic support for children visiting.</p> <p>Evaluate short and long term effects.</p> <p>Consider each child individually as part of a family group.</p> <p>Develop and test specific written information for well family members – involve other experts.</p> <p>Proactively seek the assistance of the Child Health Team to develop resources.</p> <p>Consider child friendly facilities – allow play, homework, etc.</p> <p>Information video.</p> <p>Research –</p> <p>Action research could be used to plan, implement and evaluate facilitated support for children visiting an adult ICU.</p>
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Winch, 2001, USA	Discussion paper	Pediatric Clinical Nurse Specialist in a children's hospital within a hospital	<p>Discusses Craft and Wyatt (1986) study on siblings of hospitalized children. Categorized into 4 areas – 1) what is wrong? Is my brother/sister going to die? Is he/she going to get better? 2) Is it my fault? 3) Could it happen to me too? 4) Don't you care about me? Links that these same concerns may occur if parent is ill.</p> <p>Additional stresses of family illness – competing role demands may lead to reduced availability or attentiveness to the children in the family. Parental distress may be overwhelming and consuming that</p>	<p>She is often consulted by nurses working with adults concerned about how to talk with children regarding illness and treatment of relative. Also gets questions from the community – friends, neighbours, teachers, church members, parents.</p> <p>Pediatric nurses can be instrumental in helping colleagues recognize the potential benefits of children visiting an ill parent or relative in the hospital or ICU.</p> <p>Knowledge valuable in the development of guidelines and positive involvement of nurses and families in preparing children.</p> <p>Visits allow discussion in relation to child's fears and misconceptions.</p> <p>Should never be coerced to visit.</p> <p>Benefit the nurse by providing opportunities for assessment and recognition of the patient's role in the family.</p>	<p>Practice- Research -</p> <p>Further study to identify which children are most at risk and what interventions are most effective for children dealing with the illness of a parent or other adult family member.</p> <p>What happens to children who are acting as carers at home?</p> <p>More resources and understanding of how children are affected.</p>
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			<p>parents are unable to reassure their children or respond to their needs. Feelings of helplessness and depression may undermine parent's confidence. Coping ranges from denial of the child's needs (he's too young) to guilt and sadness. Tired are less likely to be patient, understanding or willing to try to communicate.</p> <p>Discusses a case involving a mother of 3 with breast cancer and the differing needs of each child.</p>	<p>Important to prepare the parent or relative – bed position, privacy, familiar objects.</p> <p>Well family members need to be prepared – expected behaviours, nurse's role, and time frame.</p> <p>Nurse's presence supports the patient and family. Active participation can help the nurses to assess family strengths, roles and coping strategies – can be used to individualize care. Can help with questions about equipment, etc.</p> <p>Also teach the family techniques for reducing post visit stress – discuss visit, talk about feelings, prepare adults for possible questions, behaviours which may indicate stress or adjustment difficulties.</p>	
Macpherson and Cooke,	Pilot study of a workbook for children visiting	13 children recruited in 26 months – 7 were eligible, 5 withdrew at	Workbook designed to allow the child to start drawing or	All the children enjoyed having the workbook. Used it in different ways and at different times/places.	Need an individual approach in practice.

<p>2003, Scotland UK</p>	<p>a relative in a hospice.</p> <p>Short informal face-to face interviews with each child.</p> <p>Semi-structured face-to-face interviews with 6 parents.</p> <p>Telephone interviews held with the nurse who spent time with the children completing the workbook</p>	<p>discharge or death and 1 consent form was missing.</p> <p>Aged 5 – 12 years.</p>	<p>writing about themselves and those people special to them, then the environment and the people working in the hospice, then draw themselves with happy, sad, angry and frightened expressions - encourage exploration of feelings and reactions to the experience</p>	<p>Nurses and parents predominantly thought it was a good idea.</p> <p>It allowed the children to be more involved in their visits and appeared to encourage them to express their feelings.</p> <p>Helped the nurses and parents respond to questions or start discussion.</p>	
<p>Knutsson, Otterberg and Bergbom, 2004, Sweden</p>	<p>Multi-centre descriptive study.</p> <p>Quantitative.</p> <p>Survey Swedish</p>	<p>All general adult ICU's in Sweden invited to take part – 72.</p> <p>64 (89%) accepted.</p> <p>56 responded.</p>		<p>39 (70%) claimed to have unrestricted visiting hours.</p> <p>17 (30%) claimed to have restricted visiting hours on an individual basis.</p> <p>16 (28%) applied verbal</p>	<p>If parents ask for advice staff must be able to support and guide them with experience, information and knowledge based upon research and evidence</p> <p>Further research needed</p>



	<p>ICU's policies, guidelines or recommendations about children visiting, examine the reasons given for and against restricting child visits' if parents sought advice in relation to children visiting and if there were any differences in demographic data.</p> <p>Invitations were sent out to Lead Nurse Managers – asked to complete a questionnaire (20 questions based upon findings and</p>			<p>policies/guidelines concerning children visits. 39 (70%) had no form of policies/guidelines.</p> <p>7 (12%) stated that all information given before, after and when the child was on the ICU was important – included explanation of the technical equipment, the environment, the patient's condition, appearance, ability to speak listen and comprehend. Back-up support when answering children's questions was included in some guidelines. Also mentioned were taking care of and interacting with the child, being able to play games, draw or watch videos. 1 (2%) stated that all child visitors were contacted by an almoner/hospital social worker.</p> <p>8 (14%) reported that it was up to the family to decide whether a child should visit.</p> <p>16 (29%) reported that allowing a child to visit must be judged on an individual basis.</p>	<p>concerning children. parents/guardians and patients experience of child visits to ICU</p>
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	<p>discussions from previous research and the authors own experience). Then contacted by telephone.</p> <p>SPSS was used for data analysis. Descriptive statistics data used to chart and illustrate results. Chi-square test and Fishers' Exact test used for comparisons between hospitals and geographical areas. Comments and open questions were analyzed</p>			<p>29 (52%) stated that written guidelines and specific visiting procedures for children were not necessary.</p> <p>The number of children visiting could not be confirmed – no records kept.</p> <p>18 (32%) reported that in taking the decision of whether to allow a visit the following issues were of determinative importance – the child's relationship to the patient, the patient's condition, the age of the child.</p> <p>Reasons for restrictions –</p> <p>Infection risk for patient and child, the patient's condition, the environment could be frightening, the age of the child, the child's relationship to the patient, children are too noisy and uncontrolled for the patient's wellbeing.</p> <p>40 (71%) the younger the child the more parents/guardians sought advice.</p> <p>No significant differences found in visiting hours and policies/guidelines in</p>	
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	using categories recommended by Polit at al (2001).			relation to the type of hospital or location.	
Vint (a), 2005, UK	Postal survey aiming to identify how many ICU's had a policy on children visiting, determine what information visitors receive on children who wish to visit, what resources are available to help the nurse support the child, what educational support is provided to the nurse, what restrictions may still be imposed	<p>90 UK adult general and cardiothoracic ICU's.</p> <p>15 were found to admit both adult and children – primarily these that are reported (had been initially excluded due to influence of pediatric training).</p> <p>Senior clinical ICU nurse/lead nurse invited to respond.</p> <p>67 (74%) replied including the pilot group of 6.</p>		<p>3 (20%) had a resource folder/information for staff. Of the 12 that didn't 9 (75%) felt they would benefit from one.</p> <p>14 out of 15 had an RN (Child)/RSCN available to provide advice and support.</p> <p>6 (40%) stated that over past 1 year a decision has been made by a child's well parent or carer for them not to visit – reasons given child (5/7 years old) would not handle the emotions/needed protecting, concern about disruption (3 year old), admission had been sudden, it was an infection risk.</p> <p>7 (47%) reported that this decision had not been taken.</p> <p>3 (20%) were aware of a decision by a member of staff not to allow a child to visit, 10 (67%) were not, 1 did not know</p>	<p>Implications for practice –</p> <p>Policies regarding children visiting should be evidence based.</p> <p>An opening for discussion regarding the impact of the admission on a child or any wish to visit by an ICU nurse may be beneficial.</p> <p>Need to question whether a child is at significant risk of infection Restrict any visitor who has a communicable disease. Provide information leaflets to highlight infection risks to visitors.</p> <p>Explore whether there is any correlation between the increased provision for nurse education and resources, written visitor information and play materials to</p>

	<p>on children and by whom.</p> <p>Open and closed questions, but primarily focused on quantifiable data – numerical data conducive to descriptive statistical analysis.</p> <p>Content validity assessed by peer panel of critical care lecturers. Revised version piloted for reliability.</p>			<p>and 1 did not respond. 2 indicated that it was the nurse-in-charge of the shift who most frequently made the decision. 1 stated that it was the Clinical Nurse Manager. Most common reasons given were the risk of infection to the patient or the child,</p> <p>6 (40%) thought it should be the well parent/guardian and child who should ultimately make the decision regarding visiting. 1 (7%) thought the nurse-in-charge, 5 (33%) the well parent/guardian, 2 MDT approach, 1 declined to answer. Within adult ICU 21 (47%) thought the well parent/guardian and child should decide.</p> <p>9 (60%) had no play area/play box. 6 (40%) did.</p> <p>7 (47%) thought that those under 6 months were most at risk of infection. 24 (52%) of the adult ICU's also answered under 6 months.</p>	<p>the apparent reduction in frequency of parent/carer decisions not to allow a child to visit in comparison to the adult only ICU.</p> <p>Provision of informational resources for staff and development of specific written information for the well parent/carer and children.</p> <p>Collaboration with other nursing colleagues specialized in care of children, and other professionals such as play therapists.</p> <p>Provision of toys, colourful displays, children's books in waiting area.</p> <p>Structured facilitation, supervision and emotional support before, during and after visits by children could be developed.</p>
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				<p>3 (20%) of adult ICU provided specific education.</p> <p>None of the mixed ICU's had policy on children visiting either a child or adult. 5 (11%) of the adult ICU's had a policy – 4 clarified that it was not a written policy.</p> <p>14 (93%) provided written information for visitors. Of those 7 (50%) included referring to children visiting. Of the 43 (93%) adult only ICU's that provided written information 13 (30%) referred to children.</p>	<p>Research –</p> <p>Short and long term effects of visiting.</p> <p>Benefits or harms to the critically ill adults in seeing children or grandchildren.</p>
Vint (b), 2005, UK	<p>Positivist paradigm.</p> <p>Survey design.</p> <p>Postal quantitative questionnaires.</p> <p>As above.</p>	<p>Specialist liver and neuro ICU's were excluded. Also excluded were those ICU's that admitted children and high dependency patents.</p> <p>90 adult general and cardiothoracic ICU's were identified and invited to participate as</p>		<p>3 (7%) had a resource folder/information pertaining to children and their needs when visiting. Of the 43 that did not, 32 (70%) felt that there unit would benefit from one.</p> <p>23 (50%) had an RN (Child)/RSCN available to provide advice or support. Of the 19 that did not 10 (53%) felt that their unit would benefit from one.</p> <p>28 (61%) stated that over the last year a decision had been made by a child's well</p>	<p>Nurses need to challenge previously held assumptions, discuss and reflect on current practice.</p> <p>Development of evidence based policies.</p> <p>Provide information for staff and specific information for the well parent/carer and children.</p> <p>Provision of toys, books, colourful</p>

		<p>above.</p> <p>67 (74%) replied. 46 were adult only.</p>		<p>parent/carer for them not to visit. 8 (17%) indicated that they had not made this decision, 9 (20%) did not know and 1 declined to answer.</p> <p>Reasons given for stopping a visit were – it would be too upsetting for the child, the child would not cope, the child would not wish to see their loved one due to disfigurement, the child would be too young to understand, there would be an infection risk to the patient or the child, it would be better to wait for the patient to recover or for the child to remember them from before the admission, they would want to wait for the patient to give permission, the child was involved in the decision.</p> <p>10 (22%) were aware of a decision by a member of staff not to allow a visit. 6 indicated it was the nurse in charge of the shift – reasons given were infection risk to the child or patient, it would be too unsettling for the child, the turnover on the unit was too high, it was not appropriate, policy did not support it.</p>	<p>displays and appropriate informational resources in a waiting room.</p> <p>Collaboration with other nursing colleagues specialized in the care of children – facilitating visits and act as resource. Same with play therapists etc.</p> <p>Qualitative comparative study on how collaboration with children's nurse to facilitate visits to act as resource is perceived by the specialist nurse, ICU nurse and child/family.</p> <p>Structured facilitation, supervision and emotional support before, during and after visits could be developed through further research.</p> <p>Exploration of the short and long term effects of visiting could be</p>
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				<p>21 (47%) thought it should ultimately be the well parent/carer and child who make the decision about visiting.</p> <p>34 (74%) did not have play area or box for children.</p> <p>24 (52%) considered under 6 months of age to be most at risk of infection. 16 (35%) thought it should be between 6-24 months. 9 responded no risk at any age, 4 responded 2-8 years.</p> <p>45 (98%) nursing staff received no education on the support of children. 1 declined to answer.</p> <p>39 (85%) did not have a policy on children visiting, 5 (11%) did (4 clarified that it was not written) and 2 (4%) did not respond.</p> <p>43 (93%) provided written information for visitors – 13 (30%) of these made reference to children, 2 of which advised a minimum age of 14 years.</p>	<p>researched.</p> <p>Other research could include the benefits (or not) to the critically ill adult of seeing the child.</p>
Forrest,	Question paper	37 mothers with newly	Mothers – semi	Children learnt about cancer from the	

<p>Plumb, Ziebland, et al, 2007, UK</p>	<p>relating to a qualitative study.</p>	<p>diagnosed stage I-IIIa breast cancer and 31 of their children (6-18 years).</p>	<p>structured interviews – experiences of talking with their families about illness and their perspectives of their children response to diagnosis and treatment,</p> <p>Children interviewed at home by child psychiatrist – asked about their awareness of cancer before the diagnosis, experience of the illness, diagnosis and treatment and sources of information.</p>	<p>media, direct experience of someone with cancer or from school (science)</p> <p>Some mothers believed their children knew cancer could be life threatening, whereas others were shocked when their children showed concern that they may die.</p> <p>Children often suspected something was wrong before being told due to changes in behaviour etc.,</p> <p>Children – first visited mother in hospital during early postoperative period were shocked by drowsiness or by seeing blood (sheets, drains).</p> <p>Children of different ages expressed different needs. Younger children more confused about causes of cancer, Several older children wanted more information. Most adolescents wished some websites had been recommended. Some older children wanted to speak directly to health professionals to learn more.</p>	
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<p>Perry and Goulet, 2006, Canada</p> <p>(Conference abstract)</p>	<p>Practice development</p>	<p>Intensive care unit</p>	<p>Child visitation intervention program – teddy bear therapy.</p> <p>Each child visiting parent receives a plush bear with an explanation from the nurse regarding the parent’s condition and to answer any questions from the child.</p>		
<p>Moore, 2006, UK</p>	<p>News</p>	<p>Portsmouth Hospitals Trust.</p> <p>National Patient Safety Agency – Gabrielle Teague, Head of Hand Hygiene Improvement.</p> <p>Julie Potter, Chair of Infection Control Nurses Association</p>	<p>Portsmouth Hospitals Trust drawn up contingency plans to severely restrict child visitors of patients are at risk from diarrhoea and vomiting. If outbreak in the community.</p>	<p>JP – ‘as a general rule I think banning children in times of increased risk makes sense’</p> <p>GT ‘I don’t understand the rationale of saying children represent a higher risk than adults’</p>	
<p>Ihlenfeld,</p>	<p>Discussion regarding</p>	<p>Intensive care units</p>		<p>Condition of patient is paramount. Nurse best able to determine if the patient can</p>	<p>Invites comments from others</p>

2006, USA	visitation policies			<p>see visitors.</p> <p>Use developmental guidelines to help assess and manage.</p> <p>Child should be accompanied by adult who is responsible for their behaviour.</p>	Provides guidelines for visits in table form.
Blot, Foubert, Kervarrec, Laversa, Lemens, Minet, Petetin, Raynard, Wolff, et al, 2007, France	Prospective study.	ICU, a surgery ward with 11 beds, in a cancer unit of 380 beds	<p>Opened to children (0-18 years age) visiting for 3 years. 2002 cancer ICU opened to children visiting parents. Until 2002, the visits were limited to 2h30 per day, in two periods, and children access was restricted.</p> <p>Survey of 12 ICUs - Policy initiated by psycho-oncological teams and by the group "children of the hospital" – evaluated sequentially and</p>	<p>Prior survey 12 ICUs in Paris region – visiting was restricted, children under 15 years authorised to visit regularly in 2, occasionally in 2 and never in 8. Where admitted to visit psychologist support sometimes requested, in 1 reception done with child psychologist and palliative care staff. Confirmed visiting was still restrictive</p> <p>Survey 200 – 80% staff, 62%patients and 69% families in favour of receiving visit from children in the ICU.</p> <p>The results of this survey being positive, a new policy for receiving and informing was established. Visiting times were extended for adults 15 hours per day, from 3 pm to 6 am next day. Children encouraged to visit their hospitalized</p>	<p>Further evaluation of this policy in other units.</p> <p>Limitation noted limited number of cases in one Centre. Did not prospectively analyse reasons parents refused visits, long term psychological consequences of approach not known. Did not use validated scales of anxiety or depression for parents or children surveyed.</p>
Required translation					

			<p>prospectively.</p> <p>200 responses from staff, patients and families – 50 staff members, 50 patients and 100 relatives.</p> <p>Policy established and</p> <p>new survey 2 years later of the staff</p> <p>During 12 months 52 children visited 26 parents</p>	<p>parents as often as possible according to 5 phases.</p> <p>The children were very often, only received by a physician and a nurse of the unit. Proposed to the child and the accompanying parent to take part to the monthly group of children created by the unit of psychologists of the hospital.</p> <p>Assessment after 2 years – 16/21 nurses, 6 caretakers, 6/7 physicians answered second survey. Large majority confirmed ready to receive children and to explain care to them.</p> <p>7/27 nurses considered should be restricted to 1 year old.</p> <p>During 12 months 52 children visited 26 parents. Age of parents 39-53 years, duration of disease 2-12 months, 31% mechanical ventilation, 27% sedation or coma, Opinions of visits by children – 64% positive, 8% negative, 28% not evaluated, 31% died in ICU, 425 died in hospital.</p>	
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				<p>Children age 4012 years, 56%child, 38% grandchild, 6% other.52% prior visit, Visit proposed by child 20, patient 13, accompanying parent 27 staff 17.</p> <p>51 welcomed by nurse, 29 by physician. 77% in dedicated room, preparation time 10-18 minutes. Immediate reactions – emotional 14, behavior 3 hyperactive, 28 moderately active, 7 silent, 44 liked visit 2 disliked visits. General conclusion of accompanying parent positive in 43, no opinion 9, staff 48 positive 1 negative, 3 no opinion.</p>	
<p>Knutsson and Bergbom (a), 2007, Sweden</p>	<p>Quantitative, descriptive multicentre study design.</p> <p>Postal questionnaires – designed by the investigator based on previous findings and</p>	<p>All 72 adult general ICU's in Sweden were invited to participate.</p> <p>3 nurses and 3 physicians selected from each unit.</p> <p>64 (89%) of the ICU's agreed to participate. 57 (89%) completed the questionnaire. Possible 384 respondents, 291</p>		<p>The majority thought that children should visit.</p> <p>256 (88%) respondents still restrict children visiting (nurses = 149 or 92%, physicians = 107 or 82%).</p> <p>All commented that children should be assessed on an individual basis, no fixed rules or principles.</p> <p>Physicians reported that children &lt;12</p>	<p>Attitudes to visiting children need to be discussed among members of ICU teams.</p> <p>Nurses/physicians could initiate children visiting.</p> <p>Further replicate and qualitative studies conducted in other countries to describe nurses and physicians considerations in this issue.</p>

	<p>research.</p> <p>The questions concerned – reasons for restricting or not restricting children visiting, opinions and considerations regarding the child’s age and relationship to the patient, children visiting in relation to the patient’s condition and specific information given.</p> <p>Pilot study was conducted to evaluate the clarity of the questionnaire, ease of</p>	<p>(76%) completed (161 nurses and 130 physicians).</p>		<p>years should not visit more than nurse.</p> <p>10% respondents uncertain about whether children &lt;7 years should visit.</p> <p>Approximately half respondents thought the environment and patient’s condition could frighten children. 88 (85%) their opinion was that children were at risk of psychological trauma if they were allowed to visit. 14% physicians and 9% nurse had the opposite opinion.</p> <p>Significantly more (<math>p&lt;0.05</math>) physicians reported that they had refused to allow children to visit because they thought they would be too noisy for staff to cope with.</p> <p>Physicians more positive to a child visiting friends and cousins than nurses.</p> <p>Respondents more positive to allowing children &gt;7 years to visit than &lt;7 years especially when the patient is dying or unconscious.</p> <p>Significantly more physicians would</p>	<p>Qualitative research concerning children’s perceptions and experiences</p> <p>More research on short and long term effects on children or visit and on patient’s experiences.</p>
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	<p>response and feasibility of data collection - 3 general ICU's.</p> <p>Final questionnaire consisted of 10 close-ended questions and 2 open-ended questions.</p> <p>Data described and analyzed using SPSS. Chi-square test and Fishers exact test were used for comparisons between nurses and physicians.</p>			<p>allow child &lt;13 years to visit a patient who was severely injured than the nurses.</p> <p>190 (60%) of respondents thought that children should be allowed to visit regardless of the patient's condition or appearance (103 or 65% nurses, 87 or 67% physicians).</p> <p>40 (14%) respondents specified additional reasons for restricting visits – the desire of the patient not to receive visits, the patient and/or family did not want the child to visit due to their desire to protect the child, there is no family member able to respond to the needs of the child.</p> <p>All the nurses wrote comments – 9 of the physicians did not comment at all.</p> <p>Comments –</p> <p>Important that children understand what had happened and experience reality rather than be left to their own imagination, feeling involved and not</p>	
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				<p>excluded could help the child to understand other family members reactions, children have the same needs as adults, there were things which could frighten children such as machines and sounds – this was dependent on the age and individual child, they thought children could experience nightmares, stress, anxiety and anguish if the visit was traumatic – could be avoided if the child was prepared, patient and/or family should make the decision about visiting.</p> <p>Some respondents thought that older colleagues restricted more often because they thought children were too noisy and could be a danger.</p> <p>Infection risk for patient and child was another reason given for restricting – some staff used this because of their own fears, insecurity and unwillingness to act.</p>	
Knutsson and Bergbom (b), 2007,	Descriptive study design based on questionnaire –	5 general ICU's across Sweden – 1 University hospital, 2 county hospitals and 2 district		<p>20 (67%) custodians had asked the child about wanting to visit.</p> <p>9 (30%) reported that the child had</p>	<p>Implications for practice –</p> <p>Nurses need to take more initiative when discussing children</p>

Sweden	<p>one of several studies in a research programme.</p> <p>Invitations addressed to lead nurse managers who decided on and signed for the ICU's participation.</p> <p>LNM asked to inform nurses and encourage them to invite custodians whose child had visited patient to participate.</p> <p>Custodian was called and invited to participate – questionnaire</p>	<p>hospitals.</p> <p>30 custodians invited over 1 year and 2 months.</p> <p>20 regional hospital, 5 county and 5 at district hospital.</p> <p>30 custodians with a total of 54 children aged between 4 months and 17 years who visited and 10 children who did not.</p> <p>7 (23%) custodians reported that not all children in the family visited. 2 (7%) youngest child and 3 (10%) oldest child. 2 (7%) did not report which child did not visit.</p> <p>8 (27%) patient was in own room. 20 (67%)</p>		<p>initiated the visit.</p> <p>2 children did not want to visit but were forced to – 1 by sister and 1 by parent.</p> <p>Custodians felt that the children showed many different reactions – ranging from happiness to fear or no reaction. The 2 children who did not want to visit were reported to have been frightened on seeing the patient and the ICU equipment.</p> <p>28 answered question about the child's reaction to the whole ICU visit – 27 thought it was a good and positive experience. Some reported that the child felt happy and proud at being able to visit. Also reported to be educational as it resulted in an increased awareness of the patient's condition, their need for help/recovery, appreciation of the staff and their work and increased curiosity/interest.</p> <p>Some children became calm by kissing and hugging the patient – others behaved as they normally would – did</p>	<p>visits with custodians.</p> <p>Incorporate information about children visiting in patient's notes.</p> <p>Develop pre-strategies, strategies during visits and follow-up strategies.</p> <p>Research –</p> <p>Need qualitative studies that reflect the complexity of the issue. Further studies on children's, custodians and staff perceptions, experiences and opinions.</p> <p>Intervention studies on facilitating children visiting.</p> <p>Views/considerations of custodians who do not bring children to visit.</p> <p>Short and long term effects on children of the visits.</p> <p>What patients experience and</p>
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	<p>was then sent.</p> <p>Investigator developed questionnaire – designed to provide information and answers to questions about custodian’s viewpoints and experiences and some demographic data – based on findings and discussions from previous research and experience.</p> <p>Pilot study was conducted – 6 custodians (were included</p>	<p>patient was in room with other patients.</p> <p>At the time of completion of the questionnaires – 4 patients had died and 26 were still severely ill or injured.</p>		<p>not seem to be influenced by the situation/environment. Others reported that the child became shy of the patient, was calm, quiet, tense, bored, horrified and bothered. Some cried. Some reported that the impersonal unreal environment was frightening. Some reported that the child was frightened at first and then became curious.</p> <p>5 (17%) child’s greatest interest was the patient. 15 (50%) both patient and ICU equipment. 2 (7%) child was more interested in the toys than the patient. Other 8 reported that the child sat by the bed or on someone’s knee and talked, sang to the patient. Some wanted to be close to the patient and sit on the bed.</p> <p>Children &lt;10 years more curious about the equipment than the older children who were more interested in the patient.</p> <p>1 (4%) reported that the children were not informed by him during the visit because he felt the information from the staff was good, sufficient and</p>	<p>want in relation to children’s visits.</p>
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	<p>in the main study). 4 new questions were formulated during the pilot; the new questionnaire was then tested and retested by 6 new custodians.</p> <p>The questionnaire was completed retrospectively 2-4 weeks after the child's visit.</p> <p>Statistical packages were used for data analysis. Descriptive statistics were used.</p> <p>Comments and</p>			<p>satisfactory.</p> <p>Where information was given to the child (20 cases) 15 (75%) of custodians thought the quality was good, 3 (15%) satisfactory and 2 (10%) poor.</p> <p>24 answered question about staff attitude – most reported that the staff were nice, fantastic, wonderful, very good and that they had warm, positive friendly attitude. A few reported that staff did not pay attention to the child. 1 thought that the staff did not want the child in the room.</p> <p>23 (77%) were of the opinion that visiting is not a risk to future health and well-being.</p> <p>5 (17%) thought there was risk that the child could be frightened and worried if not given explanation and support.</p> <p>20 thought that stopping the child from visiting may be a risk to future health and wellbeing – unanswered questions, guilt,</p>	
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	answers were gathered together.			anxiety, anger , not included, forgotten. Found to be important that the child had an opportunity to choose whether to visit.	
Knutsson and Bergbom (c), 2007, Sweden	Condensed article reporting research above.				
Knutsson, Samuelsson, Hellstrom and Bergbom, 2007, Sweden	Gadamer's hermeneutic philosophy used to interpret and analyze the data.  Aim to describe children experiences of visiting a seriously ill/injured relative in ICU.  Theoretical framework –	29 children were invited to take part (15 girls, 14 boys). Aged 4 -17 years (average age 9.5). Differing relationships with the patient. 1 declined.  None had visited an adult ICU before.  4 general ICU's at different hospitals.		Four themes generated <ul style="list-style-type: none"> <li>▪ It meant waiting – had to wait to enter the ward, wait in the waiting room, had to wait their turn if there were a number of visitors., wait for information, wait for the relative to get well again. Waiting was difficult, they had nothing to do.</li> <li>▪ It was strange – patient's appearance was strange and changed which some children found frightening/repulsive, patient behaved in a confused way which made them realize that they were seriously ill, but patient looked better than they had imagined. The environment</li> </ul>	Nurses could avoid waiting times.  Make the rooms less white.  Nurses could explain what the equipment if for  Research –  Experiences before, during and after a visit by interviewing the children directly after the visit and by conducting follow-up interviews over a longer period of time.  Children who are not allowed to

	<p>humanistic perspective.</p> <p>Interviews carried out within 3 months of the visit at the child's home. If the child wished to draw what he/she saw and experienced they could – the picture was then the starting point for the interviewer's questions. 5 of the younger children did this.</p> <p>Sample size aim was 20, but not enough children visited.</p>			<p>was also strange, some children did not dare to approach, and a few felt the machines were frightening but the majority did not, some thought the machines were interesting. The patient was perceived to be dependent upon the technology, wondered what would happen if there was a power cut. Some were afraid that the ECG would show a straight line, they had seen this on TV and it meant that the person had died. Many children did not care about the strangeness – they wanted to touch and talk to the relative. Life was strange – talking to someone who was asleep, the relative was alone.</p> <ul style="list-style-type: none"> <li>▪ It was white – felt that everything in the patient's room was white which was perceived as gloomy. The light was disturbing and they did not feel that there was enough light. White represented an impersonal state, lacking pleasure and life, some form of sorrow, was a reflection of separation</li> <li>▪ It was good – it felt good to have</li> </ul>	<p>visit.</p> <p>Intervention studies about facilitated visits.</p>
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				<p>the opportunity to see how the relative was and that they were still alive, wanted to tell the patient things and to touch them. They were not excluded and could show the relative that they cared.</p>	
<p>Staines, 2007, UK</p>	<p>Report on Knuttson and Bergbom 2007</p>			<p>Tracy Pilcher Chair of BACCN – she had never said a child could not visit – it is about preparing them appropriately – most adapt to the environment and are not concerned by the technology – important for them to understand the patient’s condition,</p> <p>Mandy Odell Nurses Consultant – “the evidence may not be there but children are more likely to have picked things up from school”</p>	
<p>Anzoletti, et al, 2008, North East Italy</p>	<p>Survey – descriptive and analytical goals</p>	<p>110 ICU’s contacted – 104 completed the questionnaire (94.5%).</p> <p>23 cardiological</p> <p>15 specialist (heart surgery, neurosurgery,</p>		<p>Under 12 allowed to visit 22%</p> <p>Under 12 not allowed 78%.</p> <p>More often permitted when the total visiting time was more than 4 hours and when more than one person allowed at the same time,</p>	

		transplantation). 12paediatric/neonatal. 71% city hospitals 27% university hospitals 2% private clinics.		Paediatric ICU's refused access in 64% of cases.	
Hanley, 2008, USA	Conference abstract	Neuro ICU	Introduction of workbook for children visiting.		
Kean, 2009, UK	Constructivist grounded theory  <i>Same study as next article by same author (Kean, 2010) – focus on how children accessed information whilst patient in ICU.</i>	9 family interviews – 12 adults and 12 children/young people.  Family member in ICU.	See other section	Themes –  Adults controlling information  Keeping normality in life  Fishing for information  Themes directly from issues of clinical and functional uncertainty.  Controlling information was by parents to protect and reassure their child. Protecting their child viewed by parents as their responsibility – achieved by	Strategies used by children were influenced by their generational position.  Adults were gatekeepers to the information – influenced by their perception of children.  Children actively constructed and co-constructed their own experiences – were not passive.  Power asymmetries in families formed the context where children

				<p>managing information flow and gradually building it up – content, timing, way it was relayed and who by.</p> <p>Some parents included the children from the beginning and others took charge, Former group decided with their children if they wanted to go with then to the ICU and the latter decided for the children. Children visiting have the opportunity to talk to healthcare staff and so were in control of their own information needs. In cases where parents made the decisions – a dependency on the parent for information emerged.</p> <p>Keeping normality – from the children this is a way of managing the stress of uncertainty. Describes how children actively constructed their experiences – school life, going to school. Better to go to school than sit at home waiting, Extensive discussion about social networks and whether attended school or not and whose decision – related to power asymmetries.</p>	<p>developed their strategies to access information.</p> <p>Relevance for practice – parents and nurses need to be open and honest with children of all ages – reflect their ability and right to participate.</p> <p>Developing information resources for children may help nurses and parents support them.</p>
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				<p>Fishing for information –</p> <p>Being present – strategy employed by children acting in own interest and needs. Accounts from children suggested 3 aims – access to information, support of the ill relative, supporting the well parent. Being with an adult family member during a conversation when nurses spoke about the patient – but children find themselves as ‘silent listeners’ – there but the conversation does not include them. Need to support family members was revealed by a number of children.</p> <p>Direct and indirect questioning – evident in families where younger children did not have opportunity to be in conversation between parent and staff. Indirect used then direct if got no answer.</p>	
Bates, 2010, UK	Opinion	Recalls friends visit to casualty department	2 mothers there with 3 children under school age. Did not seem aware of surroundings.	Recalls stringent visiting rules – no children under 12 allowed in and older children were permitted a short visit only	Nurses need the authority to regulate visiting for children.



			<p>Mothers ignored children's play area and let them 'run riot' throwing food around the waiting area. One put child's food onto the floor.</p> <p>Now in some hospitals children are allowed to visit and nurses who comment are liable to be treated to mouthful of abuse</p>		
Vandijck, et al, 2010, Belgium	Descriptive multicenter questionnaire survey – prospective.	76 ICU's contacted and 57 ICU's completed questionnaire (75%)		<p>Children not allowed in 5 (8.8%)</p> <p>46 had fixed age limit.</p> <p>No age limitation in 9 centres (15.8%).</p> <p>Fixed minimum age in 46 (80.7%).</p> <p>8 and over n=4</p> <p>10 and over n = 1</p>	

				12 and over n = 27 14 and over n = 14 16 and over n = 2	
Kean, 2010, UK	<p>Constructivist grounded theory approach.</p> <p>Aim to explore families' experiences with critical illness in ICU and nurses perceptions of families.</p> <p>9 families interviewed.</p> <p>2 phases – family group interviews and focus groups with nurses.</p> <p>Theoretical sampling</p>	<p>9 families (12 adults from 35 to 55 years and 12 children 8-14 years, young people 14-25 years).</p> <p>English speaking.</p> <p>1 adult family member had spent at least 3 days in ICU and was stable at the time of interview.</p> <p>Families of unstable or dying patients were excluded as were distressed families.</p> <p>In 6 families the husband and father was the patient. In 3 adult son and brother</p>		<p>The way the different age groups discussed their experiences suggested 2 different levels of understanding. Children spoke about ICU on a concrete level and focused on the environment. Young people understood their experiences on an abstract level and focused on the function of ICU.</p>	<p>Focus on the development of appropriate information material for families and children.</p> <p>Intervention studies reflecting on perspectives of children and young people , parents and ICU nurses to develop material that supports the information needs across ages and enables parents and nurses to support children and young people</p> <p>Nurses need education in listening skills and understanding children and young people's needs when an adult family member is in ICU.</p>

	<p>involving simultaneous collection and analysis of data was employed,</p> <p>Interviews were recorded, transcribed verbatim and saved as rich text. Constant comparative data analysis used. Moved from open to focused coding. Used NVIVO 2.</p>	was the patient.			
Bruck, 2011, USA	Tips for families	For ICU visits – written for family members (parents)	Top 10 tips detailed for parents of children		<ol style="list-style-type: none"> <li>1. Check rules</li> <li>2. Time visits</li> <li>3. Short visits</li> <li>4. Prepare the child</li> <li>5. Follow-up after visit</li> <li>6. Ask for Child Life Specialist</li> <li>7. Give child a choice</li> </ol>

					<p>8. Ask about family support programs</p> <p>9. Use IT</p> <p>10. Respect other patients</p>
<p>Christensen, 2011, Denmark</p> <p>(Abstract)</p>	<p>Case description of 8 year old girl visiting father on ICU</p>	<p>Intensive care units</p>		<p>Theoretical perspective on the case – Jean Piaget development theory.</p> <p>The visit evokes different feelings in the children.</p> <p>Preparation before and after is beneficial.</p> <p>Child depends upon concrete actions to make logical conclusions.</p>	<p>Verbal explanations not sufficient to increase the child's understanding.</p> <p>The nurse must take starting point in what the child already knows and help them to gain new knowledge and understanding.</p>
<p>Hanley and Piazza, 2012, USA</p>	<p>Practice change- Literature review, case study, evaluation survey of book used as a resource.</p>	<p>15 bedded neurosurgical Intensive care unit</p>	<p>Introduced open visitation policy which was positively received by staff and relatives. One restriction persisted – under 16's were allowed but continued to be discouraged.</p> <p>Tools to facilitate –</p>	<p>Reasons for discouraging –</p> <p>Staff – infection control, effects on intracranial pressures, how to talk to children, disruption on the unit.</p> <p>Family – how to prepare the child, concerns about appropriateness, worries about how to explain things some adults do not always understand – Lead to literature review.</p>	<p>Practice –</p> <p>Provide each family member the tools to cope with a loved one's serious illness or death.</p> <p>Patient and family should be partners in their care</p> <p>Research –</p> <p>Long term effects of planned</p>

	<p>2 evaluation surveys developed. 1 sought to measure staff satisfaction using a 5-point Likert scale and 6 questions. The other survey polled parents using a 5-point Likert scale and 5 questions.</p>		<p>In-servicing from child life department, overview of developmental goals, guidance on appropriate language and explanations for different aged children.</p> <p>Child life department created a resource book – covered key concepts and had recommended reading for staff, parents and children as well as interventions that could be used.</p> <p>Also book explaining the unit to kids – developed with a staff nurses. Used for families to take home prior to a visit or in the waiting room</p>	<p>Case study –</p> <p>Staff objections – risk to the patient – potential line and tube displacement, emotional upset, causing physiological changes such as vital signs instability and potential infection.</p> <p>Risk to children – acquiring infection, emotional trauma caused by what they would see, worry about how it would be handled if it did not go well.</p> <p>Also noise, running around, disruption for other patients and families.</p> <p>Uneasy about explanations they would give to children.</p> <p>Book – problems with disappearing books. Plan is to put on hospital website - available at home.</p> <p>Evaluations –</p> <p>All staff (n=20) found it to be useful – strongly agreed that it assisted them in</p>	<p>pediatric visitation and how to address family centered care partnerships consistency across disciplines.</p>
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			<p>before going in.</p>	<p>providing emotional support, aided them in answering questions and made the family more comfortable.</p> <p>The families (n=14) felt it was most helpful in preparing the child for a visit, answered their questions and that the child seemed more prepared. Agreed it allowed them to feel more comfortable bringing the child to visit and eased fears.</p> <p>Comments – also that book opened up communication between children and staff.</p>	
<p>Barchue, 2012, USA</p>	<p>Opinion paper</p>	<p>Intensive care units</p>	<p>Describes personal experience – sister had a stroke. Her son very close but was unable to visit – children not allowed in ICU.</p>	<p>Pro children visiting ICU.</p> <p>Child should want to visit, not be forced or coerced.</p> <p>Need preparing – details some actions.</p> <p>Changed practice in own ICU after own experience.</p> <p>ICU visit can be an excellent life experience</p>	

Morgan, 2012, USA	Opinion paper	Intensive care units	Presents the cons.  Cites personal experience of children clinging to their parent because a loved one was swollen and oozing blood.	Children under 12 should not be allowed or should have restricted visits.  Discusses that ITU can be intimidating to adults so impact on a child greater.  Problems – adverse physiological effects on the patient, disruption of care, increased incidence of infection and incidents caused by unsupervised children, risk of damage to equipment.  Traumatic for the child.	Current practice – under 12's only allowed to visit if a family member is at the end of life.  Should not expose them to resistant infections.  Need to know more from research
Sutter and Reid, 2012, USA	Summary of support needs of children of seriously ill adult inpatients and report on developing a child life consultation service – palliative care team.	Adult palliative medicine	Child life specialist – master's degree prepared health professional – provides developmentally driven psychosocial assessments and interventions to paediatric patients, their parents and siblings. Also facilitate communication	Interventions varied depending on the child's development level and coping style.  Overall needs assessed by talking with the patient, the partner/spouse and/or healthcare team – to determine what child already heard and how responded to the info. Previous coping style discussed and previous experiences with illness, injury or loss.  Support options chosen by family. Family's premorbid communication style	Practice –  Cross training of other staff.  Attention to environmental factors.  All hospitals should consider providing broad based in service training enabling their staff to improve the support they offer to the children of seriously ill parents,

			<p>among the patient, family and healthcare team. Child life teams have existed for more than 50 years. Interventions have been shown to decrease emotional distress, improve coping effectiveness, promote comfort, reduce sympathetic activation, improve understanding of hospitalization and procedures, speed surgical recovery and facilitate overall adjustment.</p> <p>Primary focus is acute coping with hospitalization and illness – short term aiming to assist with immediate coping mechanisms.</p>	<p>supported and not challenged.</p> <p>If child present at hospital the child life specialist met directly with them away from the patient's bedside. Used art materials, books and props such as dolls, informal assessment of each child's anticipated stress points, misunderstandings, questions and unresolved feelings were assessed – pertinent issues then communicated to parent.</p> <p>Also helped child and family to prepare for and structure visits, providing information and using activities designed to enrich understanding, promote coping and decrease stress – such as review of medical equipment, what can do (hold hands, give hug)</p> <p>Time and barriers –</p> <p>Time varied – short (30 mins) for specific request, to multiple visits for complex interventions such as withdrawal of life-</p>	<p>Research –</p> <p>Immediate and long term measures of coping, anxiety, grief and psychiatric dysfunction – especially that witness death of their parent.</p> <p>For patients and partners/family document complicated grief as well as satisfaction with hospital experience and fulfilment in their parental role.</p> <p>Comparison of the effectiveness of child life specialist consultation with structure developmentally based training of unit staff/palliative care team members.</p>
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			<p>Rarely utilized within adult palliative care.</p> <p>Offering child life specialist to families of patients with life-threatening illnesses who have children under 18. Focus on communication between parent and child, changes in parent's health and prognosis, support both before and during hospital and end of life visits.</p> <p>Interventions were directly with child or indirectly with parents/care giver, staff.</p>	<p>sustaining treatments or witnessing death in hospital.</p> <p>Patient and family factors –</p> <p>Referrals often in emotionally charged times – adults may not be emotionally ready to focus on or discuss needs of the children at the time.</p> <p>Differing cultural norms – ethnicity, national origin, family structure, faith, parenting style, generational differences, and socioeconomic status.</p> <p>Workplace –</p> <p>Difficulty incorporating into previously existing programs, difficulty accessing child life services in hospitals without pediatric programs, scarcity of funding, resistance to new role within the team or administrative pressure to incorporate support into roles of existing team</p>	
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				members.	
Falk, et al, 2012, USA	<p>Changing practice.</p> <p>Literature search – higher risk of infection from children – none.</p> <p>Inquiries with experts in the department of infectious diseases – could not provide any evidence to support this assumption.</p>	Adult inpatient lymphoma/myeloma unit in Cancer Center.	<p>Children under 12 not allowed to visit.</p> <p>Restricted due to immunosuppression of patients.</p> <p>Cite case of 33 year old patient whose children could not visit but when she was cared for on the pediatric unit (overflow) the children had unlimited visiting. Husband questioned this.</p>	<p>Formation of multi-professional action coordinating team (PACT) to develop child visitation policy.</p> <p>Extensive literature review – concentrating on infections, neutropenic patients, and stem cell transplant patients – no evidence to support restriction of children.</p> <p>Also checked all relevant guidelines – all irrespective of age. Major recommendations were to screen all visitors for combinable illness and vaccinations, all visitors to wash hands.</p> <p>Surveyed other institutions – 17 hospitals – 12 allowed children, 4 did not and 1 discouraged.</p> <p>Institutional visitation policy committee determined that the child visitation policy and guidelines amended to allow child visitation as part of the overall institutional policy on visitation.</p>	<p>Nurses should be encouraged to examine current child visitation policies and determine need for revision, elimination or creation of new policies.</p> <p>Research –</p> <p>Child visitation and related issues to generate updated evidence to support policies and practice</p>

				<p>Visitors entering directed to information desk for screening – welcome center staff member assigned to assist visitors in completing the screening documentation. Children who are cleared are required to wear a bright yellow visitor's passport and be accompanied by an adult at all times.</p>	
Rainer, 2012, USA		ICU		<p>Children under 14 years generally excluded from visiting ICU.</p> <p>Society of Critical Care Medicine in Clinical Practice Guidelines for Support of the Family on the Patient-centered Intensive Care Unit – supports child inclusion. Recommends pre-visit education to facilitate positive experience.</p> <p>No clear distinction regarding children visiting ICU during outbreaks from the CDC.</p> <p>Details implantation of policy for child visitation to cardiothoracic ICU (Fanning, 2004) – successful and extended to</p>	<p>Age appropriate training required for staff.</p> <p>Restraining and driving forces must be explored in staff meetings.</p> <p>Potential for pandemic outbreaks must be planned for to avoid disruption of family-centered care</p> <p>Colouring books and stickers should be available.</p> <p>Nurses must drive home the importance of family visitation rights and ensure positive experiences.</p>

				other ICU's at the facility.	
Pinoël, 2015, France  Required translation	Practice development	Psychologist in Neurosurgery ICU and paediatric department organized the welcoming of children visiting a parent in Neurosurgical ICU.	<p>Meeting between the psychologist and family, then second meeting with the child. Then the visit can take place. All the team involved.</p> <p>Assistant prepares patient – put at the right level.</p> <p>Nurse welcomes the child (using child's name to show is included).</p> <p>Child meets the psychologist and resuscitator. Check understanding. Then visit to the patient.</p> <p>Welcome leaflet – 2 versions. I represents</p>	In 2013 leaflet 2 <sup>nd</sup> prize in Innov's Soins. (Care Innovation)	Limited to parents. Now considering expanding to include relatives, etc.

			mum and 1 dad.		
Davis, 2015, USA	Practice development	Medical ICU	<p>Introduction of child visiting tool (booklet)</p> <p>Pre-survey.</p> <p>Social worker did literature review.</p> <p>Located a hospital development booklet online for young visitors – then created own booklet for MICU.</p>	<p>Pre survey 100 day and night MICU employees. (49 respondents). 16% felt well equipped to prepare children, 6.1% indicated adequate resources, 6.1% satisfied with resources available.</p> <p>Then 90 day post survey – (28 respondents). 21% agreed booklet helped to equip them in preparing children for MICU environment. 29% said they had adequate resources, 26% satisfied with the resources.</p> <p>8 booklets used in 3 months.</p>	
Schofield, 2016, Canada	Abstract	ICU	Resources for staff, children and families were developed to facilitate child visitation – no details provided.	Identified gaps in resources available to provide family centered care prior to withdrawal of treatment.	

# **Appendix 2**

## **MCRN YPAG Consultation Questions**

**PhD RESEARCH PROJECT**  
**CONSULTATION QUESTIONS FOR CHILDREN'S GROUP TO GUIDE**  
**RESEARCH PROJECT PLANNING**  
**JANE JERVIS, PhD Student, Keele University**

The researcher works as an Advanced Nurse Practitioner (ANP) in a large teaching hospital. This role primarily involves responsibility for the initial clinical assessment and management of adult medical patients and as a lead member of the cardiac arrest team. Ensuring that quality care is provided on the wards through education and support of both nursing and medical staff and the development of policy/procedures is essential in these roles. Regularly in practice, there are children present visiting acutely ill or dying patients. Although the majority of the patients are grandparents there are occasions where the patient is an older sibling or parent. These situations have caused considerable discussion as many nursing and medical staff are concerned that they have either very limited or no knowledge and experience of dealing with children in this type of situation. It has also been noted that there is no guidance within the hospital policy or procedures about how to support children as visitors in the adult acute medical environment who may be experiencing an extremely stressful situation due to the acute illness of their family member. In order to address this gap in our knowledge, the researcher aims to conduct an action research project within the hospital with the ultimate aim of improving the care/support provided by the hospital staff to children who visit adult relatives who are acutely unwell.

To aid planning the research project I wonder if the children's group that you work with could provide a little feedback regarding this research idea. I have put a few questions together and would be grateful if any feedback could be provided.

1. Do any of the children have experience of visiting adult relatives in hospital? If so:
  - a. Could they share some of the experiences?
  - b. What helped them when they visited the hospital?
  - c. Who helped them when they visited the hospital?
  - d. Was anything not helpful?
2. If any of the children have not experienced visiting adult relatives in hospital, what do they feel might be important? Specifically:
  - a. What do they think might help them when they visit the hospital?
  - b. Who do they think might help them when they visit the hospital?
3. What would the children suggest is required to provide support when visiting?
4. Do they have any suggestions regarding communication when visiting hospital?

Importantly, (although my aim is to be working predominantly with the hospital staff) I am interested to know whether the children think that I should:

1. Approach any children who visit an adult patient to get their feedback. If so when and how do they think that it would be appropriate to approach a child?
2. Or, alternatively, do they think it more appropriate for me to take plans, leaflets etc. to your groups and/or into schools, clubs etc.?

Jane Jervis  
PhD Student, Keele University  
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# **Appendix 3**

## **Structured Ethical Reflection Grid One - Pre-step Phase**



Structured Ethical Reflection Grid Template (Based on Brydon-Miller, 2012) Pre-step 2013

Values	Developing partnerships	Constructing research question	Planning project/ action	Recruiting participants	Collecting data/taking action	Analysing data/evaluating action	Member checking	Going public (presentation and publication)
Self-awareness	Awareness of own senior position and the effect this may have on partnerships Approaching others with a vested interest in the possible findings which may affect the power relationships in the research.	Aware of own biases and values and how this may affect the research question.	Awareness that the participants should lead the research and so it may change during the process.	Opportunities to recruit – not using power relationships/own senior position to coerce colleagues to participate.	Looking beyond own values and assumptions so as not to lead the participants. Not take the easy path – most convenient route to complete research quickly.	Looking beyond own values and assumptions in the findings.	Check analysis/own understanding with participants before moving onto next stages.	That findings may be received differently by different audiences – how this will affect self.
Responsibility	Limit any harm related to the research to participants (staff). To include all possible stakeholders including users/young people/children	To formulate a research question that leads to change – not wasting valuable time of the participants	To avoid causing extra stresses to participants based upon the methods, actions of the research. How to ensure confidentiality, anonymity and mutual respect	Ensure that participants are aware of consent process and all information/expectations. To avoid harm to participants caused by approach to recruitment/ no coercion.	To follow the research plan and complete data collection as described to the participants. To follow data protection laws to ensure confidentiality. To facilitate an environment of mutual respect.	To consider all angles and perspectives. Not to allow personal values to affect the analysis and evaluation.	Those participants check the analysis prior to next steps.	Clear about possibility and presentations/publications from the research. To present in a professional and representative manner.

Candour	Clear aims of the research and my positionality. Honest about expectations for the participants.	To formulate a research question which is clear and reflects clinical practice issues	Develop a plan which is flexible and responsive to the needs of the participants	Search for others interested in the research question. Honesty with potential participants in relation to my values, assumptions, position.	To be open and honest throughout the data collection of my position and values whilst respecting those of the participants	To demonstrate transparency in data analysis and member check prior to next steps.	Provide participants with the opportunity to respond to all steps of the research	To demonstrate transparency and honesty in any presentations/publications.
Inclusiveness	Include all parties affected by the issues	Is this a problem for children and young people in the area? Ensure that research question is valid	Participants to be included in all stages of the research – consultation and collaboration on research plan/action.	Participants to be included in all stages of the research – consultation and collaboration regarding recruitment, especially with children and young people as sensitive subject area	Participants to be included in all stages of the research – consultation and collaboration on stages of data collection.	Participants to be included in all stages of the research – consultation and collaboration on analysis.	Participants to be included in all stages of the research – provide opportunity to respond to findings.	Participants to be included in all stages of the research – provide opportunity to be involved in presentations and publications.
Mutual respect	Awareness of the constraints of partners in relation to resources and competing organisational/political. Encourage partners to respect the views of each other.	Question is based in clinical practice dilemma – effect on participants	Develop a plan which is flexible and responsive to the needs of the participants and encourages MDT respect.	Respecting those who do not wish to participate. Ensure that participants are aware that they can withdraw from the research at any point.	Flexibility in all aspects of data collection. Supporting potentially argumentative groups.	Being aware that opinions may change over time or that meanings could be misinterpreted.	Provide participants with the opportunity to respond to all steps of the research	Clear about possibility and presentations/publications from the research. To present in a professional and representative manner.

# **Appendix 4**

## **Consent Forms Cycles 1 and 2**



## CONSENT FORM

**Title of Project:** A Participatory Action Research (PAR) Study to improve support provided to children and their Families when visiting relatives in hospital

**Name and contact details of Principal Investigator:**

Jane Jervis

Address – Research Institute for Social Sciences, CMO.18 Claus Moser, Keele University, Keele, Staffordshire, ST5 5BG, UK

E-mail Address - j.e.jervis@keele.ac.uk

Telephone – 01782 733641

**Please tick box if you  
agree with the statement**

- 1 I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time.
- 3 I agree to take part in this study.
- 4 I understand that data collected about me during this study will be anonymised before it is submitted for publication.
- 5 I agree to the interview/focus groups being audio/video recorded
- 6 I agree to allow the dataset collected to be used for future research projects
- 7 I agree to be contacted about possible participation in future research projects.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## CONSENT FORM (for use of quotes)

**Title of Project:** A Participatory Action Research (PAR) Study to improve support provided to children and their Families when visiting relatives in hospital

**Name and contact details of Principal Investigator:**

Jane Jervis

Address - – Research Institute for Social Sciences, CMO.18 Claus Moser, Keele University, Keele, Staffordshire, ST5 5BG, UK

E-mail Address - j.e.jervis@keele.ac.uk

Telephone – 01782 733641

**Please tick box if you  
agree with the statement**

1 I agree for any quotes to be used

2 I do not agree for any quotes to be used

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

# **Appendix 5**

## **Information sheet Cycles 1 and 2**



Keele University

## Information Sheet

**Study Title:** A Participatory Action Research (PAR) study to improve support provided to children and their families when visiting relatives in hospital

### **Name and contact details of Principal Investigator:**

Jane Jervis

Address – Research Institute for Social Sciences, CMO.18 Claus Moser, Keele University, Keele, Staffordshire, ST5 5BG, UK

E-mail Address - j.e.jervis@keele.ac.uk

Telephone – 01782 733641

### **Aims of the Research**

To identify and critically explore the issues involved when children visit acutely ill adult relatives at the [REDACTED]

To explore the feasibility for staff to change current practice and improve the experiences of child visitors and their families.

To inform future education, policy and procedure within the NHS to improve the quality of service provided to children and young people when visiting hospitals.

### **Invitation**

You are being invited to consider taking part in a Participatory Action Research (PAR) study to improve support provided to children and their families when visiting relatives in hospital. This project is being undertaken by Jane Jervis.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is unclear or if you would like more information.

### **Why have I been chosen?**

All Registered Nurses and Nursing Assistants on identified wards/departments are invited to participate as the main aims of the research are to explore, challenge and advance current nursing practice. The rationale for this being that nursing staff are the predominant group supporting relatives of acutely ill patients.

Third Year Adult Degree Nursing Students on placement on identified wards/departments are also eligible to participate in a focus group discussion, as at this

stage of their training such students should have gained experience of dealing with relatives in clinical practice.

**Do I have to take part?**

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons.

**What will happen if I take part?**

You will be asked to take part in a maximum of 4 focus group discussions over a 12 month period. The aim is that the focus group discussions will be progressive. The initial focus group discussion will be used to identify and explore the issues involved when children or young people visit acutely ill adult relatives at the hospital and to develop strategies to address these. The later focus group discussions will focus on evaluating these strategies in addition to exploring issues/experiences which occur during the project.

You will be asked to keep a diary of any incidents which involve children or young people visiting adult relatives in the course of your work. You will be asked to record what happened, what went well, what did not go well, any issues identified and any ideas for solutions to these issues. You will be asked to ensure that no patient identifiable data is recorded in this diary. The aim of this is for participants to share and learn from each other's experiences, and work collaboratively to find solutions to practical problems encountered.

**What are the benefits (if any) of taking part?**

There is the opportunity to improve your own knowledge and skills in dealing with children and young people who visit adult relatives and to contribute to improvements in clinical practice for this group.

You will gain experience in working in focus groups.

**What are the risks (if any) of taking part?**

The sensitive nature of the topic, involving discussions about providing care to relatives of acutely ill patients may involve recounting stressful events. You will not be expected to discuss anything that makes you feel uncomfortable. Details of Staff Support Services will be available for any participant who requires support. Informal debriefing is available from the researcher and will not be recorded as part of the research process.

**How will information about me be used?**

The focus group discussions will be audiotaped so that the researcher can accurately transcribe the discussions held. At the end of the study the audiotapes will be destroyed. Written work produced in workshops will be analysed and may contribute to future policy/procedure or resources which would be agreed by the group participants. No personal information will be reproduced by the researcher. The results of the study may be published or presented at professional meetings or conferences.

**Who will have access to information about me?**



Participation is confidential. Each participant will be allocated a code known only to the researcher. All data will be stored securely in a locked cabinet at the University and will be retained for a period of 5 years. The researcher will carry out the data analysis using a password protected computer.

As the research will be carried out using focus groups, other members of the group will be asked to maintain confidentiality. Although the focus group discussion process may result in the participants sharing ideas generated by the groups in the clinical areas, participants will be required not to identify other participants individual comments, Participants will be required not to disclose the names of the other group members.

I do however have to work within the confines of current legislation over such matters as privacy and confidentiality, data protection and human rights and so offers of confidentiality may sometimes be overridden by law. For example in circumstances whereby I am made aware of future criminal activity, abuse either to yourself or another (i.e. child or sexual abuse) or suicidal tendencies I must pass this information to the relevant authorities.

#### **Who is funding and organising the research?**

The research is being organised by the researcher as part of their PhD. There is no external funding.

#### **What if there is a problem?**

If you have a concern about any aspect of this study, you may wish to speak to the researcher who will do their best to answer your questions. You should contact Jane Jervis on [j.e.jervis@keele.ac.uk](mailto:j.e.jervis@keele.ac.uk). Alternatively, if you do not wish to contact the researcher you may contact Professor Sue Read on [s.c.read@keele.ac.uk](mailto:s.c.read@keele.ac.uk)

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research at the following address:-

Nicola Leighton  
Research Governance Officer  
Research & Enterprise Services  
Dorothy Hodgkin Building  
Keele University  
ST5 5BG  
E-mail: [n.leighton@uso.keele.ac.uk](mailto:n.leighton@uso.keele.ac.uk)  
Tel: 01782 733306

# **Appendix 6**

## **Ethical Approval**



RESEARCH AND ENTERPRISE SERVICES

16<sup>th</sup> December 2014

Jane Jervis  
CM0.18  
Claus Moser Building

Dear Jane,

**Re: A participatory action research (PAR) study to improve support provided to children and their families when visiting relatives in hospital.**

Thank you for submitting your application to amend study for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel.

If the fieldwork goes beyond the date stated in your application you must notify the Ethical Review Panel via the ERP administrator at [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on [uso.erps@keele.ac.uk](mailto:uso.erps@keele.ac.uk) Stating ERP1 in the subject line of the e-mail.

Yours sincerely

J

**Dr Jackie Waterfield**  
Chair – Ethical Review Panel

CC RI Manager

# **Appendix 7**

## **Deductive codes**

## Deductive analysis codes

Children's perspectives	Parents or custodians perspectives
Hospital as an environment Hospital as a function Kept waiting It was strange It was white Visiting was good Need for information Emotional turmoil Family disruption Need for support or information Ignored	Misinterpretation of reactions Misinterpretation of child's need for information Differing reactions from children Children are not frightened Children are inquisitive
Healthcare staff perspectives	Reasons for restricting or excluding visits
Lack of policy Lack of education Lack of available information for visitors Parental capability	Too upsetting Too frightening Child would not cope Child too young to understand Infection risk to child Infection risk to patient Child did not want to Wait for patients permission Risks to the child health Disruptive Severity of illness or injury Family decision No under 12 years
Policy and procedures	Contemporary strategies
Strict policy Age restrictions Using clinical judgements Adherence Inconsistency	Play facilities Play rooms Facilitated visiting to ICU Teddy Bear Therapy Support from Paediatric Nurse/Nurse Specialist Workbook (hospice) Resource folder for staff Written information for visitors Child Life Consultation Service Child psychologist Child Visitation Policy

# **Appendix 8**

## **Recruitment poster**

## Invitation to participate

Improving the support provided to children and their families when  
visiting adult relatives in hospital

A Participatory Action Research Study

Jane Jervis— Advanced Nurse Practitioner/PhD Student



### Children visiting their relatives

Need information, reassurance,  
expression of feeling and the  
opportunity to be involved.

Are you prepared ?

*If you have any questions or would like to  
be a part of this research please contact  
Jane Jervis  
Advanced Nurse Practitioner/PhD Student  
Research Institute for Social Sciences  
[j.e.jervis@keele.ac.uk](mailto:j.e.jervis@keele.ac.uk)  
Pager 07623614333*

This Participatory Action Research (PAR)  
study will identify and critically explore  
the issues surrounding children visiting  
adult relatives at the \*\*\*\*\*

The objectives are

- To increase understanding into how  
staff could be better prepared to deal  
with children who visit acutely ill  
adult patients at the Trust
- To change current practice and im-  
prove the experience of child visitors  
and their families
- To enhance the knowledge and skills  
of staff in dealing with child visitors  
and their families
- To inform future education, policy and  
procedure within the NHS to improve  
the quality of service provided to chil-  
dren and young people when visiting  
hospitals. This may be through devis-  
ing guidelines, resources or educa-  
tion packages

If you decide to participate, you will be  
invited to attend up to 4 focus group dis-  
cussions over a period of 12 months.  
These will take place at \*\*\*\*\* and each  
focus group will last approximately 1 to 2  
hours.



# **Appendix 9**

## **Structured Ethical Reflection Grid Two - Post Cycle 1**



Structured Ethical Reflection Grid Template (Based on Brydon-Miller, 2012) – Post Cycle 1 2014

Values	Developing partnerships	Constructing research question	Planning project/ action	Recruiting participants	Collecting data/taking action	Analysing data/evaluating action	Member checking	Going public (presentation and publication)
Self-awareness	Awareness of own senior position and the effect this may have on partnerships. Having to liaise with the senior team which may affect the power relationships in the research. Need to ensure participants remain in control of the planning and actions.	Aware of own biases and values and how this may affect the research question.	Awareness that the participants should lead the research and so it may will change during the process.	Increased risk of coercion in recruitment as liaison with senior team required to address issues preventing participation – during recruitment at meetings care must be taken not use own senior position to coerce colleagues to participate.	Looking beyond own values and assumptions so as not to lead the participants. Not take the easy path – most convenient route to complete research quickly.	Looking beyond own values and assumptions in the findings.	Check analysis/own understanding with participants before moving onto next stages.	That findings may be received differently by different audiences – how this will affect self.
Responsibility	Limit any harm related to the research to participants. Be aware of workload pressures and political situation within the organisation – how this may affect participation in the research and partnerships across staff groups.	To formulate a research question that leads to change – not wasting valuable time of the participants	To avoid causes extra stresses to participants based upon the methods, actions of the research. How to ensure confidentiality, anonymity and mutual respect	Ensure that participants are aware of consent process and all information/expectations. Having an awareness of the possible effects on recruitment of the current organisational pressures. To avoid harm to participants caused by approach to recruitment/ no coercion.	To follow the research plan and complete data collection as described to the participants. To follow data protection laws to ensure confidentiality. To facilitate	To consider all angles and perspectives. Not to allow personal values to affect the analysis and evaluation.	Those participants check the analysis prior to next steps.	Clear about possibility and presentations/publications from the research. To present in a professional and representative manner.

					an environment of mutual respect.			
Candour	Clear aims of the research and my positionality. Honest about expectations for the participants.	To formulate a research question which is clear and reflects clinical practice issues	Develop a plan which is flexible and responsive to the needs of the participants	Search for others interested in the research question. Honesty with potential participants in relation to my values, assumptions, position. Honest about expectations for the participants. Clear about right to withdraw.	To be open and honest throughout the data collection of my position and values whilst respecting those of the participants.	To demonstrate transparency in data analysis and member check prior to next steps.	Provide participants with the opportunity to respond to all steps of the research	To demonstrate transparency and honesty in any presentations/publications. Not to exclude research cycle 1 which resulted in only 1 participant.
Inclusiveness	Include all parties affected by the issues	Is this a problem for children and young people in the area? Ensure that research question is valid	Participants to be included in all stages of the research – consultation and collaboration on research plan/action.	Aware that some staff who want to participate may be unable to due to workload pressures or redeployment to other locations. Using the quality nurse meeting days will exclude those who are not in this role. Participants to be included in all stages of the research – consultation and collaboration regarding recruitment, especially with children and young people as sensitive subject area	Participants to be included in all stages of the research – consultation and collaboration on stages of data collection.	Participants to be included in all stages of the research – consultation and collaboration on analysis. Take into account that by using the quality nurse meeting days staff not in these roles will have been excluded from participating.	Participants to be included in all stages of the research – provide opportunity to respond to findings.	Participants to be included in all stages of the research – provide opportunity to be involved in presentations and publications.
Mutual respect	Awareness of the constraints of partners in relation to resources	Question is based in clinical	Develop a plan which is flexible and	Respecting those who do not wish to participate.	Flexibility in all aspects of data	Being aware that opinions may change	Provide participants with the	Clear about possibility and presentations/publications from the research.

	and competing organisational/political. Encourage partners to respect the views of each other.	practice dilemma – effect on participants	responsive to the needs of the participants and encourages MDT respect.	Ensure that participants are aware that they can withdraw from the research at any point.	collection. Supporting potentially argumentative groups.	over time or that meanings could be misinterpreted.	opportunity to respond to all steps of the research	To present in a professional and representative manner.
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# **Appendix 10**

## **Focus Group Schedule Cycle 2**

## **A participatory action research (PAR) study to improve support provided to children and their families when visiting relatives in hospital**

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**Date:**

**Name of facilitator:**

### **Introduction to the process**

Thank the participants for agreeing to attend a focus group discussion around their experiences of supporting children visiting relatives in the acute care setting. Provide the participant with a consent form to complete. Answer any questions that may arise as comprehensively as possible. Emphasise to the participant that:

1. The focus group discussion will take no longer than two hours.
2. To accurately capture what is being said the interview will be audiotaped.
3. All information that is recorded will be kept strictly confidential.
4. Any participants will remain anonymous in any dissemination work undertaken by the researcher external or internal to the University
5. In addition to consenting to be interviewed, the participant will also be asked to give consent for direct quotations from the interview to be used in the write up of the evaluation.
6. Any quotations that are used will be completely anonymous.
7. If anyone says something that they do not want transcribing they just need to say 'not for recording' and those particular words will not be transcribed.

Ensure that the above points have been fully considered by the participant, prior to collecting the participants consent forms. Ask if anyone has any questions. When written consent has been obtained, ask the participants if it is OK to turn on the tape recorder and conduct the interview. Switch on the audiotape.

## Sample Questions

1. Did they have any experience of dealing with children visiting acutely unwell relatives within the hospital and what were these experiences like. No patient demographic detail is required.
2. Did their wards/departments have any guidelines to assist with dealing with children or young people?
3. Had they any training of how to deal with children in stressful situations, such as when a relative was unwell or had died?
4. What resources or training did they think would help in supporting children and young people in this situation?
5. What would make a good experience/help make the experience of visiting a very ill relative better and what would make it worse.
6. Do you have anything else you would like to tell me about your experiences?

Thank everyone for participating.

# **Appendix 11**

## **Data Analysis Coding Example Cycle 2**

Different perspectives	Transcription extracts	Codes
Experiences as a child	<p>From personal experience as children who've visited Grandparents in hospital when they've been poorly to the point where it doesn't bother me coming into hospital but then I'm a nurse whereas my brother would never step into a hospital again unless it was an emergency he doesn't like the smell doesn't like the environment so you can't say that it doesn't not have an effect on them because it effects people in different ways it didn't affect him then but as he's grown older he associates hospitals with death (Lines 180-186)</p> <p>I remember when I was a little girl I came into hospital, my Mum was a nurse and I came to hospital all the time visited did everything and that made me want to be a nurse but I mean my sister she came and visited her Nan about an hour before she died. My Sister hates hospitals now she would never do it and I know when I used to come in all the nurses were like so lovely to me and talked to me about everything and I think it isn't just the age of the child or what they're seeing it's the experience as a whole (Lines 192-198)</p> <p>weren't you as children when I was young and you went to visit your Grandparents in hospital you went and sat in the waiting room while your Mum and Dad went in and that was that you never clapped eyes on but you know like you say things have changed and there are a lot more children in the hospital setting on the adult side and there should be something to help support them (Lines 524-528)</p>	<p>1- Grandparents  2- No bother  3 - Never step into hospital again  4- Smell/Environment  5- Effect is individual  6 -Hospital with death    7- Visiting made me want to be a nurse  6 - Hospital with death  8 - Nurses were lovely to me    9 - Grandparents  10 - Left waiting  11 - Times have changed  12 -Something to help support</p>
Experiences as a parent	<p>on a personal point of view I've had my husband in hospital and a young baby and I wanted that baby near me at all times he came to the hospital to visit his Dad and he was only 6 months but I needed him there (Lines 21-23)</p> <p>This is it, this is it if you've had like a personal experience of it you want your children there from the word go (Lots of Erm, yea – in the background) but if you haven't you'll go with</p>	<p>13 - Wanted baby near me  14 – Allowed to visit  13 - Needed baby there    13 - Want your children there</p>



	<p>what the majority and what your management are saying no no no they can't come in (Lines 146-149)</p> <p>Excuse me when I had my little boy who was only 12 weeks old and he still came to me The Sister on the ward where I was allowed him to come to me (Lines 154-155) (Relating to Policy conversation)</p> <p>And my and my, when I was bringing my 6 month old son in to see his Dad I was like well I work in the hospital he's he's probably been open to everything I've been bringing home anyway so (Lines 314-316)</p>	<p>15 - Majority and management 16 - Cannot come in 14 - Allowed to visit 14 - Son to see Dad 17 - Open to everything I've been bringing home (Linked to infection control)</p>
Family experiences	<p>ways it didn't affect him then but as he's grown older he associates hospitals with death (Line 186)</p> <p>my sister she came and visited her Nan about an hour before she died. My Sister hates hospitals now (Lines 194-196)</p> <p>You can't just exclude it all, we're going to ban children unless it's really bad and then we'll involve them you're going to end up in 20 years with a bunch of kids that'll think you only ever die when you go to hospital (Lines 472-474)</p> <p>It's that perception that I mean my husbands in his you know his late 40's and he says he doesn't like hospitals, I don't like going into hospitals because everybody that goes into hospital don't come out again because his experience of Grandparents coming into hospital was that they never came out or they came out in a box and that's that's his preconceived and I go home and he's like go get changed you smell of hospitals. It's that obviously it's that attitude that you got in the way you either weren't allowed to go or you got shunted around to different people to look after while (Lines 532-538)</p>	<p>6 - Hospital and death 6 - Hospital and death 18 - Ban unless really bad 6 - Hospital and death 6 - Hospital and death 9 - Grandparents 19 - Preconceived ideas 4 - Smell 14 - Not allowed to visit</p>

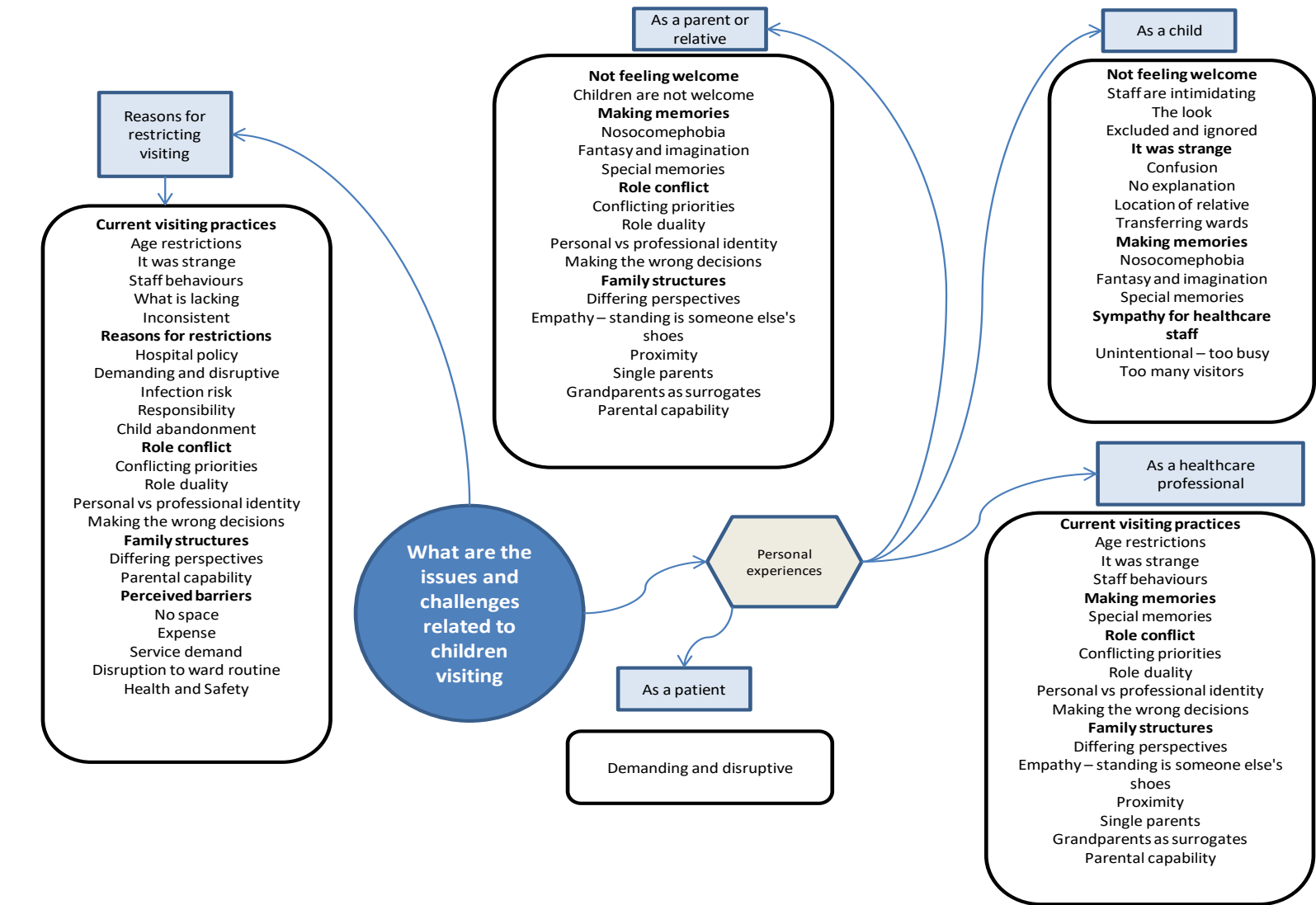
# **Appendix 12**

## **Thematic maps**

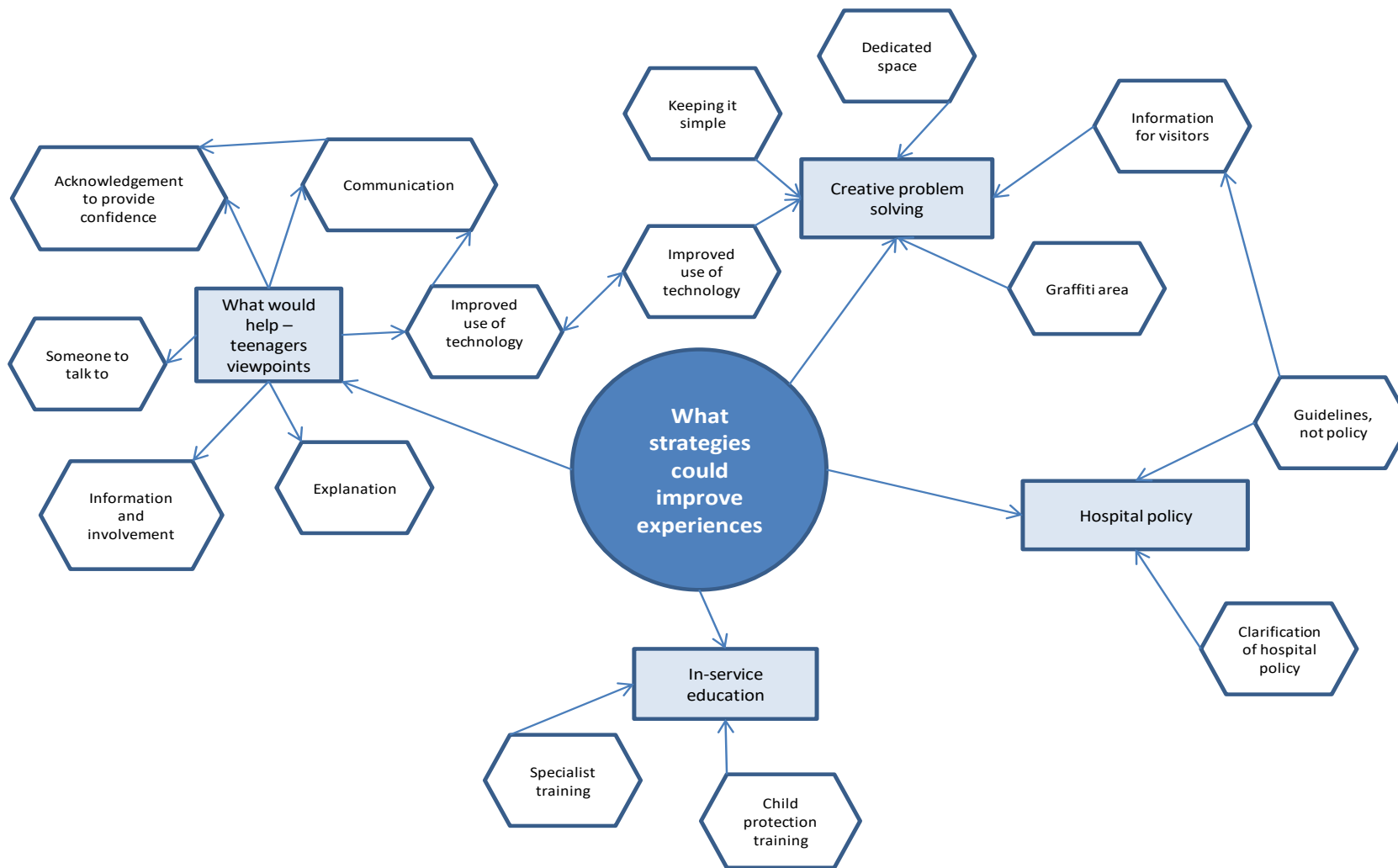


Thematic map Number 1

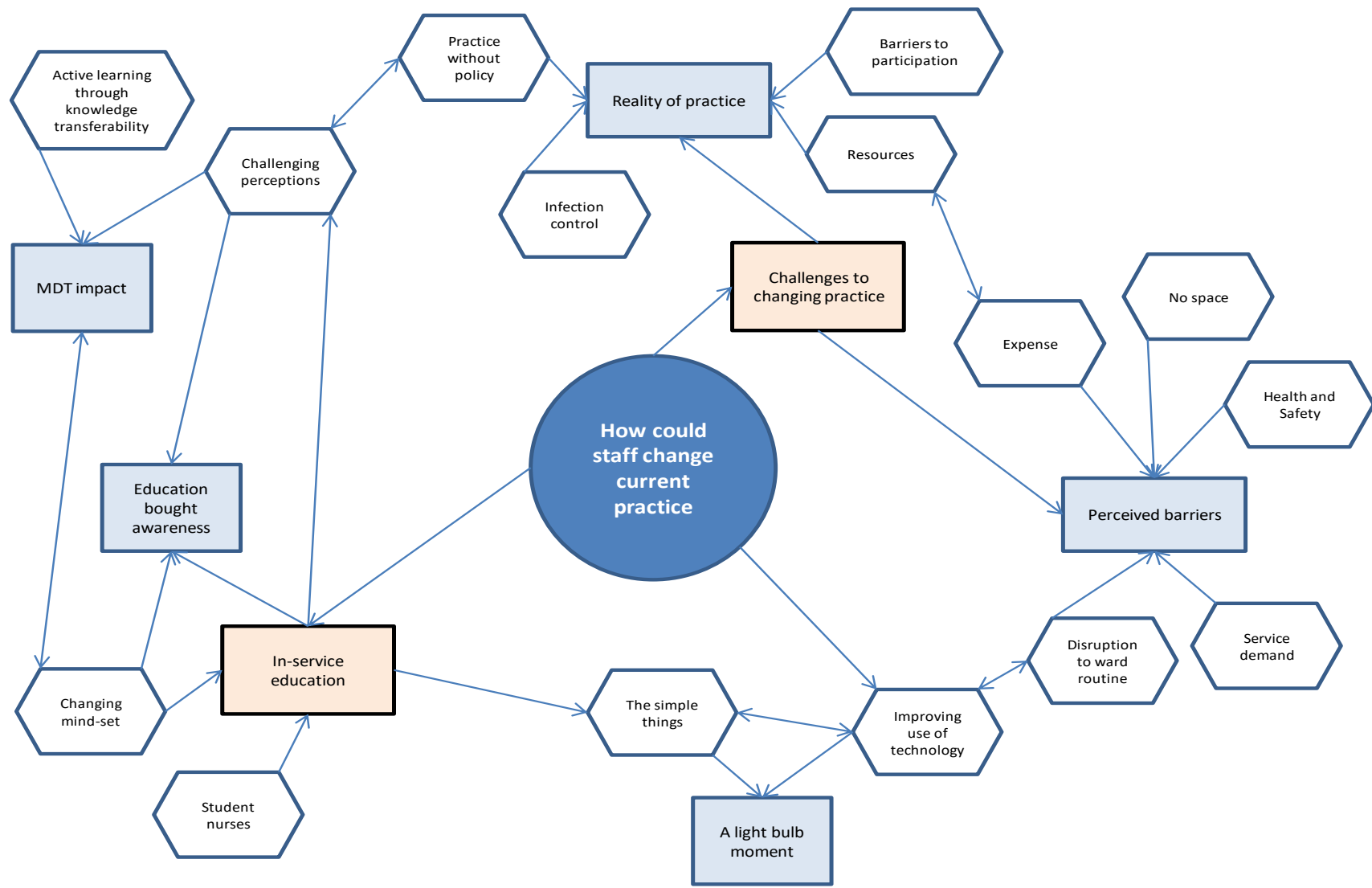




**Thematic map Number 2**



**Thematic map Number 3**



**Thematic map Number 4**

# **Appendix 13**

## **Ethical Approval for Amendments Cycle 3**



22<sup>nd</sup> May 2015

Jane Jervis  
CM0.18  
Claus Moser Building

Dear Jane,

**Re: A participatory action research (PAR) study to improve support provided to children and their families when visiting relatives in hospital – Amendment 2**

Thank you for submitting your application to amend study for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel.

The following revised documents have been reviewed and approved by the panel as follows:

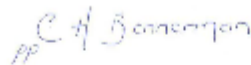
Document	Version	Date
Focus Group Schedule	1	March 2015
Information Sheet – College Students	1	March 2015
Consent Form	1	March 2015
Consent Form (for the use of quotes)	1	March 2015

If the fieldwork goes beyond the date stated in your application (30<sup>th</sup> September 2015) you must notify the Ethical Review Panel via the ERP administrator at [uso.erns@keele.ac.uk](mailto:uso.erns@keele.ac.uk) stating ERP1 in the subject line of the e-mail.

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on [uso.erns@keele.ac.uk](mailto:uso.erns@keele.ac.uk) Stating ERP1 in the subject line of the e-mail.

Yours sincerely



**Dr Jackie Waterfield**  
Chair – Ethical Review Panel

CC RI Manager  
Supervisor

# **Appendix 14**

## **Structured Ethical Reflection Grid Three - Cycle 3**

Structured Ethical Reflection Grid Template (Based on Brydon-Miller, 2012) – Cycle 3

Values	Developing partnerships	Constructing research question	Planning project/ action	Recruiting participants	Collecting data/taking action	Analysing data/evaluating action	Member checking	Going public (presentation and publication)
Self-awareness	Awareness of own position and the effect this may have on partnerships. Need to ensure participants remain in control of the planning, actions and focus group.	Aware of own biases and values and how this may affect the research question.	Awareness that the participants should lead the research.	Approached with offer of participation – aware that full facts of the offer are unknown. Risk of coercion in recruitment via Health Society Co-ordinator. Risk of coercion from the college.	Looking beyond own values and assumptions so as not to lead the participants.	Looking beyond own values and assumptions in the findings.	Check analysis/own understanding with participants before moving onto next stages.	That findings may be received differently by different audiences – how this will affect self.
Responsibility	Limit any harm related to the research to participants.	To formulate a research question that leads to change	How to ensure confidentiality, anonymity and mutual respect. Plan steps to limit harm to participants. Provision of support services.	Ensure that participants are aware of consent process and all information/ expectations. To avoid harm to participants caused by approach to recruitment/ no coercion.	To follow the research plan and complete data collection as described to the participants. To follow data protection laws to ensure confidentiality. To facilitate an environment of mutual respect.	To consider all angles and perspectives. Not to allow personal values to affect the analysis and evaluation.	Participants check the analysis prior to next steps.	Clear about possibility and presentations/publications from the research. To present in a professional and representative manner.
Candour	Clear aims of the research and my positionality. Honest about expectations for the participants.	To formulate a research question which is clear and reflects clinical practice issues	Develop a plan which is flexible and responsive to the needs of the participants	Honesty with potential participants in relation to my values, assumptions, position. Honest about expectations for the participants. Clear about right to withdraw.	To be open and honest throughout the data collection of my position and values whilst respecting those of the participants.	To demonstrate transparency in data analysis and member check prior to next steps.	Provide participants with the opportunity to respond to all steps of the research	To demonstrate transparency and honesty in any presentations/publications.
Inclusiveness	Include all parties affected by the issues.	Is this a problem for	Participants not involved	Approached with offer of participation by	Participants not involved in all	Participants not involved in	Provide opportunity to	Provide opportunity to be involved in presentations

	Need to have effective partnership with the college in order to limit harm to participants.	children and young people in the area?	in all stages of the research – ensure there is flexibility in the plan/action for participants to be enabled to engage to their desired level.	college. Risk of coercion in recruitment via Health Society Co-ordinator. Risk of coercion from the college. Honest about expectations for the participants. Clear about right to withdraw. Parental or student consent – how to increase inclusiveness and trust	stages of the research – ensure there is flexibility in the plan/action for participants to be enabled to engage to their desired level.	all stages of the research – ensure there is flexibility in the plan/action for participants to be enabled to engage to their desired level.	respond to findings.	and publications. Provide link to increase opportunity to work with the local hospital.
Mutual respect	Encourage partners to respect the views of each other – hospital staff and college students.	Question is based in clinical practice dilemma – effect on participants	Develop a plan which is flexible and responsive to the needs of the participants	Respecting those who do not wish to participate. Ensure that participants are aware that they can withdraw from the research at any point.	Flexibility in all aspects of data collection. Supporting potentially argumentative groups.	Being aware that meanings could be misinterpreted.	Provide participants with the opportunity to respond	Clear about possibility and presentations/publications from the research. To present in a professional and representative manner.

# **Appendix 15**

## **Consent Forms Cycle 3**

## CONSENT FORM

**Title of Project:** A Participatory Action Research (PAR) Study to improve support provided to children and their Families when visiting relatives in hospital

**Name and contact details of Principal Investigator:**

Jane Jervis

Address – Research Institute for Social Sciences, CMO.18 Claus Moser, Keele University, Keele, Staffordshire, ST5 5BG, UK

E-mail Address - j.e.jervis@keele.ac.uk

Telephone – 01782 733641

**Please tick box if you  
agree with the statement**

- |   |  |                          |
|---|--|--------------------------|
| 1 | I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time.  | <input type="checkbox"/> |
| 3 | I agree to take part in this study.  | <input type="checkbox"/> |
| 4 | I understand that data collected about me during this study will be anonymised before it is submitted for publication.             | <input type="checkbox"/> |
| 5 | I agree to the focus groups being audio recorded   | <input type="checkbox"/> |
| 6 | I agree to allow the dataset collected to be used for future research projects   | <input type="checkbox"/> |
| 7 | I agree to be contacted about possible participation in future research projects.  | <input type="checkbox"/> |

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## CONSENT FORM (for use of quotes)

**Title of Project:** A Participatory Action Research (PAR) Study to improve support provided to children and their Families when visiting relatives in hospital

**Name and contact details of Principal Investigator:**

Jane Jervis

Address - – Research Institute for Social Sciences, CMO.18 Claus Moser, Keele University, Keele, Staffordshire, ST5 5BG, UK

E-mail Address - j.e.jervis@keele.ac.uk

Telephone – 01782 733641

**Please tick box if you  
agree with the statement**

1 I agree for any quotes to be used

2 I do not agree for any quotes to be used

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Version 1 March 2015

# **Appendix 16**

## **Information sheet Cycle 3**



## Information Sheet – College Students

**Study Title:** A Participatory Action Research (PAR) study to improve support provided to children and their families when visiting relatives in hospital

### **Aims of the Research**

To identify and critically explore the issues involved when children visit acutely ill adult relatives at the [REDACTED]

To explore the feasibility for staff to change current practice and improve the experiences of child visitors and their families.

To inform future education, policy and procedure within the NHS to improve the quality of service provided to children and young people when visiting hospitals.

### **Invitation**

You are being invited to consider taking part in a Participatory Action Research (PAR) study to improve support provided to children and their families when visiting relatives in hospital. This project is being undertaken by Jane Jervis.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is unclear or if you would like more information.

### **Why have I been chosen?**

It was identified in Focus Groups with nurses that resources are required at [REDACTED] to assist staff in providing improved support the children, young people and their families. As you belong to a group of young people engaged in the [REDACTED] participation programme who have offered to assist in the development of resources we would like to explore your experiences of your contributions to the development of such resources.

### **Do I have to take part?**

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons.

### **What will happen if I take part?**

You will be asked to take part in a maximum of 2 Focus Groups over a 6 month period.

The aim of the Focus Groups is to explore how your group's experience of completing the project, particularly focusing on the resources produced, any experiences used to help the process, if and how the process has influenced your thoughts/ideas on what support is required for children and young people visiting the hospital, whether anyone has experienced a change when visiting the hospital.

**What are the benefits (if any) of taking part?**

You will gain experience of working in Focus Groups as part of a healthcare related research project.

You will have contributed to the knowledge of healthcare professionals about the support required by children, young people and their families when visiting relatives in hospital both locally and nationally.

You will have contributed to a project which improves the quality of healthcare in your local hospital.

It will enhance your learning in relation to services, citizenship and team working to create a product.

It could enhance your CV

**What are the risks (if any) of taking part?**

The sensitive nature of the topic, involving discussions about providing care to relatives of acutely ill patients may cause anxiety or distress due to recounting painful memories.

You will not be expected to discuss anything that makes you feel uncomfortable.

A Counselling service is available at the college as well as access to your Learner Managers who can support you if required.

Informal debriefing is available from the researcher and will not be recorded as part of the research process.

**How will information about me be used?**

The Focus Groups will be audiotaped so that the researcher can accurately transcribe the discussions held. At the end of the study the audiotapes will be destroyed.

Any written work produced will be analysed and may contribute to future policy/procedure or resources which would be agreed by the group participants.

No personal information will be reproduced by the researcher.

The results of the study may be published or presented at professional meetings or conferences.

If any of the data is used for future research further ethical approval will be sought.

**Who will have access to information about me?**

Participation is confidential. Each participant will be allocated a code known only to the researcher. All data will be stored securely in a locked cabinet at the University and will be retained for a period of 5 years. The researcher will carry out the data analysis using a password protected computer.

As the research will be carried out using groups, other members of the group will be asked to maintain confidentiality.

I do however have to work within the confines of current legislation over such matters as privacy and confidentiality, data protection and human rights and so offers of

confidentiality may sometimes be overridden by law. For example in circumstances whereby I am made aware of future criminal activity, abuse either to yourself or another (i.e. child or sexual abuse) or suicidal tendencies I must pass this information to the relevant authorities.

**Who is funding and organising the research?**

The research is being organised by the researcher as part of their PhD. There is no external funding.

**What if there is a problem?**

If you have a concern about any aspect of this study, you may wish to speak to the researcher who will do their best to answer your questions. You should contact Jane Jervis on [j.e.jervis@keele.ac.uk](mailto:j.e.jervis@keele.ac.uk). Alternatively, if you do not wish to contact the researcher you may contact Professor Sue Read on [s.c.read@keele.ac.uk](mailto:s.c.read@keele.ac.uk)

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research at the following address:-

Nicola Leighton  
Research Governance Officer  
Research & Enterprise Services  
IC1 Building  
Keele University  
ST5 5BG  
E-mail: [n.leighton@keele.ac.uk](mailto:n.leighton@keele.ac.uk)  
Tel: 01782 733306

**Contact for further information**

*Normally only Keele telephone numbers and e-mail addresses should be used in all study documentation. If there are reasons to depart from this then these must be explained in your Ethical Review Panel documentation.*

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# **Appendix 17**

## **Focus Group Schedule Cycle 3**

## **A participatory action research (PAR) study to improve support provided to children and their families when visiting relatives in hospital**

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**Date:**

**Name of facilitator:**

### **Introduction to the process**

Thank the participants for agreeing to attend a focus group discussion/workshop around their experiences of producing resources for the local hospital which staff requested during the first phases of the research to assist them in supporting children visiting relatives in the acute care setting.

Provide the participant with a consent form to complete.

Answer any questions that may arise as comprehensively as possible. Emphasise to the participant that:

8. The focus group discussion will take no longer than one hour
9. To accurately capture what is being said the interview will be audiotaped.
10. All information that is recorded will be kept strictly confidential.
11. Any participants will remain anonymous in any dissemination work undertaken by the researcher external or internal to the University
12. In addition to consenting to be interviewed, the participant will also be asked to give consent for direct quotations from the interview to be used in the write up of the evaluation.
13. Any quotations that are used will be completely anonymous.
14. If anyone says something that they do not want transcribing they just need to say 'not for recording' and those particular words will not be transcribed.

Ensure that the above points have been fully considered by the participant, prior to collecting the participants consent forms.

Ask if anyone has any questions.

When written consent has been obtained, ask the participants if it is OK to turn on the tape recorder and conduct the interview. Switch on the audiotape

## Sample Questions

7. Does anyone have any experience of visiting acutely unwell relatives within the hospital that they are happy to share? How did these experiences add to the work that was completed?  
No patient demographic detail is required.
8. How easy was it to access any guidelines which detailed how to assist with dealing with children or young people?  
How did they impact on this project?
9. What resources do you think would help staff to support children and young people visiting the hospital?
10. Could you explain the process of completing the project?  
What were the disadvantages and advantages of taking part in the project?  
Are there things that you would do differently? How would you go about doing it differently?
11. How valuable do you think the project was to you as a student group?  
How valuable do you think the project is to the [REDACTED] staff?  
How valuable do you think the project is to families visiting [REDACTED]?
12. From this project what would you suggest to improve the experience of children and young people visiting a very ill relative?  
What would you suggest are things that you think would make the experience worse?
13. Do you have anything else you would like to tell me about your experiences?

Thank everyone for participating.

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# **Appendix 18**

## **Local and regional dissemination**

## **Local dissemination**

Regular reports and meetings with:

- Chief Nurse
- Director of Nursing Education and Workforce
- Director of Nursing Quality and Safety
- Healthcare Governance Manager (Patient Experience)
- QN meetings

Presentations given at:

- Hospital Professional Advisory Group
- Hospital End of Life Operational Group
- Hospital Patient Council
- Hospital Children's Board
- Keele University pre-registration student nurses user and carer day
- Children's bereavement workshops – local adult hospice

## **Regional dissemination**

Presentations given at:

- Association of Palliative Care Social Workers regional meeting
- Keele University Palliative and End-of-Life Care Research Group
- University Hospital of North Staffordshire Conference 'Creating World Class Healthcare for Staffordshire (poster)
- West Midlands Fourth Annual Supportive and Palliative Care Research Showcase



# **Appendix 19**

## **National and international dissemination**

Consulting with Children to Inform Research Methodology: The Experience of a Nurse PhD Student. Poster presentation. **RCN International Nursing Research Conference 2014**, Glasgow, UK. March 2014

*Consulting with Children to Inform Research Methodology: The Experience of a Nurse PhD Student.* Oral presentation in conjunction with PhD supervisor, Prof Sue Read, at the 5th **International Nurse Education Conference (NETNEP)** Noordwijkerhout, The Netherlands. June 2014

*Snakes and Ladders: Conducting Action Research in Contemporary Healthcare Practice.* **CARN Conference 2015. Action Research across Disciplinary Settings: Challenges for Change and Empowerment.** Braga, Portugal. November 2015.

*Respecting the Voices of Children and Young People in Participatory Action Research.* **2<sup>nd</sup> International Conference: Where's the Patients Voice in Healthcare Professional Education – 10 Years On?** Vancouver, Canada. November 2015

*Methodological Reflections: Conducting Action Research in Contemporary Healthcare Practice* **International Institute for Qualitative Methodology. Qualitative Methods Conference 2016.** Glasgow, UK. May 2016

*Respecting the Voices of Children in Healthcare Research. (Poster presentation).* **International Institute for Qualitative Methodology. Qualitative Methods Conference 2016.** Glasgow, UK. May 2016

*Who am I? The Challenges of Multiple Positionalities in Nursing Research.*  
**International Institute for Qualitative Methodology, 16<sup>th</sup> Qualitative Methods (QM)**  
**Conference.** Banff, Canada, April 2018

*Children's Voices: Challenging Perspectives in Adult Nurse Education.* 7<sup>th</sup>  
**International Nurse Education Conference.** Banff, Canada, May 2018