

2024

# Use of Patient Diaries in pAediatric inTensive carE: UPDATE Study. A Constructivist Grounded Theory Study exploring the child, parents, and healthcare professionals' perspectives.

Lynch, Fiona

<https://pearl.plymouth.ac.uk/handle/10026.1/21882>

---

<http://dx.doi.org/10.24382/5130>

University of Plymouth

---

*All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.*



**UNIVERSITY OF  
PLYMOUTH**

**Use of Patient Diaries in pAediatric inTensive carE:  
UPDATE Study.**

**A Constructivist Grounded Theory Study exploring the child,  
parents, and healthcare professionals' perspectives.**

**Fiona Lynch**

A thesis submitted to the University of Plymouth  
in partial fulfilment for the degree of

**DOCTOR OF PHILOSOPHY**

School of Nursing and Midwifery

**January 2024**

## **Copyright Statement**

*This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with its author and that no quotation from the thesis and no information derived from it may be published without the author's prior consent.*

## Acknowledgements

I would like to thank the families who so graciously participated in my study. They gave up their time to talk to me during some of the most challenging times of their life and then revisited this time in the follow-up interviews. To those families, whose children sadly died during this time, I will not forget you or your children. I am eternally grateful to you all.

To the fantastic, inspiring nurses and healthcare assistants who worked in the PICU and the cardiology ward, and participated in the study, I salute you! You were all encouraging, welcoming and supportive, especially those who became my *Diary Champions*. Thank you to the team at the Evelina London Children's Hospital, especially Dr. Shane Tibby, and Louise Dewsbury (former Lead Nurse) for supporting and advocating for me to undertake this study. To Jane Sivyler, the PICU play specialist who introduced the diaries with me, thank you. You are a star.

Thank you to the Florence Nightingale Foundation for supporting my first year's academic fees and for all the encouragement and guidance I have received from the FNF alumni. To Kate Pye, Deputy Director for Children and Young People's Nursing, thank you for believing in me, constantly asking, "How's it going?" and rebuilding my confidence after a few difficult years.

To my wonderful supervisors, Professors Jos Latour, and Ruth Endacott, what can I say that truly expresses how grateful I am. Your expertise, guidance, support, and encouragement have been inspirational, grounding, and aspirational. I have learnt so much from both of you and feel blessed to have had you as my supervisors. I am going to really miss our "sessions". I have 'stood on the shoulders of giants' and am so grateful to have this new outlook.

To my friends Eliza, Brigitte, Jo, and Louise, thank you for always asking about me and the study. Sorry I have been an absent friend for the last few months, but I am back now! To my lovely sister who has been through it with me, thank you for letting me get on with "it" and supporting me regardless.

To my gorgeous boys, Neil, Ashton and Falcor (the dog), thank you for your love, support, and endless cups of Irish tea. I appreciate how you have supported me significantly during this time, especially as the PhD encroached on your time. I could not have done this without your unconditional love.

### Dedication

I dedicate this thesis to my mum, Maureen, who sadly died this year. I only really appreciated what she sacrificed for me, as an Irish single mum, working many jobs to support her two girls, when I became a mum. Thank you for teaching me how, through education, hard work and being a nurse, I could better myself. I owe so much to you and will always be grateful.

*Sláinte.*

## Author's Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

This thesis has been proofread by a third party; no factual changes or additions or amendments to the argument were made as a result of this process. A copy of the thesis prior to proofreading will be made available to the examiners upon request.

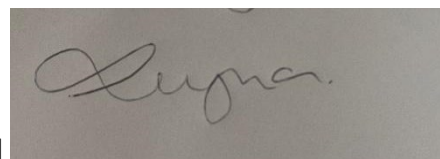
Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

The UPDATE study was financed with aid from a research scholarship funded by the Florence Nightingale Foundation and partial funding was received for academic fees by the University Hospitals of Sussex.

A programme of advanced study was undertaken, which included, MSc in Healthcare Research (completed 2015) and the Joanna Briggs Institute, Systematic Review Training (2018). Further research training and support has included the following: Grounded Theory Summer School, Grounded Theory Network, and PhD study skills.

Word count of main body of thesis: **62,819**.

Signed

A rectangular box containing a handwritten signature in cursive script, which appears to read 'Lynna'.

Date 05/01/24.

## Research Outputs

### Publications in peer-reviewed journals

Lynch, F. Endacott, R. Latour, J. (2020) **Patient diaries: Survey of paediatric intensive care units in the United Kingdom and Ireland** *Nursing in Critical Care* (2020) 25(1) 31-36. DOI:10.1111/nicc.12472.

### Conference Presentations

Lynch, F (2016) **PICU Patient Diaries** Oral presentation at *World Federation of Paediatric Intensive and Critical Care Societies* Toronto, Canada.

Lynch, F. (2018) **PICU Patient Diaries: An Intervention for Parental Support?** Oral presentation at *Paediatric Intensive Care Society* conference. Bristol UK.

Lynch, F. Endacott, R. Latour, J. (2020) **Patient Diaries: Survey of Paediatric Intensive Care Units in UK and Ireland.** Poster presentation at Paediatric Innovation, Education and Research Network Conference. Virtual.

Lynch, F. (2021) **PICU Patient Diaries: Where is the Value?** Oral presentation at *European Society of Paediatric and Neonatal Intensive Care* Conference. Virtual.

Lynch, F. (2021) **Are Patient Diaries in the PICU useful: The UPDATE study.** Oral presentation at *Paediatric Innovation, Education and Research Network Conference*. Virtual.

Lynch, F. (2023) **PICU Patient Diaries: Journal Club**. Oral presentation *European Society of Paediatric and Neonatal Intensive Care*. Virtual.

## Abstract

**Use of Patient Diaries in pAediatric inTensive carE: UPDATE Study.**

**A Constructivist Grounded Theory Study exploring the child, parents, and healthcare professionals' perspectives.**

**Fiona Lynch**

Paediatric Intensive Care Units (PICU) are essential to paediatric healthcare, providing high medical and nursing care to children who have become critically ill. PICUs offer prompt and appropriate interventions for children who have developed physiological instability, whether following surgery, from infection, trauma, or deterioration of a chronic condition. A stay in a PICU is not without potential psychological consequences for the child and family. Interventions to support recovery from the psychological impact of critical illness for the child and their family are evolving. Studies undertaken in adult and children's intensive care have explored interventions that may reduce the psychological impact of critical illness for the patient and their relatives, such as patient diaries.

The impact of patient diaries is still emerging in PICUs, and a clear picture of how this intervention is used is the logical next step. Therefore, this study aimed to ascertain how PICU patient diaries are used by critically ill children, their families, and healthcare professionals during and after admission into the PICU.

Constructivist grounded theory (Charmaz, 2006) was identified as the most appropriate methodology to study how the child, their family and the teams caring for them used patient diaries. The methods of intensive interviews and focus group interviews were adopted to generate rich data from the participants.

Two intensive consecutive interviews were conducted with children and their family. The first interviews were conducted during the admission to the PICU and then repeated approximately five to six months post-discharge from the hospital. In total, 11 interviews were conducted during the admission to the PICU and six interviews post-discharge from the PICU. Only one child was interviewed as a participant in this study.

Five separate focus group interviews were conducted with healthcare professionals to ascertain their views on the use and usefulness of the diaries. In total, 95 HCPs were recruited for the five focus group interviews, with four conducted in the PICU and one in the children's cardiology ward.

Two categories evolved from the family participants and three categories from the HCPs, leading to the development of the core category of *Making Sense*. Findings showed that patient diaries provided a communication tool which strengthened relationships between the parent and their child, the healthcare professionals and other family members by *Creating Connections*. The relationships fostered through the diaries were viewed as *Impacting Emotionally* on parents and HCPs. From this emotional involvement, the diary was considered to support the parents' emotional wellbeing. From the entries made by the family members, the diaries provided insights into how families coped emotionally, allowing HCPs to provide individualised support where needed. In an environment with an imbalance of power and unfamiliar organisational processes and cultures, the diary supported parental autonomy by *Empowering Involvement* to make decisions.



The patient diary is a tool to bridge the knowledge gap between parents and HCPs in the child's critical illness experience. Through this use, the diary offered a compendium of information about the child's PICU journey. Providing clear insights and explanations of their child's PICU admission, the patient diary filled any gaps in memory and offered an easily understandable permanent record. Therefore, the diary was a valuable resource supporting *Making Sense* of the child's complex critical illness journey. The UPDATE study has explored the uses of PICU patient diaries from the perspective of the families and HCPs. The patient diaries were valued and offered a tool to support the family, the HCP and child in making sense of the critical illness journey. Through CGT this study has provided insights not previously understood and contributes to the evolving evidence and theory about using patient diaries for the survivors of the PICU.

## **Glossary of Terms**

### **Child**

The term child refers to an infant, child, or young person under the age of 18 years.

### **Constructivist Grounded Theory**

A research methodology that focuses on generating new theories through inductive analysis of the data generated from participants.

### **Family**

Family is used to describe the socially recognised group who are connected to the child. This includes parents, carers, guardians, siblings, grandparents, uncles, aunts, friends and extended family members.

### **Family-Centred Care**

Family-centred care (FCC) is the comprehensive approach to healthcare delivery in partnership with parents or caregivers.

### **Paediatric Critical Illness**

The term 'critical illness' is used to describe the critically ill or injured child who requires paediatric critical care. The term 'intensive' is used interchangeably with the term 'critical'.

### **Paediatric Intensive Care Unit**

A discrete area within a ward or hospital where critical care is delivered to a child.

### **Parent**

The term 'parent' is used to describe mothers, fathers, guardians, and other adults with parental responsibility for caring for the child.

### **Post-Traumatic Stress Disorder (PTSD)**

Mental health condition caused by a stressful, frightening, or distressing event.

### **Intensive Care Patient Diary**

Diary written for the critically ill patient, and their family.

### **Post Intensive Care Syndrome-paediatrics (PICS-p).**

Framework to describe the constellation of physical, emotional, neurocognitive, and social sequelae that persists beyond the resolution of the critical illness period. The paediatric framework recognises the impact this syndrome has on the child and their family.

# Contents

Copyright Statement	2
Acknowledgements	3
Author's Declaration	4
Research Outputs	5
Abstract	7
Glossary of Terms	9
List of Tables	17
List of Figures	18
Chapter 1 Introducing the UPDATE Study: Aims, Objectives and the Researcher's Positionality	19
1.1 Introduction	19
1.2 Study Background	19
1.3 Research Question, Aims and Objectives of the Study	23
1.4 Significance of the Study	24
1.5 The Researcher's Background	26
1.6 Structure of the Thesis	27
Chapter 2 Scoping Review of the Literature: From Nothing to a Little.	29
2.1 Introduction	29
2.2 Contextualising the Paediatric Intensive Care Unit	29
2.3 Psychological Impact of Critical Illness	31
2.4 The Psychological Impact of Critical Illness Through the Lens of the Child and their Family	33
2.5 PICU Patient Diaries Scoping Review	38
2.5.1 Research Studies Characteristics.	39
2.5.2 Defining the PICU Diary Model.	44
2.5.3 Parents' Perspectives on PICU Diaries	45
2.5.4 Children's Perspective on the PICU Diary	48
2.5.5 HCPs' Perspective on the PICU Diary	48
2.5.6 PICU Diaries Systematic Scoping Reviews	50
2.5.7 Synthesising the Findings from the PICU Diary Literature	51
2.6 Chapter Summary	51
Chapter 3 Scope and Nature of PICU Diaries in the United Kingdom and Ireland.	53

3.1 Abstract	54
3.2 Background.	55
3.2.1 Interventions to Minimise the Psychological impact of Critical Illness.	56
3.2.2 Patient Diaries in the Critical Care Setting	57
3.3 Methods	58
3.3.1 Settings	58
3.3.2 Participants	59
3.3.3 Recruitment	59
3.3.4 Data Collection	60
3.3.5 Service User Involvement	60
3.3.6 Analysis	60
3.3.7 Ethical considerations	60
3.4 Results	61
3.4.1 Purpose of the Diaries	61
3.4.2 The Scope and Use of Diaries	62
3.5 Discussion	63
3.6 Conclusions	67
3.7 Acknowledgments	67
3.8 References	67
Chapter 4 Underpinning the UPDATE Study: Methodological Decisions	68
4.1 Introduction	68
4.2 Purpose of the UPDATE study	68
4.3 Ontology and Epistemology: The Theory of Reality and Knowledge	70
4.4 Theoretical Perspective: The Philosophical Stance Informing the Methodology.	74
4.5 Methodology: The Set of Principles that Inform the Research Strategy.	77
4.6 Consideration of Methodological Choices as a Nurse Researcher	82
4.7 Chapter Summary	83
Chapter 5 Creating the UPDATE Study: Design and Methods	85
5.1 Chapter Introduction	85
5.2 Study Setting	85
5.3 Study Participants	86
5.4 Recruitment to the Study	87
5.5 Study Methods and Stakeholder Engagement	90
5.6 Data Collection Methods and Data Generation	91
5.6.1 Intensive Interview Approach with the Child and Family Participants	92

5.6.2 Focus Group Interviews with the Healthcare Professionals	93
5.7 Data Analysis	95
5.7.1 Memo Writing	96
5.7.2 Constant Comparative Analysis and Coding	96
5.7.3 Theoretical Sampling	102
5.7.4 Theory Generation	103
5.8 Rigour in the UPDATE Study	105
5.8.1 Credibility	106
5.8.2 Auditability	107
5.8.3 Fittingness	107
5.9 Ethical Considerations of the UPDATE study	108
5.9.1 Ethical Considerations for the Recruitment of Participants	109
5.9.2 Recruitment of Healthcare Professionals	111
5.9.3 Consenting to Participate	111
5.9.4 Ethical Considerations for Interviewing the Child and Family Participants	112
5.9.5 Ethical Considerations for Interviewing Healthcare Professionals Participants	114
5.9.6 Confidentiality	114
5.9.7 Additional Support for Participants	115
5.10 Chapter Summary	115
Chapter 6 Setting the Scene: Grounding the Participants' Understanding	117
6.1 Chapter Introduction	117
6.2 Presenting the Findings of the UPDATE Study	117
6.3 Characteristics of the Child and Family Participants	120
6.4 The Perspectives of the Child and Family Participants	121
6.5 Understanding the Impact of Admission to the PICU on the Child and their Family.	123
6.6 Characteristics of the Healthcare Professionals	125
6.7 Chapter Summary	127
Chapter 7 Grounding the Findings from the Children and their Families	128
7. 1 Introduction	128
7.2 Overview of the Categories	129
7.3 Introducing their Story	130
7.4. Introducing Category 1: Creating Connections	131
7.4.1 Connecting with My Child	132

7.4.2 Connecting with the HCPs	134
7.4.3 Connecting with Others	138
7.5 Introducing Category 2: Impacting Emotionally	142
7.5.1 Emotional Attachment to the Diary	142
7.5.2 Choosing How to Read the Diary	146
7.5.3 Effecting Others	148
7.6 Introducing the Core Category: Making Sense	150
7.6.1 Understanding the Journey	151
7.6.2 Owning the Diary	153
7.6.3 Creating Memories	157
7.7 Chapter Summary	159
Chapter 8 Grounding the Findings from the Healthcare Professionals	161
8.1 Introduction	161
8.2 Overview of the Categories	162
8.3. Introducing Category 1: Creating Connections	163
8.3.1 Connecting with the Child	164
8.3.2 Connecting with the Family	166
8.4 Introducing Category 2: Impacting Emotionally	170
8.4.1 Impacting Emotionally on the Family	171
8.4.2 Impacting Emotionally on the HCP	172
8.5 Introducing Category 3: Empowering Involvement	177
8.5.1 Providing Choice	178
8.5.2 Offering a Distraction	181
8.5.3 Anticipating Grief	182
8.6 Introducing the Core Category: Making Sense	185
8.6.1 Explaining the Journey	185
8.6.2 Creating Memories	188
8.7 Chapter Summary	190
Chapter 9 Making Sense: Towards the Final Conceptual Theory	192
9.1 Introduction: The Use of PICU Patient Diaries in Making Sense	192
9.2 Storyline: Justifying the Use in a Constructivist Grounded Theory Study	192
9.3 Storyline: Narrating the findings from the UPDATE Study to Ground the Final Theory.	193
9.4 Owning the Diary: Leading to Making Sense	196
9.5 Understanding and Explaining the Journey: Leading to Making Sense	200

9.6 Creating Memories: Leading to Making Sense	204
9.7 Sense-making Theories: Informing the Core Concept of Making Sense	209
9.7.1 The Sense-making Theory	209
9.7.2 The Cynefin Framework	210
9.7.3 The Data Frame Theory	210
9.7.4 Sense-Making Model	211
9.8 Application of the Sense-Making Model to the Core Category	212
9.8.1 Situation in Time and Space	213
9.8.2 The Context	213
9.8.3 Information Gap	214
9.8.4 Bridge: Relevance and Sources	215
9.8.5 Outcome in Situations	215
9.9 Final Theory: Redefining the UPDATE Study Storyline.	217
9.10 Chapter Summary	218
Chapter 10 Conclusions, Limitations and Recommendations	219
10.1 Introduction	219
10.2 Conclusions	219
10.2.1 Answering the Research Question.	219
10.2.2 Meeting the Aim and Objectives	221
10.2.3 The Initial Impression of the Diary for the Child, their Family Members, and the HCP.	222
10.2.4 The Use of the PICU Diaries by the Child, Family Members, and the HCPs	222
10.2.5 The Value of the PICU Diaries and any Negative Connotations	223
10.2.6 The Perceived Impact of the Diary by the HCPs.	224
10.3 Limitations of the UPDATE Study.	224
10.4 Study Implications	227
10.4.1 Recommendations and Implications for Clinical Practice	227
10.4.2 Recommendations and Implications for Education	229
10.5. Recommendations for Future Research	231
10.5.1 The Child Patient's Perspective	231
10.5.2 Impact of the Diary after the Death of a Child	232
10.5.3. Long-term Benefits and Outcomes.	232
10.5.4 Understanding the Broader HCP Perspective	233
10.5.5 Cultural, Familial, Language and Literacy Considerations	233

10.5.6 Evaluation of Diary Content	234
10.5.7 Cost-effectiveness Analysis	234
10.5.8 Replication of Adult ICU Patient Diary Studies.	234
10.6 Reflecting on the PhD Journey	235
10.6.1 Understanding the Impact of the Researcher on the UPDATE study.	235
10.6.2 Understanding the Impact as a PICU Nurse and a Researcher	236
10.6.3 Understanding the Impact as a mother and a Researcher.	237
10.6.4 Looking Back and Moving Forward	238
10.7 Final Words	240
References	241
Appendices	256
Appendix 1 Advertising material for study	256
Poster and Flier for Families	256
Poster and Flier for HCPs	256
Appendix 2 Information Sheets for Participants	257
Adult Family Members	257
Child Information Sheet Index Child 4-7 years old	261
Information Sheet Index Child 8-11 years old	263
Information Sheet for the Young Person	266
Information Sheet for Siblings	269
Information Sheet for Child Siblings 8-11 years old	272
Information Sheet for Siblings 4-7 years old	275
Appendix 3 Information Sheet and Consent for Healthcare Professionals	277
Healthcare Professional's (HCP) Information Sheet	277
Healthcare Professional Consent Form	280
Appendix 4 Consent Forms	281
Consent Form for Parents or Guardians	281
Consent/Assent Form for Index Child 4–7-year-old	282
Consent/Assent Form Sibling 8-11 years old	284
Appendix 5 Interview Guides for Families	285
Interview Guide Adult Participant First Initial Interview	285
Interview Guide Child Participant	288
Appendix 6 Interview Guide for HCP Focus Group Interviews	291
Interview Guide for HCP Focus Group Interviews	291
Appendix 7 Manual Analysis Process	294



Example of processes used to manually analyse data	294
Appendix 8 Memos	295
Examples of Memos Used Throughout the UPDATE Study	295
Appendix 9 Focus Group Discussions	296
Example of Sicky Notes Generated during the Focus Group Interviews.	296
Appendix 10	297
Approval Letters	297

## List of Tables

Table 2.1 Critical Care Levels of Patient Acuity and Nurse: Patient Ratios [adapted from PCCS (2021)]	31
Table 2.2 Summary of PICU Diary Studies	41
Table 3.1 Characteristics of PICUs	59
Table 3.2 Diary Purpose	61
Table 5.1 Eligibility Criteria for the UPDATE Study Participants	86
Table 5.2 Initial Open Codes	98
Table 5.3 Focused Codes	100
Table 5.4 Applying the Standards of Rigour to Research [adapted from Chiovitti and Piran, 2003]	105
Table 6.1 Characteristics of Child and Family Participants	119
Table 6.2 Characteristics of the Healthcare Professional Participants	125

## List of Figures

Figure 2.1 PRISMA Flow diagram [adapted from Page et al., (2021)]	39
Figure 4.1 Theoretical Framework for Research Design [adapted from Crotty (1998)]	70
Figure 5.2 Diagrammatical overview of the Constructivist grounded theory Approach [Modified from Charmaz 2006]	104
Figure 7.1 Summary of the categories and sub-categories from the parent and child participants	130
Figure 8.1 Summary of the categories and sub-categories from HCP participants	163
Figure 9.1 Making Sense: A Constructivist grounded theory study of the use of patient diaries in the Paediatric Intensive Care Unit	196
Figure 9.2 The Sensemaking Metaphor (used with permission <a href="http://www.sense-making.org">www.sense-making.org</a> )	211
Figure 9.3 Sense-Making Process and Theory (adapted from Dervin, 2008)	216
Figure 10.1 Making Sense: A Constructivist grounded theory study of the use of patient diaries in the Paediatric Intensive Care Unit [replicated from Fig. 9.1]	221

# **Chapter 1 Introducing the UPDATE Study: Aims, Objectives and the Researcher's Positionality**

## **1.1 Introduction**

A comprehensive overview of the Use of Patient Diaries in paediatric intensive care, the UPDATE research study, is described in this chapter. The concepts of paediatric intensive care, the child, the impact of critical illness, and patient diaries will be introduced in this chapter. The study background, research question and objectives of the UPDATE study are explained. The significance of the study is justified in relation to its importance for clinical practice, education, and further research. The researcher's background within the context of paediatric intensive care is also explained. Finally, to orientate the reader, the structure of the thesis is outlined.

## **1.2 Study Background**

Paediatric Intensive Care Units (PICUs) provide highly specialised medical and nursing care to critically ill children. These units offer appropriate interventions for children experiencing physiological instability post-surgery, or due to infection, trauma, or the deterioration of a chronic condition. Admission to a PICU is relatively uncommon, with 18,320 children between 0 and 15 years of age admitted to PICUs across the United Kingdom (UK) and the Republic of Ireland (RoI) in 2021. This corresponds to 11.3 admissions per every 10,000-child population of the UK and RoI (PICANet, 2022).

Paediatric critical care encompasses the care provided to children who require a higher level of observation, monitoring, or intervention that cannot be safely delivered in a general children's ward. This care is categorised into three levels: Level 1, which involves basic critical care interventions such as high-flow oxygen delivery and additional clinical monitoring; Level 2, which includes intermediate critical care

interventions such as non-invasive ventilation; and Level 3, the most advanced level of critical care involving invasive mechanical ventilation and additional support interventions (PCCS, 2021).

Critical illness in a child might result in profound changes in their physical and psychological well-being. The familiar notion of a vibrant and lively child is starkly transformed on admission to the PICU: “In the PICU they lie, immobilised, at the boundary of life and death” (Place, 2000, p. 172). This vivid depiction portrays a child devoid of vitality, unable to interact or engage with their environment, existing in a state of suspended animation. While this image may occasionally hold true, it is important to recognise that critically ill children are often sedated but have periods of awareness where they can perceive and experience their surroundings (Colville et al., 2008; Manning et al., 2018). Therefore, understanding that the child may be aware of their environment and the psychological impact this may have is an important area where more evidence is required to understand how to minimise the impact and support recovery.

Latour et al.’s (2008) seminal work identified the critically ill child’s family as playing a vital role in supporting and caring for them. Segers et al. (2019), building on the seminal work of Latour (2008), described family-centred care (FCC) as the comprehensive approach to care delivery in partnership with parents or caregivers. Widely accepted as a holistic model of care, FCC is considered the optimal way to provide care for hospitalised children (Shields et al., 2012). The child’s primary caregivers are encouraged and supported to be present during the PICU admission. Therefore, the PICU experience, with the abundance of technology, the concern that their child may die, and the overall critical atmosphere, have been well-recognised

stressors for the child, their family, and the healthcare teams (Colville and Pierce, 2012; Manning et al., 2018).

Qualitative and quantitative research studies and subsequent policy exploring the consequences of the intensive care environment on adult patients acknowledge the deleterious effects this experience can have (NICE, 2009). Almost three decades ago, authors began to write about the experiences of critically ill adults, comparing these experiences to those of torture victims, where feelings of isolation, omnipotence, disorientation, and physical discomfort were articulated (Dyer, 1995a, 1995b). The physical and psychological consequences of critical illness in adult intensive care survivors have been more recently conceptualised in the framework: Post Intensive Care Syndrome (PICS) (Rawal et al., 2017). Manning et al. (2018) further developed this framework to describe the experiences of critically ill children and their families. The Post Intensive Care Syndrome – Paediatrics (PICS-p) framework is intentionally broad to include all age groups cared for in the PICU and their families. The family is seen as an interdependent unit, recognising that the impact a child's critical illness may have on family members may be profound. Family members' responses may subsequently influence the outcomes of the critically ill child; therefore, care of the child is not seen in isolation from their family (Colville and Pierce, 2012). The researcher's interest and developing understanding of the psychological impact of critical illness directed exploring interventions that could improve the outcomes for the child and family after PICU discharge.

Studies conducted in adult intensive care units (ICU) have explored interventions that may improve the psychological impact of critical illness for the patient and their relatives. Critical care patient diaries are one such intervention that has been

considered to support patients and relatives. Critical care diaries are used to chronicle the patient's time in the Intensive Care Unit (ICU), recording and explaining events that have happened. The patient diary is a written journal of the patient's critical illness experience in an ICU. The ICU staff, family members and friends often write the diary. In plain language, the diary aims to explain what has happened to the patient during a time when they may not be able to recall or understand what is happening to them. There is variation in how ICU patient diaries are defined throughout the world. However, some universal concepts of the aims of the diary, formatting and content exist. The ICU diary usually begins at admission and provides a background to the reasons for the critical illness or injury (Ullman et al., 2014). Photographs may be included to aid understanding. The structure and content of the diaries vary, and primary authorship is usually the nursing teams, with the patient's relatives encouraged to contribute (Garrouste-Orgeas et al., 2017).

On commencing the UPDATE study in 2016, there were no published studies examining the impact of PICU patient diaries. A recent scoping review (Low et al., 2023) found only nine studies that explored the impact of PICU patient diaries, and these were published from 2018–2022. These studies will be explored further in Chapter 2 and provide insights into how the PICU diaries were defined. The benefits the PICU diary provided to the child and their family was also explored as PICU diaries were explained as providing a tool to aid communication, facilitate family-centred care and fill gaps in memories (Gawronski et al., 2022; Herrup et al., 2019; Laudato et al., 2020; Mikkelsen, 2018). Nevertheless, it is important to recognise that these studies were published after the UPDATE study commenced.

While the use of patient diaries in the PICU has evolved over the past decade, the impact of this intervention is still not yet fully understood (Gawronski et al., 2022; Lynch et al., 2020). The unique nature of the PICU, where the child is often too young to comprehend their critical illness journey and a family-centred approach is encouraged, needs to be considered as being different from the adult ICU experience. Since 2010, patient diaries have been offered to all children and families admitted to the study site regardless of their condition, prognosis, or anticipated length of stay. The patient diaries were introduced by the PICU play specialist and the researcher after recognising the positive impact this intervention had in the adult ICU setting. Family feedback, collected through family satisfaction surveys at the study site, suggested that the diaries were viewed positively and valued. Nevertheless, as there were no published studies at the point of commencing this research to support or refute these findings, further investigation was warranted. Therefore, the impact and usefulness of diaries in this population required further exploration, forming the rationale for this research study.

### **1.3 Research Question, Aims and Objectives of the Study**

The overarching research question addressed in this thesis is:

*How are patient diaries used by the child, the family, and the healthcare professional (HCP) during and after admission to the Paediatric Intensive Care Unit (PICU)?*

The aim of the UPDATE study was to ascertain how patient diaries were used by children, families, and healthcare professionals during and after admission into the PICU. The study objectives were to gain insights and understanding into the following:



- The initial impression of the diary for the child, their family members, and the healthcare professional.
- How the diary was used by the child, family members and healthcare professionals.
- The perceived value and any negative connotations of the diary.
- The perceived impact of the diary by the healthcare professionals.

#### **1.4 Significance of the Study**

Much of the previous research in this area has focused on the impact and experiences of using diaries in the adult ICU setting. Adult ICU-focused research has explored how diaries support survivor recovery, inform patients and relatives, fill memory gaps, and the impact diaries have on the healthcare professionals who contribute to them.

Although a relatively new intervention, the research has supported the implementation of diaries worldwide with the recommendation for their use by several professional organisations (ICUSteps, 2023; NoECCN, 2022) The limited number of published studies on the impact of diaries in the PICU setting has resulted in a dearth of understanding and a need for further investigation. The child and family experiences in the PICU setting differ from that of the adult ICU patient, and extrapolating the findings from the adult studies is not easily applied to the PICU context. The significance of addressing the experiences of children and their families and the impact that patient diaries may have therefore warrants further investigation.

Doctoral-level study requires the researcher to demonstrate original knowledge, systematically acquire and understand the knowledge surrounding professional practice and conceptualise, design, and implement new knowledge (QAA, 2021). To my

knowledge and the current evidence, this is the first research study exploring using PICU diaries in the UK from the perspective of the child, parents, and HCPs. The UPDATE study illuminates the processes involved in using PICU diaries, which will contribute to the evidence base by identifying the value of the diary, how it was used and any drawbacks. Therefore, the PhD study fills a gap in research and clinical knowledge and informs practice during and after admission into the PICU.

The UPDATE study contributes to the understanding of the HCPs' experiences when using PICU patient diaries, providing greater knowledge and insights into how their role contributes to supporting critically ill children and their families. Furthermore, the UPDATE study has highlighted the hesitancy and uncertainty expressed by HCPs, as there is a lack of clinical and professional guidance on implementing and using diaries. This study contributes to the evolving evidence base in this setting and supports furthering professional guidance and policy for using PICU patient diaries.

In summary, the UPDATE study exploring using PICU patient diaries is essential for several reasons. Firstly, this study has explored and enhanced knowledge of the use of PICU patient diaries and the value they bring. Secondly, the study identified the social processes parents and HCPs applied when using diaries during and after PICU admission. Thirdly, the study recognises the implications for practice, education and policy, which can inform future clinical and professional guidance. Finally, this study contributes to the body of knowledge on PICU patient diaries and can provide direction for future research on this under-investigated topic.

The position of the researcher and the impact this positionality had on the study will now be explored.

## **1.5 The Researcher's Background**

This section will contextualise my position as a researcher in this study topic. The lens I used when conducting this study is complex and shaped by my experience as a PICU nurse and a mother. Being clear on my voice as a researcher and how it influenced the study is vital for the authenticity of the final theory generated. When the UPDATE study commenced, I had worked as a senior nurse in a PICU for over 24 years. With the PICU play specialist, I had introduced diaries to the PICU seven years earlier. I recognised that the critical illness experience had a lasting impact on the child and their family. I wanted to look at interventions that could provide additional emotional support and enable coping, and the diary offered a potential tool for this. Implementing the diaries as an intervention was very straightforward, with guidance, education, and support. The PICU team positively embraced and readily implemented this new intervention. Understanding my stance as an insider senior PICU nurse and an outsider as the researcher was pivotal in assuring the quality of the theory generated in this study.

My personal experiences have also influenced my position as the researcher in this study. My son is adopted and has had life experiences before joining our family. Some of these experiences have been documented in a life storybook: a social work intervention used to recognise the adopted child's past. The life storybook composition is similar to patient diaries as they provide information about the child, often with photographs and descriptions of significant life events. His life storybook is treasured. Therefore, I have a favourable view of the value of this intervention and was mindful of this bias when conducting this research. The reflexive process of memoing, adopted from the instigation of this study, has allowed me to consider my feelings, biases, and preconceptions as a researcher.

My personal and professional experiences have inspired and influenced me to research how the PICU patient diaries support the child, their family, and the HCPs. Finally, being open and honest about how my experiences may influence this research is crucial in ensuring the quality of the study.

The thesis structure will now be explained to orientate the reader.

### **1.6 Structure of the Thesis**

This thesis is organised into ten chapters.

Chapter 1 introduced the research study by defining the topic, stating the aims and objectives, and explaining the study's significance and anticipated impact. The chapter has also positioned the researcher's background in this study and finally provided an overview of the thesis structure.

Chapter 2 sets the background of this study, describing the provision of paediatric intensive care and the psychological impact critical illness has on the child and their family. However, as this is a constructivist grounded theory study, the literature presented provides a basis for the research rather than providing a systematic literature review which draws conclusions.

Chapter 3 contributes further background to this study as it contains findings from a published survey of all UK and Republic of Ireland PICUs describing the incidence, use and scope of patient diaries (Lynch et al., 2020).

Chapter 4 outlines the reasoning for the philosophical, theoretical, and methodological decisions underpinning the UPDATE study. In doing so, the justification, focus and rationale for the research approach to answering the intent of the UPDATE study is explained.

Chapter 5 critiques the methods used in the UPDATE study and presents a rationale for the adopted constructivist grounded theory methods.

The study findings are presented in Chapters 6, 7 and 8. In Chapter 6, characteristics of the patient, their family and HCP participants are presented. Chapters 7 and 8 provide findings from child/family participants and HCP participants, respectively.

In Chapter 9 the categories, theoretical sampling and theoretical sensitivity that led to the development of the core category of *Making Sense* are explained. The integration of the findings with previous studies will be discussed. The emergent grounded theory is presented using the storyline developed from the abduction of the findings.

Chapter 10 concludes the thesis, addressing the research question and explaining implications for clinical practice, education and research whilst acknowledging any study limitations. A personal reflection on the insights gained through this study will also be provided.

## **Chapter 2 Scoping Review of the Literature: From Nothing to a Little.**

### **2.1 Introduction**

In this chapter, literature on the topic of PICU patient diaries is discussed as the background to the UPDATE study. The research methodology adopted for this study is constructivist grounded theory. Conducting a literature review in a grounded theory study is a contentious aspect of the research approach (Charmaz, 2006; Birks and Mills, 2023). In the original, traditionally perceived forms of grounded theory, the formal literature review is delayed minimising the researcher imposing existing theories on the study outcomes (Birks and Mills, 2023). However, a literature review is required to justify the research topic, understand the research gaps, and focus the research question (Charmaz, 2014; Bryant and Charmaz, 2019).

To provide background to the research and to inform the study development, a review of the current literature will be provided to orientate and describe the PICU setting and the psychological impact of critical illness on the child and their family. An overview of the impact of diaries used in adult ICU settings diaries will be provided to support psychological recovery. On commencing the UPDATE study in 2016, no published studies on the impact of PICU patient diaries existed. Nevertheless, several studies have been published over the past seven years and will be reviewed in this chapter.

### **2.2 Contextualising the Paediatric Intensive Care Unit**

Paediatric Intensive Care Units provide highly specialised medical and nursing care to critically ill children. These units offer appropriate interventions for children experiencing physiological instability post-surgery, or due to infection, trauma, or the

deterioration of a chronic condition. Admission to a PICU is relatively uncommon, with only 18,320 children between 0 and 15 years admitted to PICUs across the United Kingdom (UK) and the Republic of Ireland (RoI) in 2020. This corresponds to 11.3 admissions per every 10,000 children in the UK and RoI (PICANet, 2021).

Paediatric critical care encompasses the care provided to children who require a higher level of observation, monitoring, or intervention that cannot be safely delivered in a children's ward. This care is categorised into three levels: Level 1, which involves basic critical care interventions such as high-flow oxygen delivery and additional clinical monitoring; Level 2, which includes intermediate critical care interventions such as non-invasive ventilation; and Level 3, the most advanced level of critical care involving invasive mechanical ventilation and additional support interventions. The three levels of critical care are recognised in which Levels 1 and 2 map to high dependency care and Level 3 relates to intensive care (PCCS, 2021). Further examples of the levels of critical care and the safe staffing standards, expressed as the ratio of nurse to patient, are described in Table 2.1.

Table 2.1 Critical Care Levels of Patient Acuity and Nurse: Patient Ratios [adapted from PCCS (2021)]

Critical Care Levels	Clinical Examples	Nurse to Patient Ratio
<b>LEVEL 3 Advanced Critical care</b>		
<ul style="list-style-type: none"> <li>Two or more organ system requiring technical support; including advanced respiratory.</li> </ul>	Child with severe sepsis requiring cardiovascular support with inotropes, high frequency ventilation and hemofiltration.	1:1
	Extracorporeal membrane oxygenation (ECMO).	2:1
<b>LEVEL 2 Intermediate Critical care</b>		
<ul style="list-style-type: none"> <li>Advanced respiratory support</li> <li>Two or more organ systems requiring support.</li> <li>One acute organ failure requiring support plus one chronic failure</li> </ul>	Child with a tracheostomy Non-invasive ventilation Status epilepticus requiring treatment with continuous intra-venous infusion.	1:1
<b>LEVEL 1 Basic Critical Care</b>		
<ul style="list-style-type: none"> <li>Requirement for closer observation and monitoring the is available on a standard ward.</li> <li>Single organ support</li> </ul>	Child with diabetic ketoacidosis requiring continuous insulin infusion. Severe asthma requiring intravenous bronchodilators. Reduced level of consciousness and hourly or more frequent monitoring.	0.5:1

### 2.3 Psychological Impact of Critical Illness

The PICU, with its abundance of technology, busy staff, and overall atmosphere of criticality, has been long recognised as a stressor for all those experiencing it (Colville et al., 2008; Latour et al., 2011; Colville and Pierce, 2012; Manning et al., 2017). For many decades, research studies exploring the consequences of the intensive care environment on adult patients have acknowledged the deleterious effects this experience can have (NICE, 2009). Critically ill adult patients' experiences have been compared to the Amnesty International definition of torture, where feelings of isolation, omnipotence, disorientation, and physical discomfort have been described around this phenomenon (Dyer, 1995a, 1995b).

Needham et al. (2012) conceptualised the morbidities experienced by adult intensive care survivors as Post Intensive Care Syndrome (PICS). Manning et al. (2018) further developed this framework to describe the experiences of critically ill children and their



families. The Post Intensive Care Syndrome–paediatrics (PICS-p) is intentionally broad to include all age groups cared for in the PICU, such as babies, children and young people and their families. The family is seen as an interdependent unit, and therefore, the PICS-p framework recognises that the child’s critical illness may profoundly impact the broader social connections. Family members’ responses may subsequently influence the outcomes of the critically ill child (Colville and Pierce, 2012) and, therefore, should not be seen in isolation.

The PICS-p framework describes the importance of recognising the baseline status of the child and family before and during the critical illness, recognising that the child may have varying levels of health, sociodemographic status, physiological maturity, and psychosocial development on admission to the PICU. During and post PICU discharge, the child and family’s recovery is considered in four domains of health: physical, cognitive, emotional, and social health (Manning et al., 2018; Perry-Eaddy et al., 2022). The PICS-p framework, therefore, provides a road map for understanding the outcomes for the critically ill child and family.

The domain of emotional health in PICS-p considers the concept of Post-Traumatic Stress Disorder (PTSD) as one manifestation of the negative consequences of critical illness (Manning et al., 2018; Needham et al., 2012) To meet the criteria of PTSD, a person needs to have experienced or witnessed a traumatic event, usually involving a threat to life or physical integrity. The person may present with a range of symptoms associated with functional impairment, including re-experiencing the event, avoidance, emotional numbing, dissociation, and emotional dysregulation (Colville et al., 2008; NICE, 2018).

It is acknowledged that children, young people, and their immediate family can develop PTSD following traumatic events such as threats to life, serious accidents or

trauma related to severe health issues such as critical illness (NICE, 2018). If not recognised or adequately treated, PTSD can result in a substantial deleterious effect on physical, social, and academic functioning, increased risk of substance abuse and incidence of mental health disorders (Bronner et al., 2008; NICE, 2018). Understanding the emotional domain within PICS-p and the psychological impact of critical illness on the child and their family is imperative to all who work in healthcare (Manning et al., 2018).

#### **2.4 The Psychological Impact of Critical Illness Through the Lens of the Child and their Family**

When considering the literature exploring the experience of adult patients and relatives, it is of note that there needs to be more research on the child's experience. It is universally accepted by healthcare professionals that admission to a hospital is associated with actual and imagined threats to the child's emotional well-being (Ministry of Health, 1959; Rennick et al., 2004; Colville et al., 2008; Colville and Pierce, 2012). However, the emotional impact of critical illness on the child remains an under-researched area.

Evidence from quantitative studies over the past two decades support the idea that critically ill child and their family can suffer significant and lasting psychological sequelae post-PICU. Rees et al. (2004) explored whether PICU admission is associated with more significant psychiatric morbidity in children and parents than general paediatric ward admissions. This retrospective, small, cohort study compared PICU patients' parents (n=35) with parents admitted to general paediatric wards (n=33). Children aged 5–18 were discharged from PICU (exposed cohort) and general paediatric wards (unexposed cohort) 6–12 months previously.

Together with their parents, the children were interviewed and assessed for psychiatric morbidity using various clinician-administered psychological tools for both the child and parents. The study concluded that PTSD was identified in 21% (4/19) of children discharged from PICU compared to no cases in the children admitted to non-PICU wards (0/27). Over a quarter (27%) of the parents of PICU-admitted children were assessed as being a high risk for developing PTSD, significantly higher than for parents of ward-admitted children. Whilst this is not surprising, there was also a positive correlation between PTSD symptoms in parents and PTSD symptoms in the child, length of admission and perceived threat of illness to the child's life.

Bronner et al. (2008) explored the presence or symptoms of PTSD in children after PICU (n=36). In this prospective follow-up study, 36 children (8–17 years old) completed a self-report response to trauma inventory at three months, nine months follow-up, or both. A third (33%) of the post-PICU patients had subclinical (PTSD detectable by testing but no clinical manifestations) PTSD, and 13.8% met the diagnostic criteria for PTSD, concluding that a considerable number of children have PTSD after a PICU admission (Bronner et al., 2008). Both Rees et al. (2004) and Bronner et al. (2008) acknowledged that the constellation of problems found in PTSD provides a valuable diagnostic framework for evaluating children's psychological responses to PICU hospitalisation.

These studies are also supported by the findings of Colville et al. (2008), who attempted to establish whether the relationship between the incidence of delusional memories and the increased risk of PTSD in adult ICU patients would be replicated in children. Delusional memories are defined as nightmares, hallucinations, dreams, or the sense that someone was trying to harm them (Colville et al., 2008). Adult ICU studies concluded that survivors who were unable to recall the events of their ICU

admission were at greater risk of developing PTSD (Garrouste-Orgeas et al., 2019; Jones et al., 2001; Nakashima and Gallegos, 2020).

Colville et al. (2008) interviewed 102 children, aged 7–17 years old, about their PICU experience three months post-discharge. Principal outcome measures used were the ICU Memory Tool, a checklist of intensive care memories, and a paediatric version of the Impact of Events Scale, a screening tool for post-traumatic stress disorder. The study concluded that delusional memories were reported in almost one-third of the child participants and that PTSD scores were higher in children with delusional memories (adjusted for severity of illness 3.0; 95% CI, 1.3-20.0: P=0.023). The study concluded that those children who expressed accurate memories were not at a greater risk of developing PTSD, suggesting a relationship between false or delusional memories and lasting emotional trauma.

These three studies conclude that many critically ill children and their parents may develop PTSD. Increased parental distress, greater length of PICU stay, delusional memories and emergency admission are possible predictors of developing PTSD in the child. More recently and building on the previous findings, the impact of PTSD on children can have lasting deleterious effects: physical, emotional, and social (Bronner et al., 2008b, 2008a; Manning et al., 2018; Perry-Eaddy et al., 2022). The researchers concluded that the prevalence and incidence of PTSD in the PICU population was an under-recognised issue. Nevertheless, these studies did not explore what interventions could reduce the risk of PTSD development in the child and family.

Two studies have focused on the intervention of follow-up post-PICU. Bronner et al. (2008) and Colville et al., (2010) explored the impact of parents' follow-ups post-PICU. Bronner et al.'s (2008) prospective cohort study explored the prevalence of PTSD after an acute admission to a PICU and aimed to determine the risk factors for developing

PTSD in parents. Post-discharge, 250 eligible patients and family members were invited to a follow-up appointment. Some 144 (57.6%) of the invited sample attended a visit to the follow-up clinic three months post-discharge. This study concluded that an unexpected PICU admission is stressful for parents, that psychological support should not end at discharge, and that follow-up is warranted.

Colville et al.'s (2010) randomised control trial aimed to evaluate the psychological impact on parents of providing a PICU follow-up clinic. Families post-PICU (n=77) were randomised to the intervention of invitation to a follow-up appointment with a PICU intensivist, PICU nurse and psychologist two months after discharge versus the control of no appointment. PTSD, anxiety, and depression were assessed at five months using the validated and reliable tools of the Impact of Events Scale and Hospital Anxiety and Depression Scale (Colville, 2010). Only 18 families (25%) in the intervention group chose to attend the follow-up clinic. Colville et al. (2010) concluded that due to low attendance to the follow-up appointment (25%), it was difficult to justify routine follow-up but suggested that for the most traumatised parents, long-term distress could be reduced by this intervention, recommending that a more extensive investigation is warranted.

More recent studies have considered the concept of traumatic growth, an experience of positive change after a traumatic event. A cross-sectional survey of 82 parents of children admitted to PICU found that a high proportion of parents (67.1%) reported experiencing post-traumatic growth. The parents whose child was in the PICU for a prolonged stay reported increased traumatic growth. This finding was related to parents' ability to foster a greater therapeutic relationship with the PICU team (Yagiela et al., 2022). The study did, however, conclude that 33% of the parent participants demonstrated scores concerning PTSD (Yagiela et al., 2022). Therefore,

this study highlights the high proportion of parents that may still experience difficulties and corroborates the need to consider interventions that can help support the child's and family's emotional recovery.

At the instigation of the UPDATE study, interventions that could be used to meet the child's and family's psychological needs during and after a PICU admission were limited. However, studies emerging from adult ICU explored how the ICU diary improved the psychological impact of critical illness for both the patient and their relatives (Nydahl et al., 2019; Teece and Baker, 2017). Writing a diary for intensive care patients was first noted in Denmark in the 1980s and was soon followed up in Sweden and Norway (Egerod and Christensen, 2009) In the 1990s, ICU patient diaries were reported in the UK (Combe, 2005; Robson, 2008) and have since emerged in other European and North American Countries (Jones et al., 2006; Roulin et al., 2007). The patient diary is a written journal of the patient's critical illness experience in an ICU (Nielsen et al., 2019, 2020; Nielsen and Angel, 2016b; Tavares et al., 2019). The ICU staff, family members and friends often write the diary. In plain language, the diary aims to explain what has happened to the patient during a time when they may not be able to recall or understand what is happening to them (Aitken et al., 2017; Feinblum et al., 2016; Teece, 2020). Patient diaries are usually the patient's property and will be handed over at discharge or later during a follow-up appointment (Jones et al., 2010). Several systematic reviews of the studies on this intervention have concluded that adult ICU patient diaries are a low-cost, low technology intervention well accepted by patients and their relatives (Barreto et al., 2019; Brandao et al., 2021; Ullman et al., 2014) ICU diaries have also been found to reduce the incidence of PTSD in patients (Jones, 2021; Palombi et al., 2018; Sun et al., 2021) and reduce anxiety and depression (Ewens et al., 2015; Sun et al., 2021). Nevertheless, the synthesis of current studies all

advise that further research is required to evaluate the impact of adult ICU diaries fully. Extrapolation of the adult ICU diary studies to the context of the PICU as an intervention to support the psychosocial recovery of the child and family also warranted further exploration.

## **2.5 PICU Patient Diaries Scoping Review**

An initial review of the literature, conducted in 2016 to contextualise, justify and aid the study protocol development, found no studies investigating the intervention of PICU diaries. However, a scoping review was completed in June 2023 to provide further contemporary background to the UPDATE study. The search strategy was structured using the Population, Concept and Context Model (Munn et al., 2018; Pollock et al., 2023).

The review question posed was: *What is the impact (concept) of PICU patient diaries (context) on children, families, and HCPs (population)?* The inclusion criteria were purposively broad to ensure any relevant studies were included, but the publication date was restricted to post-2016, and only studies published in English were included. The following databases were searched: CINAHL, Medline, and EMBASE. The Medical Subject Heading (MeSH) terms and keywords included in the search strategy were: Paediatric Intensive Care Unit, child, a critically ill child, family, parents, healthcare professionals, Adult ICU diaries, diaries, journals, scrapbooks, and reflective journals. Terms related to the outcome measures included: emotional, psychological, PTSD and PICS-P. Grey literature from the search engine Google Scholar was also gathered. The search of the grey literature did not result in any studies not already identified using healthcare search databases.

The initial search strategy identified 280 records (Figure 2.1). After excluding 190 duplicates, 90 articles were screened by title and abstract. A further 66 articles were

excluded, and 24 reports were assessed for eligibility to be included in the review. Of these a further 13 were excluded for a variety of reasons. The reasons for exclusion included: conference abstracts, describing interventions that were not diaries, or setting and population not PICU. Finally, 11 articles were included in this structured review.

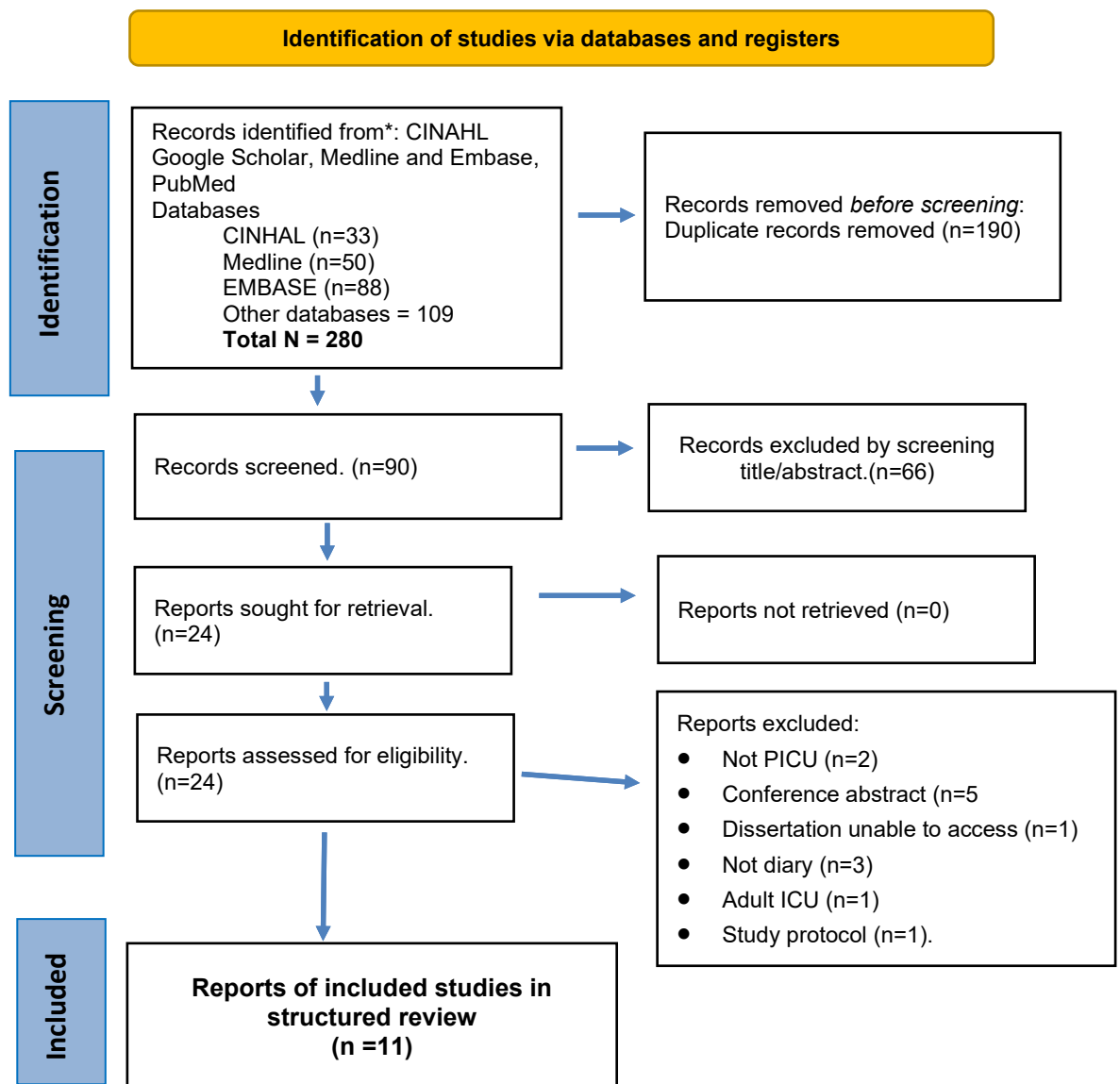


Figure 2.1 PRISMA Flow diagram [adapted from Page et al., (2021)]

### 2.5.1 Research Studies Characteristics.

Of the 11 studies identified, two were systematic reviews (Sansone et al., 2021; Low et al., 2023), three studies used qualitative methods (Mikkelsen, 2018; Jakobsen et al.,



2021; Sansone et al., 2022), three used quantitative methods (Board, 2021; Herrup et al., 2019; Lynch et al., 2020) and one adopted a mixed-methods approach (Gawronski et al., 2022). Of the remaining studies, one was a quality improvement project that used quantitative methods to capture feedback (Wang et al., 2022) and the final study, described as a prospective descriptive study, provided no information on the methods used (López Fernández et al., 2022).

Five studies recruited parents as participants (Herrup et al., 2019; Board, 2021; Jakobsen et al., 2021; López Fernández et al., 2022; Wang et al., 2022); one study recruited HCPs and parents (Gawronski et al., 2022), two studies recruited HCPs (Lynch et al., 2020; Sansone et al., 2022) and one study recruited parents and children (Mikkelsen, 2018)

A scoping review does not require an assessment of the included studies' quality. A scoping study does not seek to assess the quality of evidence (Levac et al., 2010) but instead aims to map the extent and nature of the existing literature. As a result, no formal quality appraisal was conducted as part of this review. Nevertheless, academic supervision was used to discuss the reviewed articles offering additional insights and critique. The study characteristics, main findings and synthesis of the findings are found in Table 2.2.

Table 2.2 Summary of PICU Diary Studies

Authors	Study Aim	Study Design	Diary structure/Intervention	Methods	Participants	Summary of Findings	Synthesis of Findings
<b>Systematic reviews</b>							
Low et al., 2023	Scoping review of NICU and PICU diaries	Systematic scoping review	N/A	Systematic Scoping Review	N/A	16 articles found. 9 related to PICU	N/A
Sansone et al., 2021	Scoping review of narrative health diaries in Paediatrics	Systematic Review	Different types of diaries described including paper, audio and video	Structured systematic review.	N/A	Reported only two studies related to PICU diaries (Mikkelsen and Herrup)	N/A
<b>Child and parent perspectives</b>							
Mikkelsen, 2018	To explore children's and families' experiences of using PICU diaries after discharge	Qualitative exploratory design.	Daily records written by nurses. Pre-prepared pictures and text explaining procedures and equipment. Parents do not write entries but encouraged to keep a personal diary.	Semi-structured interviews with 5 children and families 4-6 months after discharge.	Parents and children	Three main themes Value to entire family. Creating memories. The importance of pictures.	Parental perspectives Children's perspectives
<b>Parental Perspectives</b>							
Board, 2021	Exploration of the use of journal writing to reduce anxiety in PICU parents.	Longitudinal, quasi-experimental two-group study -	Parent given a composition notebook and instruction to write anything at least once a day for 15-20 mins.	Data collected at 3 time points (during, before discharge and 6-8 weeks post discharge). Stressor scales used and feedback	28 Parents – control and intervention groups	The majority of the experimental group parents wrote in their journals daily and found the intervention helpful.	Parental perspectives

Herrup et al., 2019	Feasibility and perceptions of the PICU diary	Observational pilot study	Offered on D3 with guidance on how to use. Free text and photographs encouraged, Contributed to by families and HCPs	Questionnaire with multiple choice and open questions	21 families including 21 mothers and 18 fathers enrolled into study. 12 families completed diary follow-up survey (n=12 individuals)	Diary entries authored by HCPs. Useful tool for communication and use of photographs positively received.	Parental perspectives
Wang et al., 2022	Evaluate the feasibility and efficacy of a PICU diary	Quality Improvement project-	30-paged pre-populated diary/information booklet. Guided – information and coping mechanisms. Sections that prompt families to write about feelings. Offered at D2-4 after admission	Multiple-choice survey	17 families participated and 24 parents, weekly follow-up survey. 11 families completed post-discharge	Value in documenting events to piece together and disclose emotions. Therapeutic tool to cope with child’s PICU admission	Defining the Diary Parental perspectives
Lopez Fernandez et al., 2022	Feasibility and acceptance of PICU diaries	Prospective descriptive study	Semi-structured boxes in booklet that prompted entries and stickers to illustrate medical equipment	Methods not described	24 families recruited.	Majority of diary entries completed by parents. Families reported the diary as useful and well received.	Parental perspectives
Jakobsen et al., 2021	Parental experiences during and after PICU admission and need for post-PICU follow-up	Qualitative-phenomenological hermeneutic approach	PICU diaries already established on PICU. Not described but referred to by participants	Semi- structured interviews	7 couples (parents) interviewed 6–14 weeks post-PICU discharge.	Diary was helpful in processing the experience as the diary was a tangible tool. Diary used to share their child’s experience with others.	Parental perspectives

HCP and Parental Perspectives							
Gawronski et al., 2022	Feasibility and perception of PICU diaries	Mixed methods prospective, observational study	Personal notebook. No specific headings. Parents and HCPs could report events, draw and photographs.	Parent: telephone interviews HCPs: questionnaire	HCPs at end of study period Parents 30 days post PICU discharge	Useful tool and recommend by parents. Diary part of the child and family's life story.	Defining the diary HCP perspectives
HCP Perspective							
Sansone et al., 2022	HCP perception of the implementation of PICU diaries	Qualitative study	Personal notebook. No specific headings. Parents and HCPs could report events, draw and photographs.	3 focus groups and 4 interviews with staff	HCPs- multi disciplinary group of nurses, physicians and physiotherapists.	3 main themes emerged: Meaning attributed by HCPs to the diary. Enablers to using diary. Barriers to diary writing.	HCP perspectives
Lynch et al., 2020	Incidence, use, and scope of patient diaries in paediatric intensive care units (PICUs) in the UK and Rol	Scoping Evaluation	N/A	E-survey open and closed questions	HCPs- nurses and doctors	43% PICUs offered diaries. Parents were the main contributors to the diaries (94%). The owner of the diary was the family (82%, n = 14) and the child (12%, n = 2)	Defining the diary HCP perspectives

Additionally, it is helpful to consider the definition of patient diaries described in the reviewed studies and compare these with those of the study sites' PICU diary model. The main findings and subsequent synthesis of the included evidence will now be presented using the themes of the PICU diary model definition, parents', children's, and the HCPs' perspectives on the diary.

### **2.5.2 Defining the PICU Diary Model.**

Since 2010, patient diaries have been offered to all children and families admitted into the study site PICU regardless of the child's clinical condition, prognosis, or anticipated length of stay. The diary was an A5 (15 cm x 21 cm) hard-backed notebook. A brief explanation of how the diary could be used was published on the first page. The guidance, directed to the child's parent or guardian, explained that consent would be sought and documented agreement to instigate the diary. The guidance explained that the family owned the diary, not the PICU staff. The study site's PICU diary was initially completed by the nurse caring for the child, who would write a reason for the child's admission using plain English. The parents and HCPs would author the diary, adding content about what may have happened to the child, photographs, drawings, and keepsakes. The diary's front cover was often customised with the child's name and stickers to individualise and personalise it. The diary and crafting tools, such as stickers, photographs, and coloured pens, were all provided free of charge to the family. The diary would remain in the child's bed space and as owned by them, continued to stay in their possession.

The diary model used in the study setting is replicated in other studies. Lynch et al. (2020) collated descriptors of the PICU diaries from the UK and the RoI, and the diary structure was reported as offering explanations for the child's admission and progress, with parents as the main contributors. Gawronski et al. (2022) used a free-form

approach to the diary, with an A5 notebook offered to families with no specific headings. HCPs and families populated the diary, and photographs and drawings were encouraged. However, some variations of the diary structure model have been reported. Mikkelsen (2018) and Wang et al. (2022) reported diary models that were semi-structured, with pre-populated pages that provided information and explained procedures and equipment. Nevertheless, all the diaries described in the studies were paper based; none were audio, video or digital. However, it is recognised that alternative modalities of diary composition will evolve, and future studies will undoubtedly include alternative diary forms.

The research studies retrieved for this structured review will be grouped by subject population to present a comprehensive literature account.

### **2.5.3 Parents' Perspectives on PICU Diaries**

The perspectives of parents were the focus of seven of the studies reviewed (Mikkelsen, 2018; Herrup et al., 2019; Board, 2021; Jakobsen et al., 2021; Gawronski et al., 2022; López Fernández et al., 2022; Wang et al., 2022). The main aim and objectives of the reviewed studies were to explain the feasibility and acceptability of PICU diaries by parents. The overwhelming finding from these studies was that the PICU diary was well received by parents, making this intervention feasible for this population.

Three studies used a quantitative approach to survey parents during and after discharge from PICU to ascertain the acceptability of using PICU diaries (Herrup et al., 2019; Board, 2021; Wang et al., 2022). Herrup (2019) recruited 21 families into an observational pilot study. Participants were offered a diary, although authored by the HCPs, and encouraged to write free text and photographs in their child's diaries. The families were followed up two weeks post-discharge. Some 95% (n=21) of those

offered a diary accepted the intervention, and 60% (n=12 families) completed the follow-up survey. The study concluded that the PICU diaries were a feasible intervention and perceived by parents as beneficial. The study recognised that the primary respondents to the survey were mothers (n= 9/12) and that there may be differences in the coping approaches to the experience of having a critically ill child compared to that of fathers, recognising the need for further investigation in this area. Wang et al. (2022) conducted a quality improvement project to explore the feasibility and efficacy of the PICU diary. Using a multiple-choice survey questionnaire, the study collected feedback from PICU families during admission and on day two, post-discharge. Seventeen families enrolled to receive a pre-populated information booklet about the equipment and interventions used in the PICU. The diary also offered information on family coping strategies and sections that prompted personal journaling. Twenty-four parents completed the weekly follow-up survey during the admission, and 11 families responded to the follow-up survey. Wang et al. (2022) concluded that the parents were positive about using the diary and believed it was beneficial to them.

The findings of these two studies are replicated in the study by Board (2021). This surveyed 28 families in a longitudinal quasi, two-group study. The intervention group received a composition notebook and was instructed to write daily for at least 15 minutes during their child's PICU admission. This intervention did not follow the more traditional diary format, although it did encourage narrative journaling to support parents writing about their experiences. The study also concluded that the participants reported this intervention as helpful. Finally, a study by López Fernández et al. (2022), published as a scientific letter with limited information on the methods used, recruited

24 families and reported that they perceived the diary as valuable and quickly adopted, concluding that it is a feasible and readily accepted intervention for parents. Exploration of parents' perceptions and experiences of using PICU diaries was investigated in two studies (Mikkelsen, 2018; Gawronski et al., 2022). Mikkelsen (2018) was the first published study on PICU patient diaries. This qualitative study explored children's and families' experiences using diaries and the perceived support the intervention provided for emotional recovery from critical illness. This study conducted semi-structured interviews with five children and their families up to six months post-PICU discharge. The study concluded that diaries made the paediatric intensive care experience meaningful by providing explanations of what had happened, often in the context of misunderstanding or confusion. Three main themes emerged from the study: the perceived value to the entire family, the ability of the diary to create memories and the importance of the visual explanations offered using pictures. The study also concluded that a diary could catalyse coping by "filling in the missing gaps" to support the child's understanding of this experience.

Gawronski et al. (2022) used a mixed-method, prospective observational approach to elicit parents' perspectives. Twenty families were enrolled on the study and were offered a notebook with no pre-defined headings, in which the HCP, parents and caregivers could write about events, draw pictures, and include photographs. Families were interviewed up to 30 days post-discharge. They were asked four-initial closed-ended questions to gather feedback on diary satisfaction and then open-ended questions to explore their personal opinions and elicit suggestions for improvements. The study concluded and validated the previous studies that the diary was helpful and that families recommend it to other families. Parents reported the diary as a tool to communicate with their children, allowing them to express feelings and emotions they



did not have anywhere else to share. Parents also explained how the diary helped to re-frame the PICU admission into a positive experience. Finally, the diary was considered integral to their child and family's life story.

The studies on parental perspectives of PICU diaries conclude that this intervention is well received, provides an opportunity to express emotions and feelings that may not be otherwise shared and offers a communication tool to aid understanding.

No studies looked at the experiences of other family members, such as grandparents, and only one study (Mikkelsen, 2018) explored the experiences of the child patient.

#### **2.5.4 Children's Perspective on the PICU Diary**

Mikkelsen's (2018) study interviewed five children and two siblings. The child participants, aged 5–14, were interviewed with their parents present. The children's experiences of the PICU diary were unique to their parents. They spoke of how they recalled very little of the PICU admission and how the diary was used to help them understand their illness trajectory. The children could not distinguish between recalled memories and what they had read in the diary. Although there were no reports of delusional memory recall, the concern that the presence of unreal memories may be associated with a higher incidence of PTSD (Colville et al., 2008) was acknowledged, recommending the need for further research involving children as participants. This small sample study concludes with findings which are not easily transferable. However, the recommendation that using the diary for children to provide information to fill the missing gaps in the PICU experience is encouraging and supports the need for further research.

#### **2.5.5 HCPs' Perspective on the PICU Diary**

Three studies investigated the HCPs' perceptions of the feasibility and scope of PICU patient diaries (Lynch et al., 2020; Gawronski et al., 2022; Sansone et al., 2022).

Gawronski et al. (2022), as part of a prospective observational study, also surveyed HCPs alongside parent participants. A multi-disciplinary group of nurses (n=17), physicians (n=9), physiotherapists (n=2) and student nurses (n=2) were surveyed to elicit perceptions of the diary implementation, any barriers to use and suggestions for improvements. The HCPs described the diary as valuable, and 53% (n=16) reported that it improved their relationship with families. Barriers to diary writing were concerns about maintaining confidentiality and assuring privacy for the child and family. The findings of this study illustrated a correlation between the parents and the HCPs' views on the benefits and feasibility of diary use. Additionally, the HCPs identified that they perceived the diary as less beneficial for the younger child and that diary writing had a negative impact on their workload.

Sansone et al. (2022) conducted a qualitative study in the same setting as Gawronski et al. (2022) and further explored the perception of HCPs in implementing PICU diaries. Three focus groups and four individual interviews were conducted with a multi-disciplinary group of HCPs, including nurses, physicians, and physiotherapists. Three main themes emerged from the interviews: meaning attributed to the diary, enablers, and barriers to diary writing. The HCPs spoke of how the diary offered moments of personal reflection and a break from the usual work routine. Contributing to the diary was seen as positively benefiting communication between the family, the child, and other HCPs. Enablers to the diary were seen as the personal relationship an HCP had with a child. Barriers identified to diary use included anxiety about writing contributions that the wider family would read, work pressures and scarcity of time, the potential legal consequences, and the concern that the diary could be used against the HCPs. These findings were corroborated in the earlier study by Lynch et al. (2020).

A national survey of all PICUs in the UK and the RoI was conducted to scope the prevalence and nature of PICU diaries (Lynch et al., 2020). An electronic survey, with closed and open-ended questions, was sent to all senior nurses and medical leaders in each of the 30 PICUs. The response rate was 100%, capturing information from all government funded PICUs in both the UK and RoI. Thirteen of the 30 PICUs (43%) offered diaries. Of those PICUs who did not offer diaries, the reasons given were concerns about the legal and professional implications and the subsequent lack of guidance on diary use. Diaries were reported as offering an additional opportunity for the HCPs to engage with families, provide information to fill gaps in memories and a tool to support family-centred care. This study concluded by acknowledging the benefits of PICU diaries whilst recognising that gaps in understanding and knowledge required further investigation through research. Chapter 3 provides the published version of this study as additional background to the UPDATE study.

### **2.5.6 PICU Diaries Systematic Scoping Reviews**

The structured literature review included two systematic review papers (Sansone et al., 2021; Low et al., 2023). Sansone et al., (2021) although not explicitly looking at PICU diaries, explored the use of narrative diaries in the paediatric setting. Thirty-six articles were reviewed, of which only two PICU diary studies were included (Mikkelsen, 2018; Herrup et al., 2019). Sansone et al (2021) concluded that the value of narrative diaries was that of an intervention that offered families and children a tool to articulate their experiences. This conclusion further supports the use of PICU diaries. This conclusion was similarly drawn by Low et al. (2023) in the scoping review of the use and impact of PICU and neonatal intensive care unit (NICU) diaries.

Low et al.'s (2022) scoping review retrieved 14 studies: five related to NICU and nine to PICU diaries. The scoping review concluded that diaries were beneficial to children and

their families. The review also identified the geographical disparity in study locations, meaning that most studies were conducted in economically affluent countries in Europe and North America. The scoping review concluded that there needed to be more studies related to this topic. Therefore, it was difficult to provide concrete conclusions due to the heterogeneity of the diary definition (Low et al., 2022). Both scoping reviews discussed studies already described in this chapter. The chapter has also included two additional studies published after the scoping reviews (López Fernández et al., 2022; Sansone et al., 2022). However, two studies included by Low et al. (2022) were rejected for review in the chapter (Laudato et al., 2020; Perry et al., 2021). The rationale for not including the studies is that Laudato et al. (2020) only briefly mentioned PICU diaries in the study about parents' communication needs, and Perry et al. (2021) described a study protocol with no findings. However, the two scoping reviews have provided insights to support the use of PICU diaries and map the scope of studies in this area of investigation.

### **2.5.7 Synthesising the Findings from the PICU Diary Literature**

Eleven PICU Diary articles have provided some understanding on the definition of PICU diaries, and the perspectives of the child, parents, and the HCP on the impact of the diary. The scope and nature of the available literature on this subject matter remains scant and valuable in quality. Nevertheless, the contemporary studies to provide further insights that will be further discussed in Chapter 9.

## **2.6 Chapter Summary**

In this chapter, literature regarding the concept of PICU patient diaries and the background for this study was established. The impact of critical illness on the emotional recovery of the child and family was described. Consideration of the intervention, patient critical care diaries, was explored with a definition of the diary

concept and a structured review of the contemporary studies related to PICU diaries. The perspectives of the child, their family, and the HCPs around PICU diary usage were considered to provide background knowledge concerning this study. The structured scoping review identified the need for future studies to explore the long-term effects, the optimal diary format, and strategies to overcome potential barriers to implementation. Finally, a study scoping the prevalence and nature of PICU diaries adding to the background of the UPDATE study, presented in the following chapter, was introduced.

## Chapter 3 Scope and Nature of PICU Diaries in the United Kingdom and Ireland.

In this chapter, a survey to scope the practice of the patient diaries in PICUs located in the UK and Republic of Ireland is presented. This survey contributes to the UPDATE study by providing background to the prevalence and use of PICU patient diaries.

This survey was published in the journal *Nursing in Critical Care*. The bibliographic details of the work, a description of the work and an estimated percentage of contribution (%) of each author are as follows: Lynch F (90%), Endacott, R. (5%), Latour, J.M. (5%). The percentages of contribution have been agreed among all authors.

The full reference of the paper is:

Lynch, F., Endacott, R., and Latour, J. M. (2020). Patient diaries: Survey of paediatric intensive care units in the United Kingdom and Ireland. *Nursing in Critical Care*, 25(1), 31–36. <https://doi.org/10.1111/nicc.12472>

Date Accepted: 20<sup>th</sup> August 2019.

### **3.1 Abstract**

**Aim:** The aim of the study was to explore the incidence, use, and scope of patient diaries in paediatric intensive care units (PICUs) in the United Kingdom and Ireland.

**Design:** This was an electronic survey sent to 30 PICUs in the United Kingdom and Ireland.

**Results:** All PICUs (n = 30) responded, and 43% (n = 13) offered diaries. For those units that did not supply diaries, the reasons given were concerns around the legal and professional implication of using diaries. Parental/carer consent to use a diary was obtained informally (79%, n = 11), and once there was agreement to provide a diary to parents, diaries were usually started immediately (72%, n = 12). Parents were the main contributors to the diaries (94%, n = 17), and the diaries were populated with photographs (94%, n = 15), drawings (100%, n = 16), and stickers (94%, n = 15). The reasons for offering diaries were to fill gaps in memories, to engage with families, and to explain what has happened in lay language. The owner of the diary was reported to be the family (82%, n = 14) and the child (12%, n = 2).

**Conclusions:** The use of patient diaries is an evolving intervention in paediatric intensive care settings in the United Kingdom and Ireland. This national survey has provided a clearer picture of how this intervention is used in the United Kingdom and Ireland. PICU patient diaries are used in a significant number of units, and how these are used is relatively standardized, although in some different ways from general ICUs.

**Relevance to clinical practice:** This survey provides a baseline for future exploration, understanding, and promotion of patient diaries, as a well evaluated tool for the critically ill child and his or her family.

#### **KEYWORDS**

children, diary, paediatric intensive care, parents, social support, survey methods

### **3.2 Background.**

Annually, around 20 000 children aged between 0 and 15 years received care in a paediatric intensive care unit (PICU) in the United Kingdom and Ireland (PICANet, 2018). The incidence of admission has remained steady at around 141 admissions per 100 000 population in the United Kingdom (PICANet, 2018) Therefore, there are a small, but not insignificant, number of children and their families who are exposed to the PICU environment.

Research with children has focused on the impact of hospital admission (DoH, 2003; Ministry of Health 1959) In comparison, the long-term emotional impact of critical illness has been less explored (Colville et al., 2008; Rennick et al., 2004). A small number of studies, adopting a quantitative approach, provide evidence that the critically ill child and his or her family can suffer significant and lasting psychological sequelae post-PICU admission (Bronner et al., 2008; Colville et al., 2008; Rees et al., 2004). These studies demonstrate that a significant number of critically ill children and their parents may develop post-traumatic stress disorder (PTSD) and that increased parental distress, length of PICU stay, delusional memories, and emergency admission are possible predictors of the development of PTSD in children. The impact of PTSD on the child can have lasting deleterious effects, physically, emotionally, and socially (Bronner et al., 2008a, 2008b). Studies concluded that the prevalence and incidence of PTSD in the PICU population was a concern; however, these studies did not explore or consider what interventions could support coping or reducing the risk of PTSD (Bronner et al., 2008; Colville et al., 2008).

A qualitative study using a responsive interview technique and an arts-based, visual approach was used by Manning et al (2017) to explore long- term psychosocial well-being. Nine children were interviewed to discuss their experience of surviving critical



illness through their stories. This study concluded that the children identified many challenges and adversities when attempting to readjust to life following critical illness that both enhanced and impaired their psychosocial well-being.

A conceptual framework to better understand the experience of the child and his or her family during and post-PICU has been developed (Manning et al., 2018). The Post Intensive Care Syndrome in Children (PICS-p) framework provides understanding of the phenomena of surviving childhood critical illness. Utilization of the PICS-p framework will also provide researchers with a guide to measurement future outcomes for interventions.

Although there remains a dearth of literature pertaining to the psychological impact of critical illness on the child, the literature and evidence available does support the negative consequence that this can have on the child's well-being.

### **3.2.1 Interventions to Minimise the Psychological impact of Critical Illness.**

Two studies have focused on the intervention of follow-up post- PICU (Bronner et al., 2008a; Colville and Pierce, 2012). Bronner et al, (2008) and Colville et al, (2012) both explored the impact of follow-up of parents post-PICU. Bronner et al (2008) prospective cohort study explored the prevalence of PTSD after an acute admission to a PICU and aimed to determine the risk factors in developing PTSD in parents. Post-discharge, 250 eligible patients and family members were invited to attend a follow-up appointment. Of them, 144 (57.6%) parents visited the follow-up clinic at 3 months post-discharge. This study concluded that an unexpected PICU admission is a stressful event for parents, that psychological support should not end at discharge, and importantly that follow-up is warranted.

The randomized control trial of Colville et al, (2012) aimed to evaluate the psychological impact on parents of the provision of a PICU follow-up clinic. Post-PICU,

families (n = 77) were randomized to the intervention of invitation to a follow-up appointment with a PICU intensivist, PICU nurse, and psychologist at two months after discharge versus the control of no appointment. The study concluded that, because of low attendance to the follow-up appointment (25%), it was difficult to justify routine follow-up but suggested that, for most traumatized parents, long term distress could be reduced by this intervention.

It is clear from the limited evidence available that the admission of the child into PICU can have a significant impact on the psychological recovery of the child and his or her family. There are no studies looking at what or how interventions can be used to meet the psychological needs of the child post-PICU, and the ways to best identify those at risk or effected and then help this population remain elusive. However, studies exploring the use of patient diaries in adult intensive care units (AICUs) may offer an intervention to meet these unmet needs.

### **3.2.2 Patient Diaries in the Critical Care Setting**

Literature emerging from adult ICUs has explored interventions that may improve the psychological impact of critical illness for both the patient and his or her relatives. The use of patient diaries is one such intervention, used either exclusively or in combination with follow-up appointments. In the literature related to this intervention, patient diaries used in the adult intensive care environment have been shown to be a low- cost, low-technological intervention that is valued by patients and their families, (Bäckman and Walther, 2001; Bergbom et al., 1999; Johansson et al., 2015) which may reduce the incidence of PTSD, (Jones et al., 2007) reduce anxiety and depression, (Fukuda et al., 2015; Knowles and Tarrier, 2009) and increase perceptions of quality of life (Backman et al., 2010).

Only a few studies explored the use and impact of diaries in the PICU population. Mikkelsen (2018) explored children's and family's experiences of using dairies after discharge and the role these diaries had in the process of recovery from critical illness. This qualitative study collected data from five children and their families up to six months after discharge from the PICU. The researchers concluded that diaries played a role in making the paediatric intensive care experience meaningful by providing explanations. The diary can also serve as a catalyst for the coping process by 'filling in the missing gaps' to support the child's understanding of this experience. Herrup et al (2019) undertook a pilot study to determine the feasibility of implementation and the perceptions held by the family members who received the diaries. They surveyed 20 families of children admitted to a PICU in the United States and concluded that the use of diaries is feasible and is perceived as beneficial by families. These studies have offered some insights but have only partially contributed to a wider understanding of how diaries are used in the PICU.

The use of patient diaries is evolving in paediatric intensive care settings, but a clear picture of how this intervention is used is not fully understood in the PICU settings. Therefore, the aim of this survey was to explore the incidence, the use, and scope of patient diaries in PICUs in the United Kingdom and Ireland.

### **3.3 Methods**

#### **3.3.1 Settings**

In the United Kingdom and Ireland, there are 30 government funded PICUs. The type of PICUs varied, with some providing general intensive care, some designated cardiac intensive care, and some that were combined. All 30 PICUs in the United Kingdom and Ireland were invited to participate in this survey.

### 3.3.2 Participants

The survey was circulated to the medical and nursing leads in the PICUs; the aim was to recruit all PICUs, and only one response from each unit was required.

### 3.3.3 Recruitment

A total of 102 email invitations to participate were sent to the nurse and medical leads for each PICU unit. Some PICUs had identified more than one lead. Overall, 42 electronic responses were returned, and these were cross-checked to identify the units who had and who had not contributed. A reminder email was sent out. Any PICUs who had not submitted the survey were invited to complete a telephone interview using the survey questions. A convenient time was arranged to complete this, and again, the voluntary nature of participation was assured. The response rate was 100%, with all PICUs submitting data for the survey (Table 3.1).

*Table 3.1 Characteristics of PICUs*

Type of PICU	Responses % (number) Total Responses 30
<b>General</b>	53 (n=16)
<b>Cardiac</b>	6 (n=2)
<b>Combined</b>	25 (n=8)
<b>Other</b>	16 (=4)

One Level II paediatric critical care (high dependency) unit also submitted data. Although this unit had stopped offering diaries because of the time constraints experienced by staff, there was a willingness to continue contributing to diaries started in other settings. Unfortunately, as the aim of this survey was to understand the nature and scope of diaries in the PICU settings, this data was excluded. Others included high-dependency units (HDU) with PICUs or a standalone HDU.

### **3.3.4 Data Collection**

An online questionnaire using the survey tool SurveyMonkey™ (San Mateo, California) was developed. The survey included 20 questions that asked about: demographics of the PICU, prevalence of diary use, nature of use, and if not used were there any plans to implement the use of diaries.

### **3.3.5 Service User Involvement**

The questions were tested and piloted with academic supervisors and internal and external peers until there was agreement on clarity, relevance, and ease of use for respondents. Closed questions were used to collect definitive answers and open questions to provide a descriptive explanation where appropriate.

### **3.3.6 Analysis**

Once collected, the data collated were cleaned to include only one entry per responding PICU. The data were exported from a comma-separated values (CSV) file in SurveyMonkey into Microsoft Excel (Parahoo, 2014). The data were analysed primarily descriptively and inferentially. Free-text responses in the survey were analysed by thematic content analysis (Green and Thorogood, 2018).

### **3.3.7 Ethical considerations**

Local permission was sought and granted by the primary author's Research and Design Department (GSTT/2017/7399) to undertake this evaluation audit.

As this survey was not anonymized, the author was able to identify any PICUs who had either submitted data more than once or had not yet completed a questionnaire.

Explicit reassurances around confidentiality were given to respondents. Identifiable personal data were not used in the analysis and were then destroyed after the data were imputed into a database. Data collection was completed before May 2018, the implementation date of the General Data Protection Regulation (GDPR).

### 3.4 Results

Of the respondents who answered, 43% (n = 13) of the PICUs stated that they offered patient diaries, and 57% (n = 17) did not offer diaries.

Five PICUs commented that they have stopped the practice of offering diaries. The reasons for these included concerns about the legal implications of writing a diary (n = 5), concerns about professional implications (n = 4), and financial constraints (n = 1). A written example of why diaries were not used was:

*“I think that these are all reasons why diaries have not been introduced—it has taken a while to work through these. I think there are also mixed views from staff about the use of and benefit of diaries.”*

Of the units who are currently not offering dairies (n = 17), 53% (n = 9) were “considering introducing or re-introducing” patient diaries, and 22% (n = 4) “may consider” reintroducing these.

#### 3.4.1 Purpose of the Diaries

Reasons to use diaries varied amongst the PICUs (Table 3.2).

Table 3.2 Diary Purpose

<b>Perceived Purpose of the diary</b> (More than one option could be given)	% Responses (n=17)
Fill memory gaps	88 (n=15)
Explanation of what has happened	65 (n=11)
A way of engaging family members in care	94 (n=16)

The purpose of the diary was also described as a communication tool, for example, the diary was used as a way for families to communicate in a different manner with the healthcare providers caring for their child.

*“Enabling family members an alternative tool to communicate key messages about their child’s underlying condition, specific care needs, likes, dislikes, daily routine etc.”*

### 3.4.2 The Scope and Use of Diaries

The PICUs who offered diaries to parents (43%) were asked specific questions to understand the processes of how diaries are used. Diaries were offered to all families by 67% (n = 8) of the PICUs, and the remaining 33% (n = 4) offered them once an admission into PICU had been for >24 hours. The comments on this question offered further understanding of who these diaries were offered to:

*“Also, we tended to focus on families we expected to stay for medium to long term.”*

*“Offered on an individual basis if we think the child/family would benefit. Or offered once extended stay at 21 days. Too many short stay children to offer all.”*

It is difficult to interpret two free-text comments on the question of what guidance is offered regarding who should not be approached to commence a diary. However, the responses given indicated that diaries are not offered to families who do not understand English or if there are any child safeguard concerns.

Consent to use the diaries is gained informally and verbally by 79% of PICUs (n = 11), with only one unit (7%) seeking “formal consent,” and the remainder 7% (n = 1) of units sought informal consent and documented this discussion in the patient records. Once agreement for use has been obtained from the family or carers, in most cases, the diaries were used immediately (72%, n = 12). The remainder (28%, n = 5) reported commencing the diary within the next 24 hours of the admission.

Parents and families are reported as the main contributors of the diaries (94%, n = 17). Nurses and play specialists were the next main contributors (72%, n = 13), with a smaller number of units reporting doctors (33%, n = 6) as contributors. The diaries are populated with photographs (94%, n = 15), drawings (100%, n = 16), and stickers (94%,

n = 15). Respondents clarified their answers to this question by including comments such as:

*“Families will add photos.”*

*“This is up to the family, but we will offer suggestions (sic stickers).”*

The respondents were questioned about who owns the diary, and the stated ownership varied. The family (82%, n = 14) and the child (12%, n = 2) were cited as the owners of the diaries, with only one respondent suggesting that the PICU staff owned the diary (6%, n = 1). Understanding of the ownership of the diary was also supported by the responses related to the question: “when does the child and family receive the diary?” The respondents reported that the diaries remained with the child and family most of the time (84%), although three units (16%) presented the diaries to the child and family at discharge.

Only two units (12%) currently capture any formal feedback on the value of the diaries using an additional question in routinely administered parent/carer satisfaction surveys.

### **3.5 Discussion**

The prevalence of the use of patient diaries in the PICU settings (43%) was more common than had been expected. As this is the first survey of its type, it was unclear to what extent PICU diaries were offered; however, anecdotal evidence would have suggested this was still a rather novel intervention.

There is a predominance of literature pertaining to diaries not only coming from the adult critical care setting but also conducted in Northern Europe, where diary usage has been established for almost 30 years. A Swedish survey of the use and practice of patient diaries in the adult ICU setting found that 75% (n = 65/85) offered diaries. It is



positive to see that the potential benefits of using these has been adopted in the PICU settings, but it is clear that this intervention in PICU is still in its infancy.

It was interesting to explore the reasons why the offering of diaries may have been stopped or withheld in some units. The five units that either do not or no longer offer diaries expressed concerns about the legal and professional implications of using these. This is a previously unresearched area of understanding, and it would be of value to understand where these concerns have originated from and if these have been grounded in any legal or professional challenge. Other barriers to implementation of diaries, such as lack of time, challenges in constructing content, and the attitude of staff, were not reported as a concern by the respondents (Johansson et al., 2019; Nydahl et al., 2014)

Several PICUs reported providing staff with guidelines regarding who to offer diaries to but not how to populate these. In adult critical care units, there are examples of professional guidelines (<https://icusteps.org/professionals/news-and-updates/patient-diaries>, NICE, 2009) and educational videos on how to use diaries. As this has been identified as an area of concern for PICU settings, the sharing of good practice and support from professional bodies in the form of a guideline would be invaluable and could address the concerns raised. Although there was consensus from the PICUs on how consent to use the diaries was sought (verbally 79%, n = 11), the legal and professional concerns raised by others who were reluctant to use dairies may be compounded by this informal approach to consent. The process in which families and, in some cases, the child is introduced to the idea and value of using a diary, and 'consented', could therefore also be captured in professional guide- lines and could alleviate any apprehensions about usage.

In the PICUs that offered diaries, the ways in which these were used and populated were reported as very similar across the units. Overall, the families were the main contributors to the diaries alongside the nursing team. Although it is not uncommon in adult intensive care settings for relatives to contribute to the diaries, the main authors of the diaries are the nursing team (Fukuda et al., 2015; Knowles and Tarrier, 2009). The ethos of family-centred care in the PICU would naturally facilitate and encourage the contribution of the primary caregiver as the main author, but this survey has identified a different approach compared with adult ICU (Latour et al., 2008). Similarities in how the diaries are populated in the survey were identified between adult and child diaries in the use of text to explain the child's admission and progress. However, the use of age-appropriate language, drawings, stickers to decorate, and photographs was highlighted as a difference between the survey and literature (Herrup et al., 2019). The use of photographs to illustrate the child's stay was also commented on as imperative, and this is recognized in the literature as an important tool in supporting the understanding of the child and his or her family (Herrup et al., 2019). The adult literature also supports the use of photographs as a visual means to explain and fill the memory gaps (Åkerman et al., 2010; Bäckman and Walther, 2001). Not unsurprisingly, the use of colourful drawings and child-friendly stickers to decorate and personalize the adult diaries has not previously been commented on but was reported as a feature of the paediatric diaries. The reported purpose of the diaries in providing explanations and filling the gaps in memories was similar to the reported purpose and value in the adult literature (Ewens et al., 2015). The main finding (94%, n = 16) identified that the diaries are used to engage families in the care of their child or loved one. The adult ICU literature supports this view as the diaries have been reported as becoming a way for relatives to be present in the critical care area,

providing a focus and a task (Nair et al., 2015). Mikkelsen, (2018) qualitative study looking at the meaning of diaries to children and their families in the PICU concluded that the diaries were a tool to make sense of the time in the PICU but also as a tool to support the coping of the family and child.

Who owns the diary also provided some interesting insight. In the adult literature, there has been a paradigm shift in recognizing that the diary is owned by the patient and not the healthcare professionals (Egerod et al., 2011; Engström et al., 2009).

However, in this survey, the parent or family (82%, n = 14), not the patient, is viewed as the owner of the diary. This finding may reflect the legal, cultural, and societal status of a child. (Gov.uk, 1989; UNICEF, 1989). It would be important to explore this question in subsequent research to understand more fully what the 'ownership' of the diary really means and whether the concept of custodianship or 'looking after' the diary for the child is more appropriate. Nevertheless, the view that the diary is owned by the family rather than the healthcare professionals is an important acknowledgement of the relationships within the PICU setting.

There are several limitations to this study that need acknowledgment, including the use of a self-report survey. A limitation of self-reported surveys is that respondents might overstate the responses or provide responses considered to be socially acceptable (social response bias). Furthermore, we did not ask respondents about the guidance given for use of the diary and any professional and legal guidance, an area of concern raised by several respondents. A question to understand the facilitators and barriers to the use of diaries would also have been important. Despite these limitations, this is the first survey to attempt to explore the intervention of using diaries in PICUs.

### **3.6 Conclusions**

The use of patient diaries is an evolving intervention in the paediatric intensive care setting and is still in its infancy in comparison with the adult intensive care setting. This national survey of the United Kingdom and Ireland has provided a clearer picture of how this intervention is used. PICU patient diaries are used in a significant number of units, and the scope and nature of these are relatively standard. Of those PICUs that do not offer diaries, the concerns around the professional and legal implications were the key determinant of the reluctance to use diaries. The need for professional guidelines to support and address the concerns raised may be a solution to alleviate anxieties.

Those units that offer diaries acknowledged the positive benefits of these diaries for their patients and families and staff. As this survey is the first of its kind, the findings provide a baseline for future exploration, understanding, and promotion of this intervention for our patients and their families. Further research to explore the short-term and long-term impact of diaries from the perspective of the child, his or her family, and the healthcare professional is warranted.

### **3.7 Acknowledgments**

The authors acknowledge the PICU staff who gave up their valuable time to complete this survey and the Evelina London Children's Hospital audit department (as part of Guy's and St Thomas NHS Trust) for supporting this service evaluation.

### **3.8 References**

The reference list for this article is included in the thesis reference list.

## **Chapter 4 Underpinning the UPDATE Study: Methodological Decisions**

### **4.1 Introduction**

In this chapter, the rationale for the philosophical, theoretical, and methodological decisions underpinning the UPDATE study is stated. The purpose of the study is described followed by an examination of the underpinning theories, research paradigm, and the choice of a qualitative approach. Finally, the reasons for using a constructivist grounded theory approach will be debated. To systematically structure the methodological decisions made, Crotty's (1998) research process framework is used.

### **4.2 Purpose of the UPDATE study**

Since 2010, PICU patient diaries have been offered to all children and families admitted to the PICU at the Evelina London Children's Hospital. Anecdotal feedback collected through the family satisfaction survey suggested that the diaries were viewed positively and valued. Nevertheless, as there were no published studies at the point of commencing this research to support or refute these findings, further investigation was warranted. The purpose of the study was to explore how PICU patient diaries were used by children, their families, and the HCPs. Based on the findings from the background scoping review, the research question was formulated to consider the perspectives of those using PICU diaries. Therefore, the overarching research question addressed in the study was: *How are patient diaries used by the child, the family, and the healthcare professional (HCP) during and after admission to the Paediatric Intensive Care Unit (PICU)?*

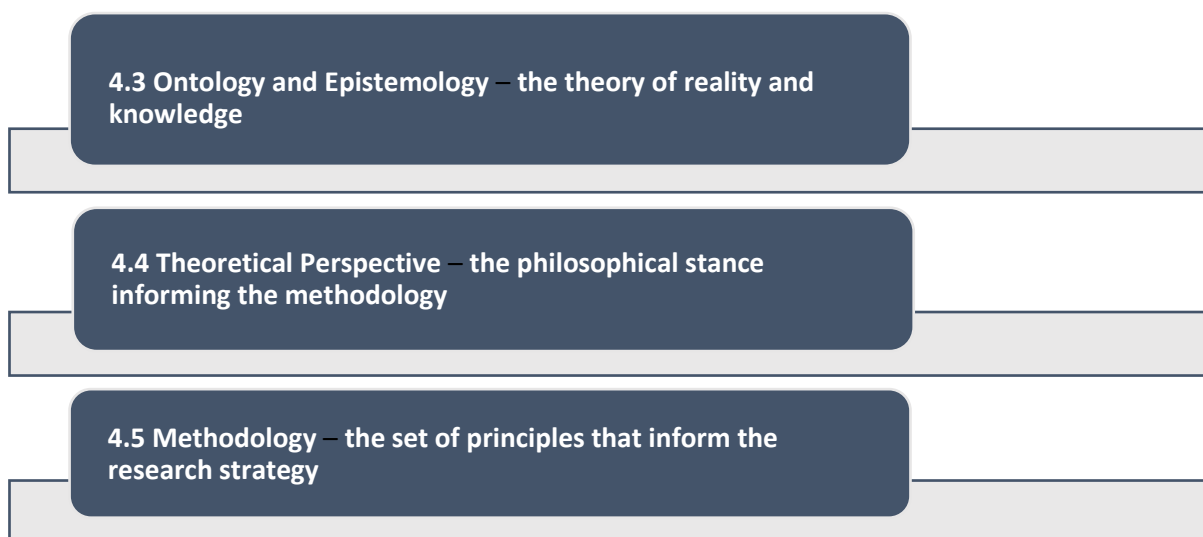
Additionally, the researcher sought to ascertain how patient diaries were used by children, families, and healthcare professionals during and after admission into the PICU. The objectives of the study were to gain insights and understanding into the following:

- The initial impression of the diary for the child, their family members, and the healthcare professional.
- How the diary was used by the child, family members and healthcare professionals.
- The perceived value and any negative connotations of the diary.
- The perceived impact of the diary by the healthcare professionals.

Any research question needs to guide the choice of an appropriate methodology to conduct the research study (Polit and Beck, 2020). Therefore, as the aim of the UPDATE study was to understand the participants' perspective, the choice of a qualitative approach to elucidate experiences was justified.

Understanding the methodological choices made when commencing any study is crucial in justifying the approach adopted. Crotty (1998) suggested that there are sequential levels of decision-making within the research design process. The first element of research design, epistemology, is to clearly define the scope and nature of knowledge and how this influences the research study (Levers, 2013). The epistemological stance underlines the entire research process and governs the theoretical perspective selected. Next is defining the theoretical perspective, a set of assumptions about reality, which must be implicit in the research question. This provides context and states the assumptions about reality, which in turn informs the methodology. The methodology, or plan of action, will inform the final choice of the

research methods adopted (Crotty, 1998). The research process framework is illustrated in Figure 4.1. To explain the methodological choices taken in the UPDATE study, the first three stages of the research design framework will now be described. The research method used in the UPDATE study will be described in Chapter 5.



*Figure 4.1 Theoretical Framework for Research Design [adapted from Crotty (1998)]*

### **4.3 Ontology and Epistemology: The Theory of Reality and Knowledge**

Ontology is the study of being, the nature of reality and being human. Furthermore, ontology is the beliefs or assumptions about reality (Corbin and Strauss, 2008; Houghton et al., 2012). Crotty’s (1998) framework does not identify ontology as a distinct, separate element of the research process framework. However, he acknowledged that “ontological issues and epistemological issues tend to emerge together” (Crotty, 1998, p. 10). Therefore, as ontology is a philosophy innately linked to epistemology, it is essential to acknowledge this as a concept before explaining the first step of Crotty’s framework. The two contrasting ontologies of critical realism and relativism will now be described and how these underpinned the UPDATE study will be explained (Levers, 2013).

Critical realism is a contemporary version of the realist ontological perspective. Critical realism proposes that reality exists independent of the human mind, regardless of whether reality is comprehensible or directly experienceable. Therefore, the world as we know and understand it is constructed from our perspective of what can be observed (Levers, 2013). From a critical realist perspective, the purpose of science is to identify a phenomenon and develop agreement regarding the description of this (Bergin et al., 2010) Critical realism suggests that there is one objective reality, which can be investigated, measured, and therefore generalised (Clark et al., 2007). Therefore, as the research question of the UPDATE study seeks to understand the various participants' perspectives, critical realism is not aligned to this study. In contrast, relativism is the ontological belief that reality is a finite, subjective experience and that nothing exists outside our thoughts (Denzin et al., 2023). Therefore, reality, from a relativist perspective, is not distinguishable from the subjective experience (Guba and Lincoln, 2005). Relativism looks at the subjective meaning of reality and holds knowledge as contextual (Stajduhar et al., 2001). Universal "truths" give way to negotiated truths in thought (Guba and Lincoln, 2005). With multiple interpretations of experience come multiple realities: as many different realities as there are people. The purpose of science from a relativist ontology is to understand the subjective experience of reality and multiple truths (Levers, 2013). Relativism underpins the research question posed, as the aim of the study is to understand the social processes surrounding how PICU diaries are used. Therefore, given the research question, relativism is the ontological approach of choice for the UPDATE study.

Epistemology is a branch of philosophy which seeks to understand the nature and scope of knowledge. Epistemology considers what knowledge is, how it is gained, what



is known, and how it is known (Green and Thorogood, 2018). Epistemology also examines the relationship between knowledge and the researcher during the research process, and therefore describing the connections between facts and values. The epistemological approach chosen by the researcher is directed by the ontological assumptions adopted, which in the case of the UPDATE study is relativism. The epistemological viewpoints of objectivism, subjectivism and constructivism are now considered, and the decisions taken on the final epistemological choice applied to the study will be explained.

Objectivism is rooted in the concept that objective meaning and an external truth exist independently of consciousness and experience (Crotty, 1998). Objectivism means that the researcher claims to remove all contextual factors (biases) and observe the known phenomenon as if independent of the human mind (Levers, 2013). Removing the researcher's (human) biases from an objectivist stance leads to the discovery of knowledge. Therefore, the researcher cannot change what is being observed, nor be influenced by what is examined (Crotty, 1998; Levers, 2013). An objectivist stance, informed by a realist ontology, does not support the UPDATE research question, and therefore is rejected as an epistemological stance.

Subjectivism, aligned to relativist ontology, explains that knowledge is intuitively created from personal experience and comes from the individual's internal mental state and view of the world. Therefore, knowledge is modified by the lenses of gender, social class, language, race, and ethnicity (Denzin et al., 2023). In the discipline of research, this means that the researcher influences the observed, and conversely the researcher is influenced by what they have observed (Levers, 2013). Denzin et al., (2023) explained that subjectivism supports the development of understanding, offers researcher sensitivity to ethical concerns, and supports personal and political

emancipation. Subjectivism proposes an approach to understand the perspective of the participants in the UPDATE study. However, with subjectivism, as Crotty (1998) explained, “meaning does not come out of the interplay between the subject and the object but is imposed on the object by the subject” (Crotty, 1998, p. 9). This view of knowledge acquisition is not supported by the objectives of the UPDATE study, as the aim is to construct understanding and generate the emergence of theory with the participants. For these reasons subjectivism was rejected as the epistemological stance for this study.

Constructivism, whilst taking a similar perspective to subjectivism, acknowledges the significance of social relationships and asserts that knowledge is constructed within and between human experiences and the broader contexts. Constructivism, therefore, “starts with the experience and asks how members construct this” (Charmaz, 2014, p. 342). As such, multiple meanings can co-exist, and knowledge is mutually created between the researcher and the researched (Charmaz, 2000).

Constructivist epistemology also acknowledges the role of the researcher in the construction of knowledge (Birks and Mills, 2023; Subramani, 2019). The constructivist approach to knowledge does not ask the researcher to shy away from their past experiences or subject matter expertise (Charmaz, 2000). However, the researcher needs to be sensitive to the participants’ viewpoints. This examination of the researcher’s influence, known as reflexivity, needs to be considered and explicit. Reflexivity is the process of reflecting critically on the self as a researcher. It is an essential aspect of decision making when choosing the methodology and methods but also in ensuring the quality and rigour of the study (Denzin et al., 2023). The researcher’s reflexive approach will be further discussed in Chapter 5. With all the characteristics of constructivism considered, this epistemological approach provided

the best fit for the UPDATE study and subsequently informed the theoretical perspective of the study.

#### **4.4 Theoretical Perspective: The Philosophical Stance Informing the Methodology.**

Crotty (1998) defined the theoretical perspective in the research design framework as “the philosophical stance informing the methodology” (Crotty, 1998, p. 3). There are potentially many theoretical research perspectives that result from epistemological and ontological viewpoints, also known as paradigms. The term ‘paradigm’ was coined by Kuhn in 1970, and these theoretical perspectives influence the types of phenomena to be researched, the methods by which they can be studied and the techniques by which data can be analysed and interpreted (Guba and Lincoln, 2005; Parahoo, 2014). Therefore, a paradigm, is a set of practices and beliefs that provide the theoretical foundations for any research study (Welford et al., 2011). Several paradigms were considered when undertaking the research study. These include positivism, interpretivism, pragmatism, critical inquiry, feminism, and post-modernism (Houghton et al., 2012). The three major paradigms of positivism, interpretivism and symbolic interactionism will now be discussed and the rationale for the final theoretical perspective applied to the UPDATE study will be explained.

Pragmatism, critical inquiry, feminism, and post-modernism will not be discussed in this chapter as the UPDATE study is not inherently linked to these paradigms.

Nevertheless, the researcher recognises the vital contribution these excluded paradigms have made to social and nursing research (Green and Thorogood, 2018).

Positivism and, latterly, post-positivism, adopt an ontological and epistemological perspective that assumes that the world is ordered and regular (Denzin et al., 2023).

This view of a static reality means that a phenomenon (e.g., biomedical marker, psychometric score) exists whether we are looking for it or not (Green and Thorogood,

2018). Applying this paradigm, a study aims to achieve objectivity, maintain tight control over the context, and answer the generalisations of the concepts being studied (Welford et al., 2011).

Positivism uses scientific methods of enquiry to describe and predict patterns in the world. The three tenets of positivism are: empiricism, unity of method and value-free enquiry (Green and Thorogood, 2018). There is emphasis on the study of empiricism, or what can be seen, and the theory established is deductively developed through formal statistical testing of a hypothesis (Welford et al., 2011). Unity of method is the tenet that eventually when mature enough, all science will share the same methods of enquiry. The main objective of science is to understand the relationship between cause and effect and the creation of laws about the natural world. Finally, the 'absolute truth' emphasises value-free inquiry in that science is held separate from society, is objective, rational, and notably neutral. The researcher must not influence the outcome of the study and any biases must not contaminate the findings (Green and Thorogood, 2018).

Post-positivism, developed after positivism, challenges the idea of the absolute truth of knowledge and asserts that reality cannot be known entirely but can be deduced through replication, control, and prediction (Phillips and Burbules, 2000; Welford et al., 2011). Unlike positivism, post-positivism does recognise that discretionary judgement is somewhat unavoidable (Guba and Lincoln, 2005). Post-positivist research, therefore, attempts to respond to the criticism levelled at positivism by using empirical evidence to distinguish between more and less plausible claims (Patton, 2015).

The research methodologies utilised from the positivist theories are founded in the experimental, manipulative, and scientific verification of hypothesis also known as quantitative methodologies (Polit and Beck, 2020). Quantitative methodologies include

experimental design, surveys, and numerical observations. As the research question posed by the UPDATE study is founded in the realist ontology and constructivist epistemology, the paradigm of positivism is not congruent with these paradigms. The interpretivist paradigm emphasises gaining understanding from the meaning individuals place on their actions (Weaver and Olson, 2006; Welford et al., 2011). Therefore, a phenomenon is studied through the lived experiences of those impacted and assumes multiple contextual realities (Green and Thorogood, 2018). Ontologically, interpretivism accepts the realist belief that 'truth' can be viewed from multiple perspectives and realities (Welford et al., 2011). From the epistemological perspective, interpretivism is juxtaposed to positivism in that the paradigm aims to build knowledge from multiple perspectives (Denzin and Lincoln, 2017; Weaver and Olson, 2006). Charmaz (2014) described interpretivism as: "giving abstract understanding greater priority than explanation" (Charmaz, 2014, p. 230). Interpretivism allows for indeterminacy rather than seeking causality, patterns, and connections. Charmaz (2014) further explained that interpretive theory aims to understand meanings and actions, and these are constructed. Therefore, the subjectivity of the action also acknowledges the researcher's partiality. These concepts form the foundation of a co-constructed research approach and are aligned to the aim of the research study (Charmaz, 2014; Flick, 2018). However, interpretivism only partially addresses the theoretical perspective that supports the research question. Therefore, the paradigm symbolic interactionism was also considered.

Symbolic interactionism is a sociological and psychological tradition, heavily influenced by interpretivism, that focuses on how people make sense of social interaction and the interpretation they attach to social symbols such as language (Charmaz, 2014; Polit and Beck, 2020). Three premises form the foundation of this paradigm: firstly, that

people act based on the meanings that people or objects have for them; secondly, these meanings are based on social interaction and finally, meanings are established through an individual, interpretative process (Polit and Beck, 2020). The paradigms of interpretivism and symbolic interactionism offer the opportunity to consider the best approach, methodology, to answer the question posed by the UPDATE study. Therefore, the UPDATE study is established in relativist ontology, constructivist epistemology and the paradigms of interpretivism and symbolic interactionism. Methodologies using interpretivism, and symbolic interactionism as theoretical foundations, are established in the overarching qualitative approach to understanding the world from the perspective of those experiencing it (Polit and Beck, 2020). The qualitative methodological options considered, and the final approach adopted for the study, will now be described.

#### **4.5 Methodology: The Set of Principles that Inform the Research Strategy.**

Methodology is the “strategy, plan of action, process or design” behind the choice and use of research methods (Crotty, 1998, p. 3). Methodologies may have the same underlying theoretical perspective, and each methodology may be implemented using different combinations of research methods. To answer the research question of the UPDATE study requires a methodological approach based on relativist ontology, constructivist epistemology, interpretivism and symbolic interactionism. These theoretical stances lead to several methodological approaches that aim to address the research question. These methodologies are ethnography, phenomenology, and grounded theory. Each will now be described and the rationale for the final methodology chosen will be justified.

Defining ethnography as a methodology has many challenges. It appears easier to describe what an ethnographic researcher does, rather than what ethnography is

(Lambert et al., 2011; Savage, 2006). Ethnography is concerned with understanding human behaviour in the cultural and social context in which it occurs. The researcher, therefore, will spend time in the company of those being studied (Parahoo, 2014). Participation by the researcher can be covert or overt in the participants' lives for an extended period: listening, asking questions, and collecting whatever data are available (Parahoo, 2014). This approach requires participant observation in the milieu, community, or social world they 'inhabit' (Charmaz, 2006). Simplified, there are three broad types of research data that ethnographic methodology aims to gather: understanding on cultural behaviour (what people do); cultural artefacts (what people make and use); and cultural speech (what people say) (Polit and Beck, 2020). It is clear from the intention of the UPDATE study that there are better suited methodological choices than ethnography. Firstly, the diverse cultural behaviours of the child, their family, and the HCPs are heterogenous in the PICU setting. Therefore, exploring this would require distinct and separate research studies. Secondly, the methods adopted by ethnography, such as participant observation, would be challenged as the researcher is well known in the study setting. Finally, as the researcher also worked in the study setting and therefore was a participant, the neutrality required of an ethnographic researcher would be compromised and not achievable (Parahoo, 2014). For these reasons, ethnography was rejected as a methodology for the UPDATE study.

Phenomenology as a research methodology has been embraced by nursing research as a dominant approach. Phenomenology aims to explicate the meaning of human phenomena and understand the lived structure of meanings (van Manen, 2018; van Manen and van Manen, 2021). Max van Manen (2018) developed the third stage of phenomenology, combining the philosophies of Husserl and Heidegger (Miller, 2003).

Phenomenology is characterised as “trying to understand someone from their perspective, in the way he or she experiences” (van Manen, 2018, p. 8). This hermeneutic approach to research design was considered by the researcher for this study. The researcher had previously used phenomenology (Lynch, 2001, 2003), so there was familiarity in using this approach. This methodology also lends itself to methods which can be used when interviewing children. van Manen (2018) used this approach to interview children and their interactions with adults, suggesting that phenomenology edifies personal insight and allows the researcher the ability to approach participants with understanding and be responsive to their needs.

However, on returning to the UPDATE study question, the aim of the study was to ascertain how patient diaries are used by children, families, and HCPs during and after admission into the PICU. Therefore, to understand the social processes underpinning the use of PICU diaries from the perspective of the few (families and the child) and the many (HCPs). Therefore, phenomenology was rejected as a methodological approach.

Finally, the methodology of grounded theory was considered as an approach to answer the UPDATE study question. Grounded theory has evolved and been widely adopted as a research methodology in social sciences, particularly nursing (Birks and Mills, 2023; Bryant and Charmaz, 2019; Corbin and Strauss, 2008). Grounded theory is a methodology that seeks to construct a theory about the important issues in people’s lives (Birks and Mills, 2023; Charmaz, 2014). It does this through a data generation process often described as inductive (Morse, 2015), in that the researcher has no preconceived ideas to prove or disprove. Instead, issues of importance to participants emerge from the stories that they share about an area of interest that they have in common with the researcher (Birks and Mills, 2023).



Grounded theory emerged in the 1960s from the collaborative work between American sociologists Barney Glaser and Anselm Strauss (Charmaz, 2006). Their approach was developed in the context of qualitative approaches in sociology being heavily criticised in favour of the quantitative approaches that had begun to dominate (Charmaz, 2006). Glaser and Strauss (1967) defined the principal doctrines of grounded theory as providing systematic strategies for a qualitative research approach. They defined the components of grounded theory to include simultaneous involvement in data generation and analysis, using a constant comparative data analysis, memo writing, theoretical sampling which is aimed towards theory generation and delayed literature reviews (Charmaz, 2006). Glaser and Strauss (1967) suggested that grounded theory is best suited to under-researched areas as theory development is grounded in the empirical data and acts of everyday social life. They also stressed the importance of the researchers' interactions with those being studied as the impetus of the study should strive to interpret the participants' social world and meaning attributed to it. Since the genesis of grounded theory, the methodology has evolved. Glaser remained consistent and true to the original theoretical underpinnings of grounded theory. He did, however, further develop the methodology in his book *Theoretical Sensitivities* (Glaser, 1978), and the term classical grounded theory has been attributed to his work (Flick, 2018). Strauss progressed grounded theory when collaborating with Juliet Corbin, a nurse lecturer (Corbin and Strauss, 2008). Corbin and Strauss (2008) emphasised the changing world that grounded theory was in and favoured an approach which was focused on "technical procedures rather than emphasising the comparative methods that distinguished earlier grounded theory strategies" (Charmaz, 2006, p. 8).

Building upon the seminal work of Glaser and Strauss, Charmaz (2006) re-visioned the methodology of grounded theory into the constructivist approach. In her more recent work, Charmaz (2014) emphasised the importance of the “interpretative threads in social sciences” (p. 231) that allow the researcher to interpret our participants’ meanings and actions. As a sociologist and occupational therapist, Professor Charmaz weaved symbolic interactionism into the theory of the constructivist grounded theory approach. She described how symbolic interactionism offers researchers an open-ended theoretical perspective that can inform studies. She went on to state: “Researchers can draw upon symbolic interactionism’s major strength of combining theory and method into a coherent, unified whole without forcing data and ideas into a prescribed set of concepts” (Charmaz, 2014, p. 227).

Therefore, the constructivist grounded theory approach assumes that we all construct realities in which we participate. The constructivist grounded theory approach allows the researcher to engage with the participants experiencing the phenomenon, gain multiple viewpoints, and build (construct) conceptual frameworks or theories grounded in the data (Charmaz, 2006). In doing so, the researcher generates a theory or conceptual framework to explain what is happening in the research setting (Charmaz, 2006).

The constructivist grounded theory methodology adopts the title of *constructivist* but has an epistemological approach aligned with the paradigm of pragmatism (Charmaz, 2014). Pragmatism views reality as characterised by fluidity, argues that there are many perspectives, studies people’s actions that are open to interpretations, and argues that the truth is provisional (Charmaz, 2014). Pragmatism assumes that people are active and creative and that meanings emerge through practical actions to solve problems, and through actions people come to “know the world” (Charmaz, 2014, p.

334). The blending of or moving along a continuum of constructivism and pragmatism, however, does allow the researcher to approach the co-construction of knowledge collaboratively with participants and lays the foundation stone of constructivist grounded theory (Charmaz, 2014).

For the UPDATE study, the researcher sought to understand better the processes involved and interconnections present in how participants use patient diaries in the PICU, an under-researched study area. Constructivist grounded theory, as an inductive approach, allows the researcher to explore, with participants, their perspectives. It provides an opportunity to utilise the ongoing data analysis to ensure that a depth of understanding is gained. A constructivist grounded theory methodology studies how and sometimes why participants construct meanings and actions in specific situations (Charmaz, 2014). In other words, constructivist grounded theory looks at how the individual views their situation, and the theory generated from this depends on the researcher's views rather than standing as an outsider of it (Charmaz, 2014). These underpinning tenets of this methodology met the requirements of the UPDATE study. However, as a researcher who is also a nurse, the appropriate 'fit' of this methodology in nursing also needed to be considered.

#### **4.6 Consideration of Methodological Choices as a Nurse Researcher**

When considering the correct methodology for the UPDATE study, other factors were crucial in using constructivist grounded theory. This included how this methodology sat with the values of the profession of nursing and nursing research. As the researcher is a nurse, how this methodology addressed nursing values was essential. The discipline of nursing underpins philosophies that value the importance of the individual and the primacy of the understanding their meanings give to situations (NMC, 2018). When

embarking as a nurse researcher, the perspectives adopted must be cognisant and aligned with these values.

The six Core Values of Nursing (competence, care, compassion, courage, commitment, and communication) are embedded in UK nursing professional and public doctrine (DoH, 2013). More commonly referenced as the six Cs, these values are evident in the nurse working in a PICU, which is required to have high levels of clinical competence and well-developed care, compassion, communication, courage, and commitment skills to address the significant emotional needs required to care for the critically ill child and their family. Constructivist grounded theory seeks to provide a systematic research approach that acknowledges the participants as equal partners and seeks to understand their perspective, which is highly congruent with the core values of nursing (Charmaz, 2014).

In summary, this methodology embeds the concept that the relationship between the researcher and the participants is reciprocal, power is shared, and it is aligned with nursing and the researcher's values (Birks and Mills, 2023). Therefore, constructivist grounded theory was the methodology of choice to address the aims and objectives of the UPDATE study.

#### **4.7 Chapter Summary**

In this chapter, Crotty's (1998) framework has been used to describe the epistemology and theoretical decisions made for the UPDATE study. The study is based on a relativist ontology and constructivist epistemology, which in turn directed the use of the methodology of choice, which is embedded in the theoretical paradigm of interpretivism.

The methodologies of ethnography, phenomenology and grounded theory were considered for the methodology for the UPDATE Study. Constructivist grounded theory

was identified as the most appropriate methodology to investigate how the child, their family and the teams caring for them used patient diaries. The methods of interviews and focus groups adopted to generate rich data from the participants were also examined. Finally, the approaches taken to demonstrate the rigour of this qualitative study were also discussed.

In the following chapter, details of the research protocol and the methods used in the UPDATE study will be presented.

## **Chapter 5 Creating the UPDATE Study: Design and Methods**

### **5.1 Chapter Introduction**

In this chapter, the design and methods used in the UPDATE study are described and a rationale for their use is presented. The purpose of the UPDATE study was to ascertain how PICU patient diaries are used by children, families, and healthcare professionals during and after admission into the PICU. Therefore, following the consideration of the epistemological, theoretical, and methodological approaches, the constructivist grounded theory approach was used: the final component of Crotty's research design framework is methods (Figure 4.1). Methods are the techniques or procedures used to gather and analyse data related to the research question (Crotty, 1998). In this chapter justification is provided for the methods adopted to gather and analyse the data sought to answer the research question posed by the UPDATE study.

In essence, the aims of the study were to discover the nature and value of patient diaries for this population, and the findings generated from this investigation will influence future practice. To contextualise the methods used, the study setting, participants, and strategy to recruit to the study will be described. How the criteria of trustworthiness were applied to demonstrate the quality and rigour of the study will also be discussed. Finally, the ethical considerations arising from the methods used will be presented.

### **5.2 Study Setting**

In 2017, the time of the initial recruitment to the study, the setting was a prominent general medical and cardiac PICU in the UK. There were just under 1,200 admissions in 2016; 42% were elective versus 58% unplanned admissions (PICANet, 2021). Although the children in the PICU are the most seriously ill, it is rare for a child to die in

paediatric intensive care, and 97% of children were discharged alive from the study setting (PICANet, 2021). Approximately 150 registered nurses, 30 doctors and ten allied healthcare professionals were working in this PICU at the time of this study. The size and scope of this unit provided a broad population of children, families and HCPs that represent a general cross-section of the PICU population in the UK. Further description of the study setting can be found in Chapter 2.

### 5.3 Study Participants

Participation was sought from:

- family members, including parents, siblings, and extended family members,
- patients,
- healthcare professionals staff working in the PICU and children’s wards.

The eligibility criteria for recruitment to the study was designed to ensure that there was clear guidance on the inclusion or exclusion of participants. The eligibility criteria are summarised in Table 5.1.

*Table 5.1 Eligibility Criteria for the UPDATE Study Participants*

<b>Participant</b>	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<b>Family member</b>	Any family member of a child admitted into the PICU who has agreed to use a patient diary. English speaking.	Any parent/guardian unable to give informed consent.
<b>Child</b>	Any child over the age of four years and who was cognitively able to discuss the research topic.	Any child admitted into the PICU with suspected or confirmed abuse or self-harm. Any child who was not expected to survive the PICU admission due to a poor prognosis.
<b>HCP</b>	HCP who is aware of the use of PICU patient diaries. This includes nurses and nursing assistants, medical or allied health professionals.	

It was estimated that a sample size of 8–10 families would be enough to collect rich and varied data from the target population, but recruitment would continue until no new themes were identified in the data. It was also estimated that three focus groups comprising 6–8 care professionals from a range of clinical backgrounds would be required.

However, as constructivist grounded theory requires the researcher to use a constant comparison and a theoretical sampling approach (Charmaz, 2006), the final number of participants changed from the initial estimate to the final recruitment of 11 families and 95 healthcare professionals. Further detail on the study participants can be found in Chapter 6.

#### **5.4 Recruitment to the Study**

An advertising campaign with fliers, posters and email correspondence was used to share information about the UPDATE study with all potential participants (Appendix 1). The researcher attended staff meetings and study days prior to the UPDATE study launch to explain the aims. A small group of volunteers, with greater knowledge of the study, explained to potential recruits the outline of the study. After the multidisciplinary morning meeting (ward round), the researcher would approach the clinical PICU team to explore if any potential participants could be approached for an invitation to the study.

Any interested participants were provided with information sheets (Appendix 2) to further explain the study and what their participation may involve.

The healthcare team was also used to inform the researcher of any parent or guardians interested in being approached to discuss the UPDATE study. The initial approach to family participants usually occurred after the first 48 hours after PICU admission. A member of the healthcare team who knew the child and family then



made initial contact with the child's parents or guardians to provide a brief overview of the study.

The researcher would then approach the family to discuss the aims and implications of the UPDATE study. The participants' right to confidentiality, anonymity, and the ability to withdraw from the study was explained to them. Written information to supplement the verbal information provided was also given. At least 24 hours was allowed between the study information being provided to potential participants and the formal request to consent to the study. This allowed potential participants the time to consider the implications of participating and the opportunity to discuss any concerns with the researcher or other family members. The researcher would typically then return a day later to seek formal consent. It was anticipated that any potential participants may require more than one discussion to inform their decision about consenting to be part of the study. However, in practice, those who agreed to participate did so after the initial formal consent meeting with the researcher. Other adult family members, such as grandparents, were only to be recruited into this study after the parents or guardians consented to participate. Therefore, during this initial stage of interviewing, only parents were recruited into the UPDATE Study.

Any child or child family members, such as siblings, were only approached once consent had been gained from the parent or guardian. Consent or assent was to be sought from the child as soon as they were well enough during their PICU admission or when they may elect to participate in the follow-up interviews. Age-appropriate information booklets were provided to supplement the verbal discussion. However, due to the nature of the child's illness or their age, only one child patient was interviewed during their PICU admission, and the remainder of the children were interviewed as part of the follow-up interview stage of the study.

Before arranging the second interview, the patient's family was contacted again via an agreed-upon contact method such as a letter, email, text, or telephone call. The participants were invited to the follow-up interview and were reassured that they or their family members were free to participate if they wished to do so.

When recruiting parents and families for the second, follow-up interviews, the researcher was aware that the participants' circumstances may have changed or there may be a reluctance to talk about the PICU experience. The follow-up interviews were scheduled for approximately six months after PICU discharge and there was concern that participants may have viewed this interview as an additional burden. To ensure an approach was sensitive to any changes within the family, several methods were adopted before approaching the families for the second time. An authorised electronic search using the hospital database was conducted to ensure the researcher knew if any children involved in this study had died. Ethical approval had agreed that approaching a bereaved family during the follow-up interview phase was appropriate if this was undertaken sensitively. The families were reassured of their rights and choice to participate only if they still wished to do so. The participants were invited to the follow-up interview at a time and location convenient to them. The researcher offered alternatives to accommodate this interview, including meeting after hospital visits, during weekends and remotely.

Healthcare professionals were recruited via a range of invitation methods. The UPDATE study was promoted via email, electronic posters and by direct approach from the researcher, for example during staff meetings or study days. Providing information to and recruiting healthcare professionals occurred concurrently with recruiting family and patient participants.

The researcher was invited to attend several pre-arranged staff study days. As these days already had confirmed attendance, the researcher used these opportunities to interview the attending healthcare professionals using the focus group interview approach. Written information about the aims of the study and the rights of the healthcare professional participants was sent out at least two weeks before attending the focus group interviews. The participant information sheet and a consent form were included in this correspondence (Appendix 3). A follow-up email was sent three days before the focus group interviews to reiterate the voluntary nature of the session. Immediately before commencing the session, the participant's rights were restated, and consent was sought. All healthcare professionals who attended the focus group sessions agreed to participate and no one declined or left the interviews.

### **5.5 Study Methods and Stakeholder Engagement**

In constructivist grounded theory, the methods of choice in gathering rich data are fluid, flexible and open. Charmaz (2014) explained that the methods used in grounded theory should facilitate flexibility so that the researcher is allowed to shape and reshape the data collection and, in doing so, increase knowledge. Charmaz (2014) suggested that although interviews will be one of the main methods of gathering data, other approaches can be used. Using diversity in the types of data gathering methods ensures that the study is of quality and credible in the process of theory generation (Birks and Mills, 2023). The broad types of data collection used in grounded theory research include interviews, focus group interviews, questionnaires, photographic images, artwork, and artefacts (Charmaz, 2014).

The decisions around which data collection methods to adopt for the UPDATE study were made to meet the objectives set by the research question, engage the perspectives of those participating and facilitate the co-construction of the data and

subsequent theory. Interviews and focus group interviews were used as the central collection methods for the UPDATE study.

The importance of involving service users in research was considered early in the origins of the UPDATE study (Menzies et al., 2016). The study setting had a group of parents and young people who were active in reviewing study protocols, offering guidance and support. The interview guide, approach and proposed settings for the interviews were discussed with the study site's service users' group to ensure that consideration had been given to the environment and interview approach for the participants. The service user group advised the researcher on the tone and approach to the interviews, particularly from the perspective of a family currently in the PICU. The researcher modified the approach to the child participant from service user feedback to include interactive toys such as Buckaroo when interviewing children. The data generation tools used with the child, family and HCP participants will now be discussed (Menzies et al., 2016; Mitchell et al., 2019).

## **5.6 Data Collection Methods and Data Generation**

An interview is a directed conversation that permits an in-depth exploration of a particular topic with a person or persons with relevant experiences (Charmaz, 2006). Through this method, the experiences and views of the participants can be explored, illuminated, and probed (Kvale, 1996). In constructivist grounded theory, Charmaz (2006) promoted the concept of intensive interviewing as a method whereby the researcher uses an "open-ended, yet directed, shaped yet emergent, and paced yet unrestricted" means to gather data (Charmaz, 2006, p. 28).

The potential limitations of using interviews as a data collection method were considered, and the mitigations to minimise the disadvantages of this approach were applied. Doody and Noonan (2013) suggested that interviews can be intrusive, time

consuming, evoke strong feelings, and are susceptible to researcher and participant bias. Several approaches were adopted to minimise the limitations of interviewing as an approach. These included using an interview guide, considering the location and the influence of researcher biases, and will be further discussed.

### **5.6.1 Intensive Interview Approach with the Child and Family Participants**

An interview guide was used to create an open conversation but with some structure to support data generation. As constructivist grounded theory requires and encourages the emergence of data and subsequent theory, the interview guide facilitated this flexibility and responsiveness approach to data generation (Birks and Mills, 2023). The interview guide (Appendix 5) was helpful in the first initial interviews, providing reassurance to the researcher. However, as the study progressed, and in response to the concurrent data analysis, the interview guide was modified to meet the theoretical sensitivities required to answer the research question (Appendix 5). The interviews with all participants were audio recorded, and field notes and memos were kept contemporaneously with the interviews. Although the classical grounded theorists, such as Glaser, opposed the audio recording of interviews, the researcher used the audio recordings as a backup for the interview process. This tool was especially useful when more than one participant was present during the interview. It, therefore, allowed the researcher to be assured that any data or the nuances around responses were not lost.

The initial interviews, whilst the child was still an in-patient in the PICU, were conducted face to face. The location of the interview was carefully considered to ensure that participants felt comfortable leaving their child, that they were contactable if there were any concerns and that they had privacy to speak freely.

During the intensive follow-up interview, the participants were asked to explore how the diary was used after discharge, what was helpful or unhelpful about the diary, to explore excerpts in the diary and to identify any suggestions on how the use of the diary could be improved. These interviews also facilitated the further understanding and expansion of issues identified in the participants' first interviews. The subsequent follow-up interviews were conducted face to face or were conducted over the phone if the distance to travel was too far. Any follow-up interviews conducted with children present also had toys and drawing equipment available to engage and relax the child and family (Coad, 2007).

During all interviews, participants were given the opportunity to be interviewed together or individually. Field notes were collected during the interviews to capture any observations during the interview process. These observations on non-verbal cues then became part of the analytical analysis of the data collected as they formed memos. All interviews were transcribed verbatim to ensure all data collected were available for analysis. Transcribing each interview allowed additional immersion in the data and the researcher wrote copious memos during the process to inform the analysis and subsequent interviews.

A constant comparative approach was used to analyse the data gathered. The insights gained from this approach informed and then directed any changes to future interviews to ensure the data were grounded and the theories generated had depth (Charmaz, 2006).

### **5.6.2 Focus Group Interviews with the Healthcare Professionals**

The aim of the UPDATE study was theory generation from *all* those contributing to the PICU diaries, including the HCP. Nevertheless, capturing the perspectives of the HCP can be challenging, with workload and time commitments making it difficult to recruit

to individual interviews. Focus group interviews are an extension of the traditional interview approach in which two or more participants engage in a specific area of discussion, led by the researcher (Birk and Mills, 2023). The main characteristics of a focus group interview approach support the ability to create interaction among the participants and generate data about the similarities and differences in opinions and experiences (Joyce, 2008) Therefore, this data collection method provided an opportunity to pragmatically gather the experiences of the HCP. An interview guide was used to frame, direct, and focus the interviews conducted with the HCPs (Appendix 6).

A researcher leading a focus group becomes a facilitator, requiring the ability to listen to the various opinions, clarify points raised and generate discussion. Birks and Mills (2023) suggested that it can be difficult for the researcher to maintain the focus of the discussion, especially in large focus groups. However, to maintain the central focus and support discussions, two techniques were used in the HCP focus group interviews to address these concerns and facilitate data generation. Firstly, the focus group interviews were audio recorded to ensure that discussions were captured for later transcribing. Secondly, the participants were asked to record their views, ideas, and concerns on 'sticky notes', which were then grouped around the three main questions of the focus group sessions. These questions were:

1. How do you use a PICU diary?
2. What do you see as the value of the PICU diary?
3. What challenges have you experienced using a PICU diary?

Each question posed generated written responses which were grouped into high-level themes during the focus group session. The researcher then facilitated discussions amongst the participants to clarify the comments raised, taking the themes generated

to open discussions. This approach also allowed those who are more introverted and less able to 'speak up' in the broader, diverse group, allowing their contribution and views to be captured. This mode of data collection mitigates some criticism levelled at the more traditional approach to focus group interviews, such as the hesitancy for some participants to share experiences (Birks and Mills, 2023). During these focus group interviews, preliminary findings generated from the interviews conducted with families and other healthcare professionals were also explored with the group to gain their insights and suggestions. The nature of the constructive grounded theory approach allowed the researcher to be flexible by drawing on initial analysis from previous interviews or focus groups that can be used to explore greater understanding with subsequent participants (Charmaz, 2006).

The tools for data collection and generation used in the UPDATE study were aligned to the methodology chosen to answer the research question. The use of intensive interviews to explore the views of parent and child participants were in keeping with the approach to be agile and responsive to the participants' needs. The use of focus group interviews for the HCPs was a pragmatic and facilitative approach to seek the HCPs' perspectives.

How the data generated were analysed will now be described.

### **5.7 Data Analysis**

Data collection and analysis occurs concurrently in a constructivist grounded theory approach. The strategies adopted to ensure concurrent data collection and analysis in constructivist grounded theory are (Charmaz 2006; Birks and Mills 2023):

- Memo writing
- Constant comparative analysis
- Coding



- Theoretical sampling
- Theory generation

### **5.7.1 Memo Writing**

Memos are written records of the researcher's thinking, feelings, insights, and ideas during the research process. Memoing is recognised as a quality strategy in grounded theory and serves as a data generation and analysis catalyst. The researcher must be reflexive during this methodology of co-constructing meaning (Charmaz, 2006, Birks and Mills, 2023). Reflexivity requires the researcher to scrutinise and acknowledge how their interests, positions, values, and assumption influence the inquiry (Charmaz, 2006). Memos laid the foundation of the developing theory and provided substance for the written presentation of the research (Birks and Mills, 2023). Therefore, the vital influence of memo writing meant this commenced at the beginning of this study and remained a constant process throughout.

The researcher used Charmaz's (2006) guidance on creating memos, including giving each memo a title, defining a category, and using codes to explore assumptions (Appendix 8). The researcher also used a less structured approach to some memos, allowing freedom in thought expressed through writing and diagramming. The memos used in the UPDATE study varied from notes in a notebook, to elaborate mind-mapping diagrams to voice notes captured during moments of inspiration. The memos were stored in the Pro NVivo folders to facilitate integration with the data generated. This included uploading voice notes and copies of any handwritten memos (Appendix 8).

### **5.7.2 Constant Comparative Analysis and Coding**

All interviews and the focus groups' data were transcribed verbatim. The transcripts were anonymised, and descriptors were used to portray but not identify the

participants. The transcripts, field notes and memos of the interviews and focus groups were intensively read and re-read by the researcher. As analysis began with the first interviews, the insights gained also informed and directed future interviews and focus group sessions (Charmaz, 2006).

The computer software program Pro NVivo (version 12) was used to assist in the management of the large amount of data generated. There are benefits and disadvantages to using computer software to manage qualitative research data. Computer-Assisted Qualitative Analysis Software (CAQDAS) like Pro NVivo 12 are compatible for use with grounded theory; the nodes facilitate formation of a coding structure and development of conceptual categories. The use of Pro NVivo helped the researcher manage the large volumes of data, whilst remaining close to it by immersion in the data analysis when moving towards constructing the theory (Houghton et al., 2017).

Management of the volume of data generated could have been overwhelming if undertaken manually. Using Pro NVivo centralised the study's paperwork and removed some of the anxiety around locating specific information (Zamawe, 2015). Manual analysis can be complex with colour coding, cutting, pasting, and securing this information is not easy (Bryant and Charmaz, 2019). However, the researcher did use a manual approach to sorting, analysing in the initial stages of the focus group interviews. This was particularly useful when sorting the HCPs' written comments. Photographs of this process was uploaded to NVivo to preserve and integrate the data (Appendix 7).

Therefore, the researcher used Pro NVivo as a repository for the interviews, transcripts, and memos in a merged manner. The researcher was able to go back,

search and interrogate the data easily and importantly this database provides an audit trail of the development and progress of the study.

Data coding in constructivist grounded theory was conducted in three phases: initial, focused and, finally, theoretical coding (Charmaz, 2006). In the initial coding phase, the transcripts of the interviews and focus groups were openly coded, line by line. In doing so, the researcher fractured the data and used codes to define sections of the data with words or short sentences which simultaneously summarised each section (Charmaz, 2006). All interviews were analysed individually and compared with those conducted previously, as expected with constant comparative analysis. Coding required reading transcripts line by line, to identify key words, phrases, or incidents. Where possible in-vivo terms, words, or phrases of the participants, were used to describe the codes generated and keep the coding grounded to the data, close to the participants (Charmaz, 2006). These in-vivo codes were identified using speech marks. An example of the codes generated in this initial stage are listed below in Table 5.2.

*Table 5.2 Initial Open Codes*

<b>Initial Coding Framework</b>	
<b>Parent and Family Codes</b>	<b>HCP Codes</b>
First Introductions	Information giving
Sharing the use	Interacting
Engaging with others	Expressing feelings
Reading the diary	“Seeing the other point of view”
Encouraging contribution	Explaining
“Love”	Demonstrating care
“Expressing my feelings” (fathers)	“Explaining who the nurse is”
“Finding the courage” (fathers)	Explaining the difficult
“Being asked to leave”	“Cathartic”
Sentimental attachment	“Supporting the family”
“My choices”	“Impacting on me”
Owning my child’s story	Going above and beyond
Diary for the child	Creative and mindful
Helping me remember	Providing choice
Collecting items	“Offering a distraction”
Understanding the journey	“Hoping and Coping”

“Giving me something to do”	Grief
Telling the story	Creating memories
	Explaining the journey
	Validating decisions

For the researcher, this initial phase of data analysis, although at times inspirational, also felt disorganised and unstructured. Memoing during this phase started to offer moments of clarity but the constant comparative nature of the study contributed to the researcher’s concern about being able to identify the key themes and concepts or not “seeing it yet”. However, over time new codes became less likely and there were clear patterns emerging in the data. The researcher then moved onto the next stage of focused coding.

The second stage, focused coding, identified the most significant codes through constantly comparing incident to incident and code to codes. This process of constant comparative analysis, comparing codes within an interview but also across all the interviews conducted, identified the emerging similarities and any differences (Charmaz, 2006). In doing so, the overriding, significant emerging codes or patterns were then grouped by the researcher into a concept. Broader groups of similar concepts were then regrouped into a category which represented the clusters of concepts (Birks and Mills, 2023). To illustrate the evolution from open to focused codes, examples of the focused codes used are in Table 5.3

Table 5.3 Focused Codes

Development of Focused Codes			
Parent and Family Codes		HCP Codes	
Open	Focused	Open	Focused
First introductions Diary for my child Being asked to leave Compassion and love “Finding the courage” (fathers)	<b>Connecting with my child</b>	Information giving. Explaining Using photographs to explain	<b>Explaining the journey</b>
Owning my child’s story “My contribution”	<b>Owning the diary</b>	Seeing the other point of view Explaining who the nurse is Demonstrating care Going above and beyond	<b>Connecting with the child and family</b>
Explaining the journey. “Helping me and my child to remember”. Collecting items	<b>Creating memories</b>	Supporting the family	<b>Impacting emotionally on the family</b>
My choices Reading the diary Timing of reading/delayed reading	<b>Choosing how to read</b>	Difficult conversations	<b>Explaining the journey</b>
My choices Consent	Providing choice	Supporting the family Consent and choice Providing choice Validating decisions	<b>Providing choice</b>
Attachment to the diary	<b>Emotional attachment</b>	Being creative	<b>Offering a distraction</b>
“My choices” Helping me remember	Managing uncertainty	Using the diary out of work	“Impacting on me”

Explaining the journey Helping me remember	<b>Connecting with others</b>	Difficult conversations	<b>"Anticipating grief"</b>
Helping me remember Telling the story	<b>Understanding the journey</b>	Expressing emotions	<b>Impacting on the HCP</b>
"Giving me something to do"	Offering distraction	Using photographs Going above and beyond	<b>Creating memories</b>
Engaging with others Differences on PICU/ward	<b>Connecting with the HCP</b>		
Engaging with others Explain the journey	<b>Effecting others</b>		

The third phase of theoretical coding involved the researcher sorting, synthesising, and organising the generated data into links between the categories and clarifying the connections between these (Corbin and Strauss, 2008). These theoretical codes specified the relationships between the categories developed in the focused coding and began the construction of the themes around the phenomenon being explored (Charmaz, 2006). From this phase the core category was constructed (Charmaz, 2006, Birks and Mills, 2023). In Table 5.3 the **bold** codes generated formed the themes around the research questions and from these the core category of *Making Sense* evolved in the final phase of theory generation. This is presented in Chapter 9.

### **5.7.3 Theoretical Sampling**

During the processes of constant comparative analysis, it became apparent that more information was needed to clarify and saturate the categories developing. Theoretical sampling means the researcher seeks pertinent data to develop the emerging theory (Charmaz, 2006). Theoretical sampling collects data strategically to develop the properties of the emerging categories until no new properties emerge (Charmaz, 2006; Birks and Mills, 2023).

For example, after initial data analysis, it became apparent that the perspective of fathers in the use of the PICU diaries was different from that of mothers. The researcher, to understand this perspective more, was then able to recruit fathers into the interview groups to explore this further. During the initial interviews, families also discussed the impact of using diaries in non-critical care environments such as the children's ward. From these insights, the researcher conducted a focus group interview exploring the perspectives of the nursing team in the children's ward.

#### **5.7.4 Theory Generation**

Through the complex phases and processes involved in the data collection and analysis: the theory on how the diaries were used by patients, their family and the PICU HCPs was co-constructed (Charmaz, 2006). Through this final stage of theory generation, the researcher looked for the logical connectivity patterns from the core category, which emerged from theoretical coding. The theory generated provided an explanatory scheme that contributed to answering the research question (Birks and Mills, 2023).

Therefore, data analysis using a constructivist grounded theory approach was performed through coding, concept development, categorising and creating a core category by constantly comparing the data. From these processes, the theory co-constructed remains grounded in the data: the overriding principle of constructivist grounded theory. The diagram below shows the process of the methods used in the UPDATE study (Figure 5.2)



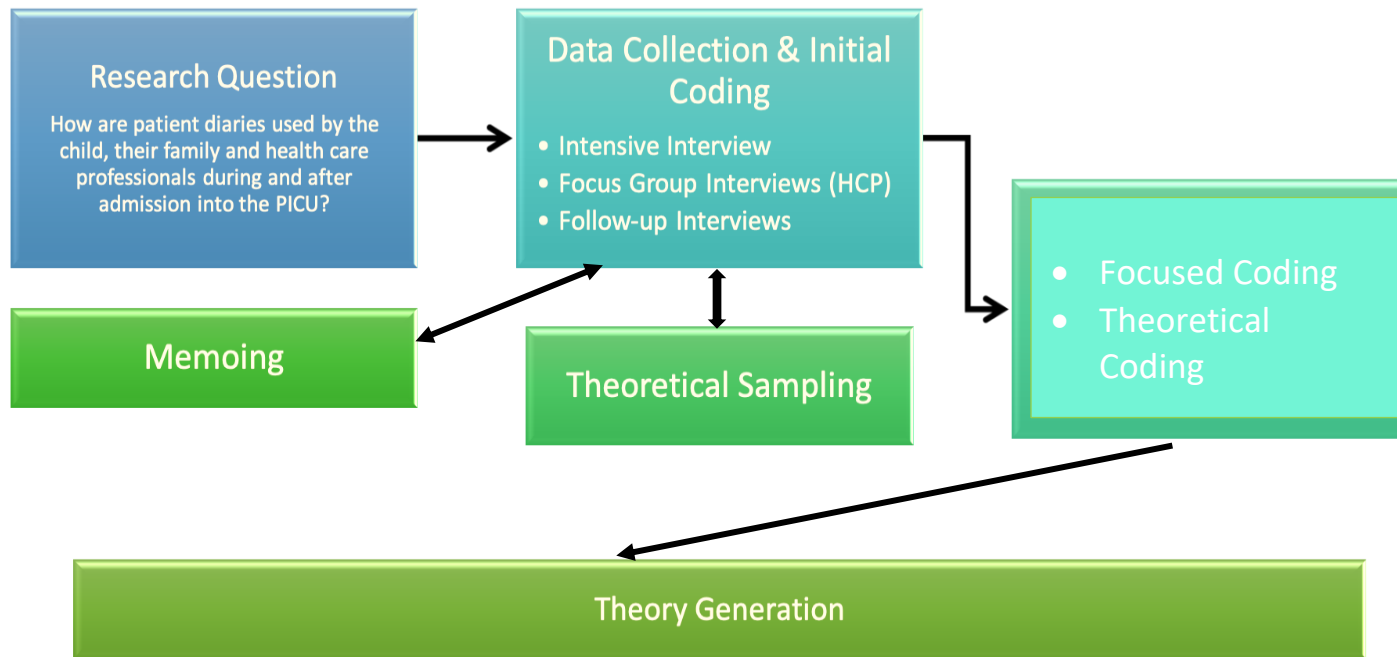


Figure 5.2 Diagrammatic overview of the constructivist grounded theory Approach [Modified from Charmaz, 2006]

To ensure the quality of the UPDATE study methods, how the study demonstrated rigour will now be presented.

### 5.8 Rigour in the UPDATE Study

Rigour in qualitative research can be challenging to assess and demonstrate.

Nevertheless, it is essential to prove a study's adequacy and quality (Cooney, 2011) To

ensure rigour in the UPDATE study, the criteria of *trustworthiness* were used. To

illustrate the trustworthiness of this research study, standards to determine rigour in a

qualitative study were used (Beck, 1993; Yin, 2011). These three standards are:

- Credibility.
- Auditability.
- Fittingness.

Building on the works of Beck, Chiovitti and Piran (2003) proposed eight methods of research practice that should be used in nursing research to enhance rigour. Table 5.4 outlines the eight methods used to ensure rigour is met.

*Table 5.4 Applying the Standards of Rigour to Research [adapted from Chiovitti and Piran, 2003]*

Standard of Rigour	Methods of Research Practice
Credibility	<ul style="list-style-type: none"> <li>• Let participants guide the inquiry process.</li> <li>• Check the theoretical construction generation against participants' meanings of the phenomenon.</li> <li>• Use the participants' actual words.</li> <li>• Articulate the researcher's personal views and insights</li> </ul>
Auditability	<ul style="list-style-type: none"> <li>• Specify the criteria built into the researchers' thinking.</li> <li>• Specify how and why participants were selected</li> </ul>
Fittingness	<ul style="list-style-type: none"> <li>• Delineate the scope of the research in terms of the sample, setting and level of theory generated.</li> <li>• Describe how the literature relates to each category which emerges in the theory.</li> </ul>

Each of Beck's (1993) three standards, illustrated by Chiovitti and Piran's (2003) eight methods of research practice, will now be discussed concerning the UPDATE study.

### **5.8.1 Credibility**

Credibility relates to how "vivid and faithful the description of the phenomenon is" (Beck, 1993, p. 264). Therefore, this relates to how trustworthy the findings are. Four research practice methods are suggested to ensure credibility: letting the participants guide, checking theory construction against the participants' meaning, using the participants' actual words and being open about the researcher's influence and views. Using an open, semi-structured approach to the interviews and focus groups encouraged the participants to guide and direct the data generation. In the interviews with families and children, the participants were interviewed using open questions, allowing discussion. The concepts discussed in the initial interviews were further explored in subsequent interviews, influencing the theoretical sampling, and shifting the interview guide to direct the inquiry process.

The theoretical construction was checked against the participants' meanings. As discussed before, the data collected were concurrently analysed and encouraged the ability to cross-check the emerging concepts. This action is evidenced in the changing interview guides for the subsequent interviews and the use of theoretical sampling to direct the enquiry. Using the participants' own words to represent their meanings also prevents the distortion of their meanings. This approach can be seen in the Findings Chapters (6, 7 and 8), where the direct quotation of the participants' words supports the findings.

The use of reflexive strategies by the researcher to elucidate her views, insights and unconscious biases was essential. The reflexive tools included a personal journal to

supplement the memos, post-interview comment sheets, voice notes and field notes.

These personal reflections were stored on the digital repository, Pro NVivo.

The researcher is an experienced PICU nurse with over 24 years of clinical knowledge in this specialism. The researcher also has experience and training in qualitative research and was supervised closely by an experienced research team. The researcher, therefore, was skilled and knowledgeable in research design, collection and analysis but also had the clinical credibility needed to be insightful and sensitive to the needs of all the participants. Therefore, the standards needed to ensure the UPDATE study's credibility were met.

### **5.8.2 Auditability**

To ensure rigour, a comprehensive record of the methodological decisions, data sources, sampling decisions and analytical procedures must be maintained (Cooney, 2011). Details on the researcher's thinking and subsequent actions are also captured in the memos. The memos clearly explained and justified the importance of the decision-making on how participants were recruited and, for example, how the theoretical sampling of fathers and HCP from the children's ward was taken. The memos that recorded the decisions thought processes, and subsequent actions by the researcher, have been captured and stored securely on Pro NVivo.

### **5.8.3 Fittingness**

Fittingness, also termed transferability, is related to how the findings have meaning to others in a similar situation. Beck (1993) described transferability as how applicable the findings generated are when they are fitted into a context "other from which they were generated" (p. 264). Chiovitti and Piran (2003) described the two final methods that ensure fittingness and enhance rigour as a) describing the research parameters and b) describing the literature to each emerging category.

In Chapter 6, the study setting, and demographic characteristics of the participants will be described. These descriptions allow the reader to judge the similarities of the study to other settings or contexts. This description allows the reader to “visualise the context from which the theory and its specific categories are developed” (Chiovitti and Piran, 2003, p. 433). However, some authors have argued that describing the study context does not mean the theory is automatically ‘transferable’ (Morse and Singleton, 2001) Therefore, caution must be taken when applying the concept of fittingness to a study, as the contextual information may not be evident and the ability to assess fit is complex and challenging.

Finally, demonstrating the probability that the research findings have meaning to others in similar situations relies on using high-quality evidence to support each category in the generated theory (Chiovitti and Piran, 2003). Chiovitti and Piran (2003) explained that the similarities in the literature to support the findings of the UPDATE study will show the potential transferability of the study findings. However, they warned that the “final judgement of the transferability of the findings ultimately rests with the reader” (Chiovitti and Piran, 2003, p. 433). The researcher’s role, therefore, is to be open, explicit, and transparent on the approaches adopted to assist the reader in making that decision. Throughout the final chapters of this thesis, the researcher has provided the detail and evidence to underpin the findings to be clear and support the reader to decide on the transferability of the conclusions to their area of practice. To further demonstrate the quality of this study, the imperative ethical considerations applied to the UPDATE study will now be presented.

### **5.9 Ethical Considerations of the UPDATE study**

The admission of a child into a PICU is an emotionally distressing event not only for the child but for their parents and other family members. Understanding how they can

best be supported during this challenging time is essential. This study will provide insight and knowledge on better supporting this population. However, conducting research with these vulnerable groups needs thought and consideration (Tisdall et al., 2009; Mitchell et al., 2019). Protection from harm and distress is the foundation of a sound ethical approach to research. Every attempt was made to ensure that participants were protected from additional distress if they agreed to be included in this study.

Before the study commencement, an agreement was sought and granted by the NHS and the University of Plymouth's Research Ethics Committee (IRAS Project ID 140655 Dec 2016), and the study site's local Research and Development department to ensure that the proper authority had been granted to conduct this study in the research setting (Appendix 10).

The project was designed to avert, minimise, and manage the burden on participants while ensuring the design was sufficiently robust to meet the research objectives. Modifications to the recruitment methods, consent to participate, the data generation methods and, finally, the support offered to participants were all ethical areas of consideration. The strategies to avert or minimise any ethical, legal or management issues that might have arisen will now be described.

#### **5.9.1 Ethical Considerations for the Recruitment of Participants**

For this study, the family is defined as the individuals that the parents or legal guardians identify as the "family" of the PICU patient. Therefore, this may include siblings, grandparents, and extended family members such as aunts, uncles, and cousins.

It was acknowledged that additional distress might be caused by approaching the family in the PICU. This approach, therefore, was managed with sensitivity and

thought. The recruitment procedure adopted several strategies to minimise any additional distress. This included confirmation from the clinical team, who knew the child and family better than the researcher that an initial approach would be appropriate and not cause any anguish. The initial approach was made to the parents or legal guardians after the first 48 hours of admission, allowing some time for the family to adapt to their child's PICU admission. The clinical team, not directly involved in the study, then approached the child's parents/guardians with a brief introduction to the study to allow the family to decline without concern about coercion.

Those parents who expressed an interest in the study were then approached by the researcher, who was not directly involved in their child's care. This was to prevent the participants from feeling pressured into participation through any sense of obligation to the researcher. Following discussions with the researcher, the parent was encouraged to consider their involvement, allowing time for them to consider this decision. It was anticipated that parental participants may require more than one discussion about their involvement. Other adult family members were only recruited into this study after the parents or legal guardians consented to participate to avoid conflict within family groups. Information about the study was widely advertised in areas such as visitors' waiting rooms, and fliers were placed in the diaries and on the PICU information boards so parents/guardians could consider their involvement (Appendix 1).

Child participants were only approached once their parents or legal guardians had consented to join the study. It was anticipated that the child participants might not be involved during the initial interviews as they may either be too unwell or not be present if they were visiting family members.

The subsequent sections will present the process of gaining informed consent and assent for the family and child participants.

### **5.9.2 Recruitment of Healthcare Professionals**

Several measures and approaches were implemented to meet the ethical needs of the healthcare professional participants. The invitation to participate in this study was sought through the hospital education leads to avoid any feelings of obligation to the researcher. As the invitation to participate was included in a pre-arranged study day, the HCP had the choice to “opt out” of the interview session if they did not wish to attend.

Therefore, the participants were self-selected and were not obligated to participate. Cognisant of her role as a senior nurse on the unit where the study was conducted, the researcher re-iterated the voluntary nature of participation and that there would be no negative impact on an individual if they declined to be involved.

### **5.9.3 Consenting to Participate**

Providing information about the study to all participants was essential to gaining informed consent. The expression of interest to be involved does not mean consent is assumed. While consenting to participate, the parents or legal guardians were informed how and when data would be collected. This verbal information was supplemented with written participant information sheets and invitation letters.

Assurances about how the data collected would be securely stored and the processes used to maintain anonymity and confidentiality were also given.

The opportunity to withdraw from this study before data analysis was made explicit to all participants. It was stressed that withdrawing from the study would not negatively impact the care of the child or their family nor be detrimental to any of the HCPs.



Gaining informed consent or assent (permission or affirmation) for any child participants was vital, but it was recognised that this was also challenging (Mitchell et al., 2019). The researcher was mindful of the child's cognitive ability to understand the power relationship between themselves and the researcher. These factors may hinder the child's ability to understand the implications of participating in the study (Kumpunen et al., 2012; Twycross, 2009). To enhance the child's ability to have a choice, the study information was provided verbally and written in age-appropriate language to assist the child in understanding what the study was about (Coad and Shaw, 2012). The information sheets were explicitly designed to be non-threatening, easy to understand, interactive and engaging. The hospital's service user group also advised on and approved the content and approach to the engagement of children (Appendix 2).

When approaching the child and family for the follow-up interview, the family was contacted and reassured of the voluntary nature of the study. As previously described, the researcher was mindful of potential changes in circumstances such as bereavement, illness, and other significant changes that may mean they did not want to continue the study. Any families who did not wish to continue to be interviewed at follow-up were not asked to provide a reason for declining participation.

#### **5.9.4 Ethical Considerations for Interviewing the Child and Family Participants**

Being interviewed about their experiences during and after their time in a PICU may be difficult for the family and the child patient. Several measures were adopted to minimise and be sensitive to any distress this may cause (Pascal and Bertram, 2014). The participants were offered the opportunity to be interviewed in an area convenient to them, either on the hospital site, at home or via the telephone. Every effort was

made to carry out interviews in a private area: to ensure privacy, confidentiality and reduce the risk of distraction.

Using a semi-structured intensive interview approach allowed the participant to control the amount of information given and set the pace of the discussion. The researcher used open-ended, semi-structured questions to allow the participants to take their time to talk about their experiences (Green and Thorogood, 2009). Any expressions of distress were handled sensitively during the interview, and the participant was allowed to pause or stop the interview. The child and their family were offered the opportunity to be interviewed together or separately if they wished, although all declined this offer, preferring to speak together.

How the researcher approached the intensive interview process for the child participants was carefully considered (Coad, 2012). A direct interview approach may threaten the child, and strategies were adopted to engage, relax, and create rapport (Coad, 2012). For example, the researcher used storytelling, games (Buckaroo was very popular), drawing, and play to engage and encourage the child to share their thoughts and feelings about the patient diaries (Coad, 2012; Einarsdottir et al., 2009).

The children were also offered ways to feel in control of the interview process and, therefore, more able to pause or stop the interview if they wished. This would include a discussion of signs or signals they could use to indicate they would like to stop the interview, such as raising their hand or pausing the digital recording equipment (Coyne and Kirwan, 2012; Tisdall et al., 2009).

The researcher used her extensive experience working with children and families to be sensitive to the needs of the participants during these interviews.

### **5.9.5 Ethical Considerations for Interviewing Healthcare Professionals Participants**

The HCPs involved in the focus group interviews were also afforded the same ethical considerations and sensitivities. Ground rules around conduct and mutual respect for the participants were discussed at the beginning of each focus group interview (Joyce, 2008) The researcher was aware of and sensitive to the perceived hierarchical barriers as a senior nurse conducting research. The HCPs were reassured of the researcher's position in this study, one as a researcher and not as a senior nurse. The researcher was cognisant of her language, body language and clothing (non-uniform) to flatten the hierarchical differences between the researcher and the participants. The HCP participants were also guaranteed confidentiality, anonymity, and the right to withdraw from this study before data analysis.

### **5.9.6 Confidentiality**

Concerns about maintaining confidentiality may have been a concern for the study participants. The guarantee of any confidentiality limits was made explicit to all participants before the interviews. Procedures to ensure confidentiality included the safe storage of any digital and written data collected. Safe storage was ensured through password-protected digital data storage, and any written data was stored in a locked cabinet. All data were anonymised with identification coding that only the research team could access. No participant identifiers were used in any presentations or publications made about the study.

Any data related to the study will be securely shredded or placed in a confidential disposal unit once the appropriate retention period has passed. Any electronic data will also be deleted from any computer used, and data saved on the encrypted memory stick will be safely disposed of.

The limitations to maintaining confidentiality were explicitly explained to all participants. It was clear that if a child or adult disclosed information about the risk of harm to themselves or others, the researcher had a statutory responsibility to take appropriate steps to secure their safety. Any safeguarding concern would have been discussed sensitively with the affected participants. The researcher has considerable experience and training in managing child and adult safeguarding issues. No safeguarding concerns were disclosed during the UPDATE study.

### **5.9.7 Additional Support for Participants**

All participants were offered access to additional emotional support and assistance if required. It was recognised that talking about difficult experiences may add to the participants' emotional burden. Therefore, the PICU's psychology, counselling and chaplaincy team agreed to provide additional support and guidance if needed. Written information on accessing this support and signposting to external organisations such as the GP and support services was also made available to all participants as they may have wished to gain support without the researcher knowing.

The researcher was also aware that she may be at risk of experiencing emotional distress caused by immersion into the experiences conveyed by the participants. After any particularly challenging interviews, the researcher planned to debrief with the PICU psychologist. Using memoing to reflect on any distressing information also allowed the researcher to process the information and decompress.

### **5.10 Chapter Summary**

The UPDATE study represents one of the first research studies to thoroughly investigate the usefulness of patient diaries from the perspective of the family, the child, and the HCP. Using a constructivist grounded theory approach, intensive interviews and focus group were used to generate the data, which were analysed to

develop a theory which answers the research question. Ensuring the methods adopted were of a quality to verify the trustworthiness of the study was presented.

Consideration of the ethical implications for the participants involved in this study was also described, and the approaches adopted to protect their rights and minimise any risks have been outlined.

The following three chapters will present the findings from the UPDATE study.

## **Chapter 6 Setting the Scene: Grounding the Participants' Understanding**

### **6.1 Chapter Introduction**

In the following three chapters the findings of the UPDATE study are described. The aim of the study was to ascertain how patient diaries were used by children, families, and healthcare professionals during and after admission into the PICU. To understand this perspective, the experiences of those impacted using the diaries were explored through semi-structured, intensive interviews and focus groups.

The characteristics of the patient, their family, and the HCP participants are reported in this chapter. A description of the PICU setting, as described by the families and the healthcare professionals, is also presented, providing additional context for the study.

### **6.2 Presenting the Findings of the UPDATE Study**

The findings are supported by direct quotes from interview participants, as indicated in *italics* and followed by the individual participant codes. Using in-vivo quotations from the participants is vital to embed their 'voice' in the findings and illustrates the rigour and trustworthiness of the study (Yin, 2011). The researcher used quotations to create a bond between the data presented and the findings (Tong et al., 2007).

Charmaz (2006) wrote of the importance of using the participants' words to: "help us to preserve the participants' meanings of their views and actions..." (pg. 55).

Therefore, consideration was given to the language used by the participants whilst presenting the findings to ensure the nuances of their experiences were not diluted (Charmaz, 2014).

To ensure the findings are presented in a comprehensible format, the below codes were used to identify the participants, the mode of data collection, and transcription conventions. Each patient group is numbered 1–11 to identify and link to the

demographic information presented in Table 6.1. Each focus group is identified with a letter A-E to identify and link to the data gathered from each of the focus group interviews (Table 6.2).

Table 6.1 Characteristics of Child and Family Participants

Identifying Code	Age of Child	Emergency/ Elective admission	Reason for admission	Participants	PICU Interview	Follow-up interview	Participants in follow-up interview	Mode of follow up interview
1	13 yo	emergency	Respiratory	mother	Yes	No		
2	8 mo	elective	Cardiac	mother	Yes	Yes	mother	telephone
3	13 mo	elective	Cardiac	mother	Yes	Yes	mother	telephone
4	2 mo	emergency	Cardiac	mother & father	Yes	No		
5	28 mo	emergency	Neurological	mother	Yes	Yes	mother	telephone
6	4 yo	emergency	Trauma	child, mother, and father	Yes	Yes	child, sister, mother and father	face to face
7	8 mo	emergency	Respiratory	mother and father	Yes	Yes	mother	face to face & written
8	4 mo	elective	Cardiac	father	Yes	No		
9	9 mo	elective	Cardiac	mother and father	Yes	Yes	child, sister, brother mother and father	face to face
10	3 mo	emergency	Respiratory	mother and father	Yes	No		
11	16 mo	elective	Cardiac	father	Yes	No		
<b>No. Participants</b>					<b>17</b>	<b>13</b>	<b>Total Participants = 30</b>	



Initial participant codes are:

- **Family members**
  - Parents (P)
  - Mother (M)
  - Father (F)
  - Sister (S)
  - Brother (B)
- **Patient**
  - Patient (Pt)
- **Nursing Team**
  - PICU nurse (RNP)
  - Ward nurse (RNW)
  - Healthcare assistant (HCA),

The codes to signify the interview type are:

- Initial interview (II)
- Follow-up interview (FU)
- Focus group Interview (FG)
- Written correspondence (Wrt)

For example, a quote from the initial interview with the mother of the third child recruited would be displayed as **II/M/3**. A quote from a PICU nurse participant in focus group D would be displayed as **FGD/RNP/1**.

When reporting direct quotations from the patient, family, and HCP participants, the following transcription conventions were adopted:

- (...) words omitted to shorten the quotation.
- [not italicised text] indicates explanatory information added by the researcher.
- ... indicates short pause.

### **6.3 Characteristics of the Child and Family Participants**

The UPDATE study's child and family participants are comprised of family members of 11 patients admitted to the PICU. No formal record was held of the number of parents who received any information about the study. However, it was estimated that

approximately 150 children were admitted to the PICU over the time of the first phase of interviews.

Two semi-structured intensive interviews were conducted with children and their families. The first interviews were conducted during the PICU admission, and the follow-up interviews were held approximately six months post-discharge from the hospital. Eleven interviews were conducted during the PICU admission, and six interviews were held at follow-up, therefore there were in total 17 interviews.

Table 6.1 outlines the key demographic characteristics of the child and family participants in the study.

#### **6.4 The Perspectives of the Child and Family Participants**

Thirteen families of children who met the inclusion criteria for the UPDATE study were approached during the recruitment phase of the study. Two declined to participate, and 11 families were interviewed during the initial interview phase.

Five families declined an invitation to the follow-up interviews. Two of these families were those of children who sadly died, and they were thanked for their valuable contribution to this study and for their decision not to be interviewed again was respected. Three other families declined to participate in a second interview and were also thanked. Therefore, six families agreed to be interviewed as participants in the follow-up interviews.

The families of the children in the study reflected the generalised admission pattern of children admitted into this PICU. Six of the children (54.5%) in the participant groups were under 12 months of age, and this age distribution was reflective of the data captured for all PICU admissions (PICANet, 2021).

The 11 children were admitted into the PICU for various reasons. Those admitted electively (n=5) were admitted before or after cardiac surgery. The PICU had an active

cardiac surgical program with two surgeons operating daily. The remaining six children were unplanned admissions to the PICU. The reasons for these emergency admissions included respiratory failure (n=3), cardiovascular instability (n=1), trauma (n=1) and neurological dysfunction (n=1). Of those children admitted as unplanned admissions, all were retrieved from their local District General Hospital (DGH). The size and scope of the study site provided a broad selection of children and families that represented a general cross-section of the PICU population in the UK.

During the initial interviews, conducted whilst the child was still an in-patient in the PICU, most participants were parents. Only one child, with her mother and father, could participate in the initial interview whilst still a patient in the PICU.

It was anticipated that conducting the initial interviews with the child patient would have been difficult as the child may be too unwell or young. It was, therefore, a bonus to have been able to speak to child 2, a very bright little girl who was very capable of explaining her experiences:

**Child:** *That tube [nasogastric tube] was in my nose and I really didn't like it.*

**Researcher** *why didn't you like it?*

**Child** *because it kept on annoying me because it keeps tickling me (laughing) One night, when Mum was there, one of the nurses got me a chocolate milkshake, and I drink down... down ...until there was no more left, and then I got the tube out! II/Pt/6.*

The composition of the participants in the remaining initial intensive interviews were mothers (n=4), mothers and fathers (n=4), and fathers (n=2). It became apparent during the initial data collection and analysis that the perspectives of the father required further exploration. Therefore, theoretical sampling was used to target fathers to seek further exploration of their experiences. One father explained:

*Yes... yeah.... that's [through the diary] how we got connected and it's a way to talk, as I can't talk about my feelings.... it's much more accepted now.... Yeah, I*

*can kind of put myself out there. Things about how I present myself, that I can write how I feel. II/F/6.*

Targeted recruitment of two fathers complemented the analysis of the interviews conducted with couples, in which fathers were also present.

The follow-up interviews, conducted within the six months following hospital discharge, were with mothers, fathers, siblings, and a child. Only one of the child participants was old enough to participate during this interview phase. The follow-up interviews were conducted at a convenient time, place, and mode to the participants. Several families lived many miles away from the hospital, so the option to be interviewed over the telephone was a popular mode (n=3). The three remaining families' interviews were arranged around work commitments and hospital appointments.

### **6.5 Understanding the Impact of Admission to the PICU on the Child and their Family.**

From the late 1990s, the provision of paediatric intensive care in the UK has changed in recognition of the need to provide safer, more efficient, and higher standard of care through a centralised model. Single PICU beds, often located in an adult intensive care unit, were decommissioned, and the hub model of larger PICUs, often located within a tertiary hospital, was seen as the gold standard (PCCS, 2021). However, this has meant that many children admitted as unplanned admissions would have been transferred from their local referring hospital.

Critical care transfer or retrieval means that a critically ill child would be initially stabilised by the local team and then transferred by a specialist paediatric critical care transport team. The child, accompanied by a parent or carer, would then be transferred to the PICU, sometimes 50–60 miles from home. It is appreciated how traumatic this experience can be for the child and their family, with the distress of not

knowing whether the child will recover, being in a strange environment and many miles away from home and support networks. The mother of a baby who underwent complex cardiac surgery described her experience of her son being born and then transferred many hundreds of miles away, without her. She explained:

**Mother:** *J [son] was born on Saturday transferred down on Sunday and I was really unwell: needing a transfusion [infusion]. I'm diabetic and my blood sugars would not go up and I wasn't feeling well. So, I was kept in until the Wednesday. I flew in [to London] on Thursday and we haven't left since. He was an emergency c-section at 34 weeks as I had pre-eclampsia. He was meant to be born here [London] but J decided he wanted to be born in Scotland.*

**Researcher** *So, he was transferred, and you had three days without him, that must have been very difficult? Can you tell me about how this felt?*

**Mother** *Yes, he had his first surgery, and I wasn't with him....* (Starts to cry and interview paused) **II/M/8**

Another mother spoke of her distress at not being allowed to be with her child, who was being stabilised at the local DGH. She said:

*They asked me to wait outside while they put the tube down [endotracheal tube] and it took ages. I sat in the room, but it seemed to take forever. I don't tend to leave her very much if they're doing anything. It did take forever. ... it took about an hour and a half before they... they said they're struggling to get their sats [oxygen saturation levels] up at the moment... I literally had to just walk out. I can't sit here and not be able to be with her, so I just walked outside. I went for a walk right around the Hospital. I just needed to get in there with her and they [DGH Team] wouldn't let me. **II/M/1.***

The reasons a child may be electively admitted to this PICU include admission pre- or post-complex surgery such as cardiac, spinal, or solid organ transplantation. Other reasons for an elective admission include for a child with complex health needs such as a neuromuscular disease or after routine surgery such as a tonsillectomy.

The family of a child with a complex heart defect who had been admitted previously to the PICU spoke about how they used the PICU diary to prepare their child and family for a second admission. The mother also spoke about the desire not to 'tempt fate' by writing in the diary:

**Researcher:** Can you tell me about the diary you had on [name] first admission?  
**Mother:** Yes this is the same one that we carried on.... yeah, we used it to show photos. I wanted to write stuff, but I didn't want to write things in it just in case. But just before we came back in [to hospital] I wrote some things in it and had some pictures because we wanted to write a few things. I just kept on holding back. I don't know why, it's just like one of those things... **II/M/9.**

The insights gained during the opening discussions in the interviews provided understanding on how the parents viewed the whole of their child's critical illness experiences. During the interviews the participants spoke broadly about their child's critical illness journey. Although not explicitly focused on using PICU diaries, these findings offered context of the PICU experience and allowed the researcher to gain a rapport with the participants.

### 6.6 Characteristics of the Healthcare Professionals

Approximately 150 nurses, 30 doctors, and ten allied healthcare professionals worked in the study site. Five separate focus group interviews were conducted with healthcare professionals to ascertain their views on the use of the PICU diaries. In total, 95 HCPs were recruited for the five focus group interviews. The below table (6.2) provides information on the place of work, profession, and size of the focus groups.

*Table 6.2 Characteristics of the Healthcare Professional Participants*

Focus Group Descriptor Code	Place of Work	Registered Nurses (N=93)	Healthcare Assistants (N=2)
A	PICU	24	1
B	PICU	19	1
C	PICU	17	0
D	PICU	21	0
E	Cardiology Ward	12	0
<b>Total HCP Participants= 95</b>			

The total number of whole-time equivalent (WTE) nurses working in the PICU in 2017 was 127.9 WTE (PICANet, 2017). Unfortunately, the exact head count of PICU nurses working was unknown but was estimated to be 150. Some 1.4% (n=5) of the staff were non-registered support workers, also known as healthcare assistants.

The large PICU nursing workforce was structured into defined teams. This allowed for the organisation of team management, nursing of long-term patients, and training for a group of registered and healthcare assistants. Each team was comprised of senior nurse managers, senior staff nurses, junior staff nurses, and healthcare assistants. The team structures, therefore, represented a cross-section of the whole PICU nursing team. The HCPs were already attending team study days and invited to participate in the focus group interviews. The PICU focus groups comprised of 83 HCPs, at least 60% of the total headcount of nurses working in the PICU.

The findings that arose from both families and HCPs elucidated discussions around using diaries in the non-PICU setting such as the children's ward. In particular, the cardiology ward, where several children had been admitted. Two mothers spoke about their views on the PICU diary use in the ward environment. They said:

*I don't know if the nurses on the wards are doing it [using diaries]? It might be nice if the child had one [diary] used on the ward too II/M/4.*

*Well, it worked slightly better in PICU than it does on the ward. When he is up here [ward] the nurses have got between 2 and 4 patients, so they don't have as much time, but they do know that I like them to write in it [diary] II/M/1.*

The PICU staff also discussed their views on the challenges of PICU diary use in the ward setting. One nurse said:

*I do worry about the cardiac nurses on the ward when they've suddenly got four patients in and four diaries to complete!... and how they might manage it, as we struggle when we have to write just one diary FGA/RNP/4.*

Therefore, understanding the perspective of the ward HCPs was sought through the theoretical sampling nurses from the cardiology ward. They were invited to participate in the fifth focus group interview. The ward team composition was

predominantly senior registered nurses experienced in caring for children and their families with cardiac problems.

### **6.7 Chapter Summary**

In the chapter, the context of the UPDATE study was presented by providing the characteristics of the children, families and HCPs who participated in the study.

The key characteristics of the patient and their families demonstrate that the sample of participants provides a cross-section of the types, ages and modes of admission usually admitted into the study setting. The use of theoretical sampling to explore fathers' experiences was also discussed and will be further explained in Chapter 7.

The HCP participants were representative of the nursing team working in the PICU. The focus groups had a good representation of experiences and registered and non-registered nursing team members. Finally, the use of theoretical sampling to further explore the experiences of the staff working in the ward setting will also be discussed in Chapter 8.



## Chapter 7 Grounding the Findings from the Children and their Families

### 7. 1 Introduction

In this chapter, findings from the child and family participants of the UPDATE study are presented. In this chapter, participants' perspectives on the use and usefulness of diaries during and after discharge from the PICU will be explored. Interviews focused on the specific research question: *How are patient diaries used by the child, their family, and healthcare professionals during and after admission into the PICU?*

During the interviews, the children and their families recalled the time before, during, and after admission into the PICU. Although not probed explicitly during the interviews, parents spoke of their experiences of having or being a critically ill child. These insights are presented and interwoven throughout the chapter.

Eleven families were interviewed during the initial study phase, and six families were interviewed at follow-up, at around six months post-discharge from the hospital. The composition of participants during the initial interviews was predominantly parents, with only one child. During the follow-up interviews, participants were parents, children, and siblings. However, only one child spoke of her experiences. Although invited to contribute, the siblings present did not participate in this phase of interviews.

Two initial categories and one core category were developed from the analysis of the interviews and are described in this chapter. The categories build upon each other to better understand how parents perceived the usefulness of their child's patient diary and culminate in a pivotal core category. These three categories are:

- **Creating Connections:** connecting through the diary with my child and others.
- **Impacting Emotionally:** the impact of the diary on feelings.

## Core Category

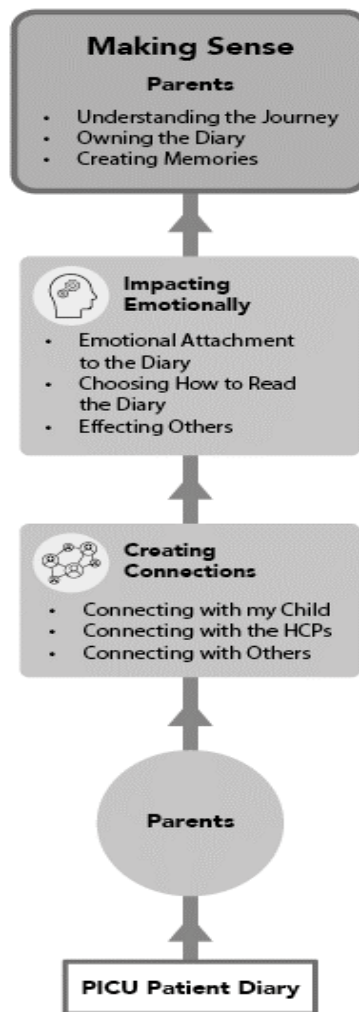
- **Making Sense:** using the diary to comprehend the journey through critical illness.

Explanation of the categories and the following sub-categories are supported with direct participant quotations. As a reminder, codes are used after the quotations to identify how the data were gathered and who the family and child participants were. Initial interviews are coded as **II**, with follow-up interviews coded as **FU** and any written correspondence as **WRt**. Participants are coded as a parent, **P**, mother, **M**, and father, **F**. The number refers to the sequence in which the child and family were recruited, i.e., the number **3** relates to the third child and family recruited to the study. The findings explored in this chapter will provide the foundation of the conceptual grounded theory model and will be discussed in Chapter 9.

## 7.2 Overview of the Categories

The first category, *Creating Connections*, explains how parents used the diary to connect with their child, their family, and the staff caring for them. The second category, *Impacting Emotionally*, explains the diaries' impact on the family's emotional well-being. The final core category, *Making Sense*, demonstrates how the participants used the diaries to improve understanding during uncertainty and anxiety through critical illness and beyond.

A summary of the categories and sub-categories for the child and family participants is depicted in Figure 7.1.



*Figure 7.1 Summary of the categories and sub-categories from the parent and child participants.*

### **7.3 Introducing their Story.**

During the interviews, it was clear that the participants spoke broadly about the experience of being a parent of a child who was critically unwell. This experience could not be distinguished from how they used patient diaries. Interviews flowed on from, and back to, the experience of having a critically ill child. The researcher used the interviews to discuss with the family and child how they came to require intensive care. Re-living the event preceding the PICU admission became a starting point during

the initial interviews and created an opportunity for the researcher to demonstrate empathy and rapport. These opening discussions then led to conversations about the patient's diaries.

Typically, parents shared, in the beginning, their stories about their child's condition, such as:

*E [daughter] was born on Sunday, Easter Sunday. It was a straightforward delivery, everything went well. ... We had E by our side in the Moses basket. We were just about to go to sleep when we saw that she was looking uncomfortable. She was trying to cough... (fighting back the tears) but couldn't. She was gagging... II/F/3.*

Parents, prepared for the planned admission to the PICU, spoke of their shock at hearing that there was a medical problem with their unborn child:

*Yes, we knew at the 20-week scan that there was a problem. So, we came back [re-scanned], and there was a measurement that they weren't quite sure about, so they sent me to an ECHO cardiologist. After 40 minutes of the ECHO [scanning], they sat me down, and I thought, 'Oh no' II/M/9.*

Although varied, the insight offered by the families about the time leading to the PICU admission helped the researcher understand the significant impact the admission had on the family. This awareness facilitated the researcher to ask more insightful and empathetic questions during the interviews.

#### **7.4. Introducing Category 1: Creating Connections**

The category *Creating Connections* describes how the participants perceived using the diaries to reach out to others. *Creating Connections* explores how the participants used the diary to facilitate connections to their child, the HCP team, other members of the child's family, and other families of critically ill children. Therefore, this category was developed from three sub-categories of the PICU diary use: connecting with my child, connecting with HCPs, and connecting with others. Using the diary created an

opportunity to express their love for their child. This was especially important in situations perceived as challenging to articulate those feelings. The diaries were used to 'bear witness' or chronicle the parents' presence during their child's admission to the PICU, capturing the evidence that the child was not without their family during this time.

Diaries create an opportunity to see the invisible aspects of the nurse's role in caring for their child. Therefore, the diary provided an understanding of the HCPs' care for the critically ill child and family. There was a sense of surprise and positive impressions of the nursing care the child received. An appreciation of nurses going 'above and beyond' expectations of the family was explicit in the interviews.

The sub-category, *Creating Connections with Others*, explored how the diary was used to explain aspects of the child's critical illness journey. In particular, the diaries were a tool to support the telling of challenging features of the child's time in the PICU.

Finally, the diary facilitated connections with the families of other children admitted to the PICU. Reading the diaries of other children as gave a sense of hope to the participants.

Each sub-category will now be described in greater detail.

#### **7.4.1 Connecting with My Child**

Using a PICU diary was explored as a way of feeling bonded and attached to their child.

This connection was imperative when the typical parental role, in the PICU, was perceived as restricted, challenging, and stressful. Parents spoke of how the opportunities to care for their children were difficult as they felt the child no longer belonged to them. Parents described a sense of disconnection or distance from their child as the inability to provide seemingly 'everyday parenting' activities such as

holding, and feeding were hindered. One mother spoke of how her son was too sick to be held and how she missed these opportunities. She explained:

*I was there every day, but he was so sick a lot of the time. I didn't get the chance to pick him up for cuddling as he was unstable, a lot of the time **FU/M/8**.*

Another mother spoke of how the diary confirmed her love for her daughter as the diary chronicled her challenges. She spoke of how the diary provided evidence of the love she had for her child, unable to nurture her in the way she would have liked:

*I love her.... love her, and this diary sort of reaffirms that because she's an amazing little thing, I'm hoping she will get something back from this. She might think, 'Why did you do that? Why were you not holding me?' Sometimes, I was holding her, and I'd be scribbling away in her diary **II/M/4**.*

Some parents suggested that the diary was a way of expressing feelings that may be difficult to articulate. One participant, the father of a nine-month-old boy who underwent cardiac surgery, explained how he found it easier to write about what he found testing to say. Using the diary as a mode in which this father could write about the love of his child was very poignant. He explained:

*What I find difficult to say, I don't really, you know... I suppose I just have the same message, that I love him. But I think of what he has gone through. He has been so brave, you know. I find it hard to speak about him, and I find it difficult to speak... but I can write about it [in his diary]. I just needed the courage to write, it was very difficult... but necessary **II/F/9**.*

Several parents explained how they used the diary after discharge to explain to their children what had happened to them. Parents discussed how reading the diary continued to help them connect with their child once discharged home. Parents suggested using the diary, like a storybook, to help them understand. One mother explained:

*I actually sit with J [son] and go through the pictures and the words with him. He doesn't understand the words, but he recognises people in the photos, like his family. So, I talked to him about it and went very slowly, going through it*

*every few days. He loves looking at the pictures, and he really loves sparkly things [artwork]. That is our very happy time looking at it, and it makes me feel close to him* **FU/M/8.**

In summary, this sub-category illuminated the usefulness of the diary in connecting parents with their children. These insights illustrated how the diary was used to create an opportunity to express their love for their child. Using the diary as a tool to 'bear witness' or chronicle the parents' presence during their child's PICU admission was explored. Finally, using the diary as a 'story' about the child, explaining what had happened was also described. Interviews also discovered ways in which diaries facilitated connecting with the PICU HCPs and will now be explored in the following sub-category, *Connecting with the HCPs*.

#### **7.4.2 Connecting with the HCPs**

Parents spoke extensively about how the diary provided insight and connection to the HCPs caring for their children. Parents spoke about how 'warm and friendly', 'compassionate', and 'kind and humorous' the entries from the HCPs were. Reading the diary entries helped develop the connection between the parent and the HCPs.

One mother explained this when she said:

*Yeah, that's it. It is the compassionate parts that you just don't hear. I might not hear [the nurses say] 'It's been a pleasure to look after her', but when it's written down, you think that's right and that they've written it... and they've had a nice day... and I've had a bit of a giggle about it and things. You know, you really understand how much the nurses really care and enjoy their job* **II/M/1.**

Parents spoke of the insight they gained into the character of the HCPs, particularly the nurses, when reading the entries in the diaries. They, on occasion, spoke with surprise about how the diary helped them view the nurse as an individual. Parents spoke of relationships, enhanced using humour, which in turn led to a closer connection with the nurses caring for their child. One father illustrated this point when he said:

*When we first met her [nurse], I thought she was really cold, but I really liked it when I saw what she wrote. She made such an effort; she was like one of the first who wrote anything. She wrote some things that were hysterical, like sucking 'bogies out'. I know when she's [daughter] 4 or 5 years old, and she will read that bit, and she will laugh at it II/F/6.*

Another parent explained how the diary entries created an opportunity to speak with the nurses, enhancing his awareness of the nurses' compassion and care for his child.

He said:

*I was thinking we've had it a few times when it [the diary] has been made easier to talk to them [nurses] after reading what they wrote in the diary. You can see those that care just that little bit more from the way they write in the diary II/F/11.*

Parents described incidents when the HCPs went 'above and beyond' their role and what these acts of kindness meant to them. One mother described an incident when the nurse, to mark the day her son had been in hospital for 100 days, added a unique entry into the diary:

*We had phoned over, and she [nurse] said, 'I've done something special'. 'Oh, he's been great, but we have done something special for you', she said. 'Come over as soon as you can!' She had put J [son] into a box and photographed him as a 'Jack-in-a-Box'. I looked at the diary, and I burst into tears as it was just amazing, and I absolutely loved it. The same nurse, when J was 100 days in PICU, made a 'Happy Hundred Days' card, which I got all the nurses and doctors to sign II/M/8.*

Connecting through the diary was a common theme shared, although some parents spoke of the unexpected feelings towards the HCP this generated. A father described how surprised he was by the positive feelings he felt towards a nurse, after reading what they had written. He explained:

*"t's been nice to be able to read what's going on. One of the nurses wrote that she was like a caterpillar, but now she's like a butterfly, and when I read that, that really made me cry II/F/6.*



It was clear from the interviews that the nursing team predominantly contributed to the diaries. Some parents also spoke of their attempts to get other members of the HCP team, primarily doctors, to add their contributions to the diaries. When asked if doctors had contributed to the diary, parents responded:

*Yes, but that is because I asked them. I'm kind of persistent with them [doctors]. Dr. S, one of the doctors up here [ward], wrote it, and she was leaving as well. I really want J's [son] cardiac surgeon to write in it II/M/8.*

*It would be nice if the doctors would write in the diary. I know they're really busy, but even if they just wrote a few words like 'you've had a great day', that would be really brilliant II/M/6.*

Some parents perceived the contribution to the diaries by medical team members as elusive. Parents reported that the doctors were perceived to be too busy. They also spoke of how they would value the contribution of other professions but assumed that these individuals could not contribute. One mother explained:

*I've never asked the consultant or a surgeon as I understand they are far too busy, so I would never ask them II/M/4.*

In contrast, another mother spoke of the importance she placed on the contribution of all who cared for her child. She sought out and asked the doctors and a pharmacist to write in the diary, explaining:

*I tell the doctors about her diary, and I say, 'You need to write in her diary'. Oh, and S, the pharmacist, because these are the people who see her every day. They may say, 'Yeah, we will', and even just having a picture [photo] is important to me II/M/1.*

There was a sense amongst some parents that the PICU diary needed to continue beyond their child's PICU admission. Parents spoke of their experiences of the diaries continuing in the ward setting. It was recognised that using the diary in the ward environment may be more challenging, but this was greatly valued. A father spoke

positively about his experiences with the nursing team on the cardiology ward writing in his daughter's diary, and he said:

*When on the ward, the nurses wrote in it, and they decorated it too [looking at entries in the diary]. Yeah, that's J [ward nurse]. She put those in II/F/10.*

Parents perceived contributing to the diary as more challenging for the ward nurses due to a lack of time. The parents acknowledged the differences in workload on the ward compared to the PICU. This consequence was not a criticism but accepted as a difference between the PICU and ward acuity. This is illustrated in the below comment from a father. He explained:

*Well, it [contributing to the diary] worked slightly better in PICU than on the ward. Up there [ward], the nurses have got between two and four patients, so they don't have as much time, but they do know that I like them to write in it II/F/8.*

This specific area of analysis led the researcher to explore further the nurses' experiences working in a non-PICU environment to understand their viewpoint.

Theoretical sampling was used to capture the experiences of the ward-based nurses, and these findings are discussed further in Chapter 8.

In summary, this sub-category has elucidated how the diary connects parents with the HCPs, particularly the nursing team. The use of the diary created an opportunity for parents to appreciate the role of the nurse caring for their child. Conversely, the contribution of doctors to the diaries was sought but challenging to gain.

Comprehension and insight into the delivery of compassionate care by the HCP were exposed through the diary use. The diaries were used to illustrate the actions of nurses going 'above and beyond', exceeding the family's expectations. This created insight into how the diary captured the unwitnessed aspects of nursing.

The interviews also explored how parents used diaries to connect with other members of the child's family and families of other children admitted to the PICU. This sub-category will now be explored.

### **7.4.3 Connecting with Others**

In the interviews, parents spoke about how they used the diary to explain to family members what had happened to their child. Parents spoke of how difficult it could be to explain their child's critical illness to family members. The aspects they reported as arduous to speak about included the reason for admission into the PICU and their child's progress. However, parents spoke about using the diary, this inanimate object, to narrate their child's critical illness story. One parent described how she used the diary to explain to her father how unwell her daughter was. In doing so, this allowed her to use the diary to explain without having to do this herself, something she felt unable to do. She said:

*My dad was worried about seeing her, and I think I try to sugar-coat things. I'd say: 'Oh, don't worry, she's really good, she's doing OK', but I don't want to put worries onto them. Now I say to them, this is her diary, and then they read it and see what she's been going through. But I think that until you've read it, you really don't understand what she has gone through II/M/1.*

Other parents explained the role of the diary in enlightening others about their child's critical illness journey. One mother spoke of how the diary explained how the nursing team cared for her son and how impressed her family were by this. She said:

*I've shown it [diary] to my mother and friends who have come to visit, and they were really impressed that somebody would have taken the time. There are a number of messages from nurses on how well he was progressing. For us, it's a reminder of the good care that he has received II/F/7.*

The diary testified to the care and compassion that was shown to the child by their parents and HCPs. This use of the diary, as an independent voice in explaining the

child's experience, was not unique. One family explained how their child had brought her diary to preschool to explain what had happened to her. They said:

**Father:** *When we went back to preschool, we felt the need to tell them what had happened, especially as you can't see from the outside.*

**Mother:** *... and also, we would be worried if she did anything at preschool to injure her throat. We would want to know straight away, and not that they wouldn't tell us, but we would be particularly worried ... That was one of the reasons why we sent it [diary] to preschool on that first day back II/P/2.*

The family further recalled a story where their daughter asked to bring the diary to a 'show and tell' session at the preschool and explained:

*They did a show and tell yesterday as the current topic is 'people who help others' this week. They were doing doctors and nurses, and they have asked E [daughter] to bring the book in. I have a picture of them all [class] sitting around whilst she shows some pictures of her book, which is so sweet II/F/2.*

Parents also spoke about how the diary explained, supported, and encouraged other families of children admitted to the PICU. They explained how positive they found sharing their experiences through the diaries with other families. A father explained:

*Some nurses asked if they could use his diary as an example for other families to give them an idea.... and yeah.... that's not a problem. We let them look through it [diary], and we don't mind. We are more than happy for anyone to look at it as it is so nice II/F/11.*

However, a few parents discussed how sharing the diary with other families in the PICU was something they were reluctant to do and wanted to be assured that if shared, this was undertaken in confidence and respectfully. One mother spoke about how important it was that she and her daughter were asked permission to share the diary with other families. She appreciated this may help other families decide whether to use the diary, but she stressed the importance of seeking consent. She said:

*They've [nurses] used it [diary] a couple of times now, just to show other parents, not to read but just to show. They asked permission, and they've asked C [daughter] if we would mind if they showed her book to other parents. They have done that over the last few weeks, and they've just shown other parents*

*about the diary. Just show them how it works, and I think it really helps, and if the parents are saying, 'Well, um, I'm not sure', it encourages them II/M/1.*

Other parents spoke of how they had been encouraged by reading other children's diaries and what a positive experience this had been. Parents spoke of their confidence in starting a diary, and a few respondents spoke about the sense of 'hope' they gained when reading the other child's diary. One family explained how valuable they found reading the diary of a child who, like their daughter, had undergone a series of cardiac operations. They said:

**Mother:** *We talked to other parents who have been here [PICU] before. They were coming to have another operation, and they said, 'Come and look at our diary'. They showed us photos of when he was a little baby. He didn't seem very healthy, and they said, 'Now look at us'. He was like a year or two older, and he was doing so well. So, looking back at his diary was really positive, and it gave us hope.*

**Father:** *yes, I really liked seeing the journey... II/P/3.*

Parents also explained how important it was to them that other family members contributed to the diary. They spoke about how they actively encouraged family members and friends to write in their child's diary, as one mother commented:

*Yep, I think most people who came have written in it, and we've got their photos in there too II/F/5.*

The contribution of siblings to the child's diary was encouraged by parents to foster continued engagement with their brother or sister. Parents spoke of how they used the diary to facilitate communication between the siblings by supporting their contribution. Parents encouraged their children to write, scribble, and draw in the diary to express their thoughts and feelings about having a sibling in the PICU. The impact of having a critically ill sibling on their other children was a concern for the parents. Many parents recognised encouraging their other children to participate in

the diary as being helpful for the sick child and their other children. One mother explained this when she said:

*We have nine-year-old and seven-year-old boys, and three-year-old and one-year-old little girls. The boys have drawn pictures and written some messages, so we stick them in the diary for her II/M/9.*

One father explained how important it was for his son, who was autistic and found expressing his feelings difficult, to be able to contribute to his brother's diary. The diary was seen as a means to articulate emotions that may otherwise be challenging. He explained:

*A [son] hasn't really written much, but where he's autistic, and he struggles with it, a bit like me. But he used loads of stickers in there, and he wrote: 'I love you G' [daughter] II/F/6.*

However, a few participants said they have yet to share the diary with others. They explained how they had not considered sharing the diary, as the experiences detailed in it felt too personal. The decision to share was one of individual choice. When one mother was asked if anyone else had read her child's diary, she said:

*No, just D [partner] and me. I mean, no one has ever really asked to read it. It's funny because I've never really thought about sharing it as it is such an outpouring of my emotions. You know, I am feeling really low when looking at it, because I know how I felt at that time. So that would be difficult to share II/M/4.*

In summary, this sub-category revealed the use of the diary in connecting the parents with others: family members, siblings, and other families of critically ill children. The diary was a tool to explain aspects of their child's critical illness journey, which may be challenging to describe to others. In doing so, the diary became a surrogate narrator of the child's journey. Sharing the diaries facilitated connecting with other members of the child's family and other PICU families. Nevertheless, it was a matter of choice as sharing this personal journey was individual to each parent. The diary was considered a

useful tool in maintaining a connection between the critically ill child and their siblings. Finally, the diary has been used to connect with other PICU parents, as a mechanism of introduction and, in some situations, sharing the diary provided feelings of hope. The emotional impact of using the patient diaries was discussed throughout the interviews when exploring connecting with the child, HCPs, and others. This concept will now be explored further in the following category: *Impacting Emotionally*.

### **7.5 Introducing Category 2: Impacting Emotionally**

The category *Impacting Emotionally* describes how the participants were affected psychologically when using the PICU diaries. It was evident that the emotional impact of having a critically unwell child was distressing for family and friends. Throughout the interviews, the participants spoke of the poignant impact having a critically ill child had on them. In all interviews, participants spoke about the emotional attachment they felt to the diaries.

This category describes how the parents were affected psychologically when reading and the subsequent attachment, they placed on the diary. Interestingly, fathers' experiences were different from those of mothers, as they described using the diary to express their feelings. The use of a diary and its impact on other family members was recognised as having an emotional consequence for all who read it.

The three sub-categories are *Emotional Attachment to the Diary*, *Choosing How to Read*, and *Affecting Others*. The following section will now explore each of these sub-categories.

#### **7.5.1 Emotional Attachment to the Diary**

During the interviews, the participants explained how important these 'little blue books' became to the children and their families. They spoke of a connection to the diary in a way that emphasised the unique value they held for this inanimate object.

This value was expressed in emotive language when describing how they appreciated the diary. Parents spoke about how they perceived the information in the diary as 'precious' and how the entries captured a moment for their child and themselves. One mother illustrated attachment when she spoke animatedly about a particular entry.

She said:

*Yes, so that's my brother and his wife [pointing to photographs], my sister wrote in... that's my mum's, P's [father] mum and dad. Dad wrote in it. Yes, we dressed up J [son] as an elf [picture of J], and then we got a toy elf the same size as him. That's a picture of S, one of the nurses. She knew I was dressing J up as an elf, and she wore an elf hat too! This is so precious to me; I will always treasure this little book **II/M/8**.*

There were many other examples from participants of entries in the diaries that they perceived as holding special significance. Families spoke of how it was important to them to keep the diary safe. They allocated unique places to store it, such as on a shelf, locked desk, or memory box. Some parents also spoke of being prepared to 'rescue' the diary if it became damaged or lost. Two parents illustrated these points when they said:

*L [mother] keeps everything like that..... she keeps breathing pipes, and things. So, she's got a box under her bed for keepsakes, and the diary will live there **II/F/10**.*

*Yes, you know the question, 'what would you grab if there was a fire?' I would want to grab the diary. I would be heartbroken, absolutely heartbroken if the diary was damaged **FU/M/4**.*

One mother spoke of her reliance on the diary as a source of information that may be required in an emergency. She also used the diary as a record and an opportunity to reflect on the progression of her child. Other parents did not mention this, although this may be a reflection as this mother's child had a complex heart defect and required ongoing healthcare support and intervention:



*Yeah, I still carry it with me because I always think if God forbid anything happens to her, it is all in there. It's all documented in there, letting me know as time has gone on. Previously, everything was kind of at the forefront of my mind, and I knew everything, but now, I kind of go 'When was that?' and I used the diary as a quick reference **FU/M/4**.*

Parents commented on how helpful and valuable the diaries have been. Most parents spoke of how the diaries were 'perfect', 'a good idea', and 'so helpful'. Nevertheless, a small number responded to the open question, 'Were there any aspects of the patient diaries that you found unhelpful?' with insightful comments. Only a small number of parents spoke of the diaries' perceived negative or unhelpful facets. A few parents spoke of their distress when reading the diary and being reminded of how unwell their child had been. One mother spoke of her decision to stop using the diary as the prognosis for her child was poor, and it was thought that he would die. She said:

*Well, after his diagnosis, I just didn't want to write it down. It was just too sad... I just thought, what's the point in it if I can't look at it [diary] with him **II/M/5**.*

This mother did restart the diary on a subsequent admission as her son was responding well to treatment. She explained:

*I wanted you to hear a balanced story, not just when somebody says the diaries are all great. You see I wouldn't say they [diaries] were unhelpful. I just needed to get over that feeling, that dip I was in, before I could start again **I/M/5**.*

Although only a few parents shared this perspective, it was stressed as an essential point that they wished to explain.

Analysis of the participants' experiences indicated that fathers' insights and perspectives were sometimes different from those of mothers. The interviewed fathers spoke of how they found it difficult to express their feelings to others, and the diaries offered the opportunity to share their emotions. This was a surprising finding, and I looked to understand the significance of this discovery through further interviews

with fathers. The challenge of being able to express their feelings about how distressed they were was explained by a father when he said:

*I've used it [diary] like when I've been struggling in hospital. When she was fighting for her life, I was thinking I just wanted my baby girl back, and it was very hard because she wasn't the same. I would write to get the stuff [emotions] out, to write in it [diary], so she knows who looked after her and what they've done. I like to log it, so I can kind of get it out of my head II/F/6.*

The same father later went on to explain how he recognised that his approach to processing difficult situations was usually pragmatic but how the experience of being the father of a critically ill child was one that he found difficult to convey. He explained:

*I don't do emotions. I'm very black and white: I get hungry, so I eat, I get tired, so I sleep... but it [diary] is about expressions of how I feel... but that doesn't come easy. It is hard for me to get it out as I just bottle it up, and that's why it's been so helpful to be able to write it down II/F/6.*

Other fathers recalled similar insights into using the diary to express the emotional impact of being a parent of a child in the PICU. A father commented on how this use of the diary was an unexpected means of support and help. The cathartic nature of writing in the diary was explained by this father who said:

*I didn't really know that it [diary] would be this good. I wasn't really allowed [by the child's mother] to write in it because I haven't got very good handwriting. This is the first time I've been allowed to write in it, and I wrote all that was in my head II/F/10.*

Fathers spoke of how they thought they needed to be resilient, strong, and irrepressible as the emotional support of the family. Fathers spoke of how this need to be seen to 'take control' was especially important if there was uncertainty about their child's prognosis. This burden weighed heavily on one father, and he spoke of how it was difficult to write about this in the diary. He explained:

*You try to support your wife, and you try to support your kids; you know, shelter them. In this case, so um, it's, um, it's very difficult to write [pause]... you know it's not very easy. It's very difficult to write because you don't know if he's going to be able to read it or if he's even going to pull through II/F/9.*

The sub-category of the emotional attachment to the diaries was described as a commonly shared experience for all interviewed parents. For some parents, the importance placed on the diaries was clearly articulated. There was a desire to preserve and keep the diary safe as it was viewed as a precious object. Some of the fathers' experiences varied from those of mothers, as fathers used the diary to express feelings they could not articulate more publicly. It was clear the impact using the diaries had on the parents and this, in turn, created the importance placed, and the subsequent attachment felt.

The attachment placed on the diaries led parents to consider the processes they used when they read the diary. The sub-category of *Choosing How to Read the Diary* will now be described.

### **7.5.2 Choosing How to Read the Diary**

During the interviews, parents discussed various experiences when explaining how they read the diaries. Choosing how to engage with the diaries post-PICU discharge was an unexpected theme. Parents spoke of a reluctance to read the diaries and how, in doing so, there was anxiety about the emotional impact this would have on them. Several parents explained how, while reading the diary, they 're-lived' the experience of having a critically ill child. Two mothers explained:

*It was after her birthday, that next day I got it [diary] out, and I read it, and I thought OK.....so that was the day she was born, this is the time we left the hospital, this is the time we got to the E [PICU], and I sort of started to process it again. That day, as it seems more sort of .....and I could almost understand it a bit more. It was as if I was back in those times FU/M/4.*

*I just thought about the diary on his first birthday. I was putting a bookshelf up in his bedroom, and I was looking at the diary and I picked it up. I was looking at it and I was thinking about having a good look at this with J [son], and it just kind of started from there **FU/M/8**.*

These two mothers had been prompted to read their child's diary due to a special occasion or anniversary. Using the diary facilitated the opportunity to re-visit the PICU experience by using it as an aide memoir to prompt reflection on their child's and family's experiences. Other participants explained how they had found reading the diary at a chosen time created an opportunity to contemplate their child's progress and those who had been part of this journey.

*Shortly after H's [son] stay in PICU, I finally had the time to look over the diary. It was good to remember all of the people we met and how he progressed over his time. H is still very young, so it is not something we have shared with him yet **Wrt/M/7**.*

*I still read it [diary]. I can probably tell you every page, and I start from the beginning. I don't get upset, but I am very proud of everything that he has been through, as he has not had it easy **II/M/8**.*

A few parents explained that they had yet to read the diary. The participants explained this delay or reluctance to read the diary was a conscious decision. A sense of permanence, that the diary would always be there, allowed participants to choose the right time to read it. One father explained:

*I think I might have seen it once, but I haven't really opened it... maybe once. I know it's there, and I know it's something we appreciate **FU/F/9**.*

This father explained that his daughter had asked to read the diary while learning about different types of careers at school. He was concerned that she had not yet come to terms with her experience of being critically ill, and he said:

*She has sort of buried it [experience of critical illness] deep down for a while. She wasn't so interested in it until recently until the 'people who help us' was*

*the school topic. And then she's been really interested in it again, suddenly it [diary] was a big thing that she wanted to look at FU/F/2.*

In contrast, another mother spoke of how she chose to share the diary with others but only when she is in a position where her daughter cannot see the diary being read. This mother used the diary to explain what had happened to her daughter, but only on her terms of where and when. Her protective concern for her daughter was explained when she said:

*I don't go through it [diary] in front of C [daughter] as I try to shield her from some of the things that have happened. So, in that way, it's brilliant as I can actually show it to people, explain what has happened but still protect her II/M/1.*

In summary, this sub-category explored parents' perspectives on their decisions about how and when they read the diary. The choice to read the diary was that of the parents. However, there were triggers to reading, such as a significant milestone for the child. It was acknowledged that reading the diary brought back memories of the child's critical illness. Therefore, reading the diary was perceived as being emotionally charged. Subsequently, avoiding or delaying the diary reading was within the parents' gift and was described as a conscious decision. This finding was especially poignant when considering how little choice the parents perceived they had during their child's critical illness.

Reading the diary by other family members and friends was an area of discussion with some parents, describing the emotional impact the diaries had on others. These findings will now be further explored in the sub-category *Effecting Others*.

### **7.5.3 Effecting Others**

The effect and impact the diary had on other members of the child's family were discussed by some parents, focusing on the emotional impact when reading the diary.

Parents spoke of how the diary became a tool to explain what was happening to their child in an independent, detached way, allowing the parents to 'step back' from having to explain to others what was happening. Some parents spoke of their responsibility to protect others and may be hesitant in what they share. Using the diary to communicate with other family members was helpful as a conduit to understanding. One mother explained this when she said:

*I don't have to go through everything again; you know they can see in black and white: this is where she's been, and she's coming through all right. So, we do tend to give them the diary to read actually because I sometimes worry that I try to protect them from everything II/M/1.*

The impact of reading the diary on other family members was discussed by other parents when they described how their family members may become upset. The participants described how they felt about the impact reading the diary had on their relatives. This was illustrated by a couple who said:

**Mother:** *Yes, my sister-in-law has read the diary"*

**Father:** *Yes, she's very thorough. I'm sure she's looked into these details. She has great attention to detail.*

**Mother:** *She was saying that she was looking at it, but she didn't actually mention anything specifically.*

**Father:** *No, but I think she got upset II/P/3.*

Some parents explained how they remained protective of their family members and were concerned that the content in the diary would be distressing for them, giving them a choice to read the diary only when they felt willing to do so. This point was illustrated by a mother who described how her mother had declined to read the diary until her grandson was home and recovering. She explained:

*Aye, my mum hasn't read it since December, the second time she was down [visiting child in the PICU]. She never got the chance even to cuddle him as he was so ill, on a ventilator, and not doing very well. She would get quite upset seeing J [son] like that. She chose not to read, but when he gets home, she*

*might be different because he's well. When he gets home, she said she will read it II/M/8.*

In summary, this sub-category has explored the emotional impact reading the diary has on others in the child's family. The diary was used to connect with and explain what had happened to the child. Overall, this was a practical consequence of the diaries. Nevertheless, a few parents acknowledged that reading the diary was difficult for some family members. Some of them avoided reading the diary in the presence of others as they were concerned that they would be emotionally overwhelmed by the content.

Building on the categories of *Creating Connections* and *Impacting Emotionally*, how the processes of using diaries developed the core category *Making Sense* will now be described.

### **7.6 Introducing the Core Category: Making Sense**

The core category, *Making Sense*, describes how the participants perceived the usefulness of the diaries in understanding the experience of critical illness in children.

This core category is grounded in the previous two categories, directing the understanding of how using the diaries leads to this core conclusion. Moving through the processes of *Creating Connections* and then the *Emotional Impact of using the Diary* leads to the final direction of using the diary to make sense of the non-sensical. Therefore, the diary became a key mechanism for capturing the moments of their child's time in the PICU in several arts-based mediums, including the curation of words, objects, and artwork.

This core category explains how the diaries helped understand what was happening to their child. The parents described how the diaries supported their understanding of what was happening. Finally, the diary was a tool to collect and store the entries that

would ensure the memories of what happened to their child were not lost. This category was developed from three sub-categories: *Understanding the Journey*, *Owning the Diary*, and *Creating Memories*. These three sub-categories will now be described and how these were built to create the final core category will be examined.

### **7.6.1 Understanding the Journey**

Parents and children spoke of how the diary was used to demystify, make sense, reiterate, and support understanding of their journey through critical illness. This situation was described by many as ‘complex’, ‘frightening’, ‘confusing’, and ‘out of control’. Parents spoke of how the diary entries provided an opportunity for clarity about what was happening to their child, seen as especially important during times of uncertainty. One mother explained this when she said:

*The diary helped me to understand and reflect on how seriously ill H [son] was and what it took to get him better. During the experience, I completely focused on getting through each day. S [Dad] tried to learn about the machines and what they were doing, what each setting meant. Everyone has their own approach. The diary gave me a reference point, as to what each day was like from the nurses’ perspective. I found that really helpful* **Wrt/M/7.**

Using the diary to understand the day’s events and make sense of what was happening to their child was perceived to be important to the families. Reading what progress their child had made and having the space to read this at a convenient time was seen by some as a crucial act to ‘unpack’ the day’s events. As one mother explained:

*I think that if it’s [events of the day] in my head but in a jumble, and if I can put it onto paper, then I can make sense of it. It [writing in the diary] was the thing I did before going to bed, reading [the diary] for 10 minutes, looking over the day and going, ‘OK, this is going to be all right’* **FU/M/4.**

A father explained how he used the diary to understand his child’s treatment but was reminded of how he felt as he re-read the diary. He described using the diary as a tool



to support reflective thinking, looking back on his experience, with the diary as a permanent record of this time. He said:

*Now, for me, it [diary] was much more about how I was feeling, rather than thinking about the medication and things that happened to him when he was in NICU [Neonatal Intensive Care Unit] and the PICU. If I want to look back, I can reference the things [treatment] he needed and used. It will be there [in the diary] **FU/F/9**.*

The above statement also demonstrates the opportunity the diary provided in supporting a parent's reflection on their child's progress and, in doing so, how this could enhance understanding. The reliance placed on the diary was not unique, and some parents directly referred to the importance they placed on this object as a source of information, support, and comfort:

*I take it [diary] with me in her change bag. If I'm going to see friends or going somewhere for any length of time where I can't get back home easily, I bring it [diary] with me. I went away for four days with Mum, and I said to him [father], 'You know everything is in that bag, including the diary'. It is like preparing a maternity bag, that you have everything you might need ....it [diary] feels like a safety blanket **FU/M/4**.*

In summary, the diary was used as a source of information gathering, allowing explanation and understanding of their child's journey through critical illness. The value placed on how the diary supported understanding was demonstrated by the importance placed on the diary as a modality for self-reflection. The diary was an important tool to aid understanding, creating a sense of dependency on the diary as a source of information. The importance placed on the value of the diary also led to discussions on diary ownership, which will now be discussed in the following sub-category, *Owning the Diary*.

### 7.6.2 Owing the Diary

This sub-category describes how the study participants understood who assumed ownership of the diary and how this decision influenced how the diary was structured.

The families reflected that once they recognised who owned the diary, there was a more precise direction on how, why, and when it would be used. This became a key discussion point during the interviews and a concept explored with all participants.

Most families spoke of how they viewed the diary as being owned their child. When asked the question, 'Who owns the diary?', parents responded:

*I would say J [son] because it is all about him II/M/8.*

*Definitely, him [very tearful]. It is almost as if I could use a different voice to speak to him [through the diary], then maybe I would feel differently, but yes, everyone who has written in it has written to him, so it [diary] is his II/M/5.*

*It is the greatest diary ever, and they [HCPs] have always said it [diary] is her's, so it is G's [daughter] diary FU/F/6.*

*I think it is H's [son]; yeah, it is his. I didn't feel it was a medical record with all the other charts and things. I think it will be something nice for him to own II/F/7.*

However, some families spoke of the fluid ownership of the diary and saw the ownership as a changing concept. In doing so, the sub-category around 'ownership' can be understood as different at stages during the child's time in the PICU. One family described how the diary is for the child once they are home. They explained:

**Father:** *I think she [daughter] owns it, actually.*

**Mother:** *I'm not sure. I think we do, at the moment.*

**Father:** *Yeah, I'm not sure who particularly owns it at the moment. Ultimately, we take it home, although it's not our initiative, and we are not even going around writing in it. So, I don't feel it is ours, but it's for her, so that makes it hers. Yeah, that's been an interesting question II/P/3.*

Another parent, who spoke about his partner's difficulty in engaging with their child, said:

*Our family [owns the diary]. It doesn't belong to somebody in particular. It's mine, and it's my partner. It's his [son]. As a family, we keep it, but everyone is allowed and able to look at it. It's a family thing, yeah, definitely II/F/11.*

None of the participants thought that the HCPs or hospital authorities owned the diary. Claiming ownership of the diary led to further exploration of how the families described being able to direct how the diary was used. The understanding that the diary belonged to the family and child was expressed in their ability to set the tone of the diary. Parents explained how important it was to them that the diary was written in a way that was clear, easy to understand, and explained to the intended audience what had happened. One mother said:

*It is really important that I understand what has been written. It goes over, in simple terms, his condition and what they were doing for him. It even mentions the morphine and the ventilation and things, not just the basic stuff. Also, how he ended up there [PICU] and what he was doing, and there were a few pictures of the machines and things II/M/7.*

The importance of the diary content, written in a manner that explained the complexity of the situation in simple terms, was shared by several parents. Additionally, the simplicity of language and structure offered the ability to explain to others what had happened to the child. Directing the content of the diaries was especially important to families when there were no obvious external signs of how unwell their child had been. One mother described how she would use the diary to explain the journey her child had been through:

*I think that when J [son] starts preschool, I'll probably show it [diary] to the teachers, but I don't expect them to read it, but this is what has happened to him ... so that they know from the outset because, apart from his feeding tube you know, he looks totally normal FU/M/8.*

Another family spoke about using the diary to explain the severity of their child's injury:

**Father:** *When we went back to preschool, we felt the need to tell preschool what had happened, especially as you can't see anything obvious from the outside.*

**Mother:** *...and also, we would be worried if she did anything at preschool, like injure her throat we would want to know straight away and it is not that they wouldn't tell us, but we would be particularly worried II/P/2.*

Assuming ownership of the diary led the parents to talk about the practicalities or functionality of the diary. Parents recalled how they were first introduced to the diary concept and how this explanation helped in their engagement with the diary, for their child. The nursing team provided the initial introduction to the diary for the child. Families expressed feeling confused and needing clarification on the function of the diaries. However, they were struck by a sense of positivity towards adopting the diary by the team introducing these. Two fathers explained:

*All I can remember really is that they [nurses] said 'we've got this diary, and you can use it to write notes in, and you can get nurses to write the notes in and take photos, and you can take photos as well...' but I didn't really know that it would be this good II/F/11.*

*Because, of course, for us, it was so worrying. We were seeing a baby with needles, and obviously, as new parents... the guys in the ambulance [transport team] were so accommodating. Then, I think the first nurse we saw said, look... um, I can't remember exactly the details of what she said, but she said we have a little book we can start that might be helpful. So yeah, it was great II/F/3.*

One parent, whose daughter had been admitted into the PICU for a short admission, spoke of discovering the diaries later in her child's admission after seeing them used with other children. When asked how the diary had first been introduced to her, she explained:

*I would like to say it was J [nurse] because she did all the first lot of writing. I would say it was J... she said, 'There's nothing in this diary, so I'm going to have to go right back to the beginning', so she wrote a shortened version of what had been going on. She went back herself, and she wrote in all the different bits..... so yeah the first part of the diary was filled out by J II/M/1.*

Families spoke of a transference of ownership and responsibility for the diary from the nursing staff to the families. This process often occurred quickly after the initial admission into the PICU. Once they accepted that they were the key guardians of the diary, the parents spoke of how the diaries gave them 'something to do', occupying their time and distracting them during a time of concern and worry. Writing in the diary allowed family members to be creative: writing, drawing, and decorating the diary for their child. Two parents explained:

*It [diary] definitely occupies my time when there wasn't much I could do for the little guy II/F/7.*

*It's [diary] a great distraction because you're kind of sitting, and you are just staring at your little one, and it actually gave me something else to focus on II/M/4.*

Most parents spoke of how they contributed to the diary and how this occupied their time. One father, who did not write in the diary, spoke of the value of reading the diary entries. He said:

*I've read bits of it every now and then, especially when we come back in, and I am sort of sitting and waiting, I think, I will have a quick look at what my friends and family have written. I think it's good. It's really good II/F/10.*

How the parents directed and framed the contributions to the diaries was also explored. Parents discussed using the written word, photographs, and creative artwork to contribute to the diary.

*When it [diary] first came, I started to write in the diary, but then you get days when so much has happened. You just get back, have something to eat, and then you forget to catch up, and you've missed things [events] that somebody else has got it... I do take pictures, though, as that is easier II/M/1.*

*I've documented the day-by-day journey writing to him as if I was speaking to him. That is the voice I've used. I have written down any visitors, took photos, and then wrote bits and prayers in it II/M/5.*

Parents were asked about how they contributed to the diaries. One parent spoke of their difficulties when participating with the diary, as they felt uncertain about how to write in it. Although this was an isolated comment, it was necessary to understand further the views of this parent, primarily as this point reflected the lack of claiming ownership of the diary and seeing it as being under the nurses' control. The father explained:

*... I think from the beginning, from my side anyway, it [diary] was presented in a way that the nurses said they were doing it, and I kind of just didn't think twice about that. Somebody mentioned, at one point, that the other visitors could fill it in then it occurred to me... well, why, of course, why wouldn't we? We haven't yet, to be honest with you. We have been so busy, but I will do it II/F/3.*

In this sub-category, ownership of the diary was ultimately awarded to the child. However, there was fluidity in the transfer of ownership from the HCP to the family and the child. The parents viewed their role as one of guardianship over the diary. Once accepted, this empowered them to direct, control, and take responsibility for how the diary was used. From this clarity of ownership, the use of the diary to create memories for the child and themselves became more evident. This sub-category of *Creating Memories* will now be described.

### **7.6.3 Creating Memories**

Parents discussed how the diaries became a prompt and a tool to collate and curate the evidence around the child's time in the PICU. Many spoke of capturing the 'moments in time' during their child's critical illness. This was important as parents were often concerned that it might be hard to recall in detail or they may even forget what had happened. Gathering concrete evidence of who was present, what, and when things happened, was explained as an essential use of the diaries. To illustrate this point, a mother explained:

*I think the idea of the diary made us decide that every time we have a visitor, we are going to take a photo of them and have it there. Whether we put it [photograph] in the diary or not, we still print it out and have it as a memory. I want her [daughter] to be able to say, 'Hey, look, I was only a few days old, but look at all these friends and family who came to see me'. For me, that idea came from the diary II/M/3.*

Parents also explained how some of the medical equipment used on their child was collected and contributed to the telling of their child's story. As a tangible reminder of what had happened to their child, this included medication labels, monitoring, and invasive equipment. Parents discussed how these items contributed to building a picture and memories of how their children looked and how unwell they were during this time. Archiving items that had been used in real-time was described by some as 'badges of honour' for the child. A mother and father explained how important this was to them when they said:

**Father** *It's [diary] got lots of bits in it like some cables and things. These explain what he's been through, even the first drawings [drawn by the cardiologist] of his heart defect.*

**Researcher:** *So, have you put more than just photographs in? Can you tell me more about this?*

**Mother:** *Yes, he [father] even put in things like the consent form that we had to sign before he goes in for the [cardiac] operation. We do this so he can see all he went through.*

**Father:** *So yeah, we put the labels of the drugs that he had.*

**Mother:** *Those that saved his life... I even have a breathing tube [endotracheal tube]. We asked the nurses if we could keep it, but they were reluctant as they said we had to throw it away for infection control. We kept his blood pressure cuff a really tiny one. Every random thing that they use, I think, 'Can I keep it?'. So, anything that he's touched, or you see... you see, has been part of him, which is really nice II/P/6.*

Another parent spoke of the importance of the diary being handled by family members and how their contribution created a poignant memento for her child. She explained:

*For her to be able to see her grandparent's handwriting, it's that, you know, that outpouring of love for them onto paper, and I think for her to see all the scribbles feels so important... FU/M/4.*

This sub-category explains how parents used the diaries to collect tangible testimony of the child's journey through critical illness and, in doing so, facilitated the creation of a repository of memories. Parents stressed the diary's usefulness in compiling a record of the PICU events for the child and the wider family. The diaries were seen as a precious memento, supplementing the understanding of the events through a personalised record for the child and their family.

In summary, the core category of *Making Sense* described how parents used the diaries to understand what was happening to their child. The diary was viewed as being owned by the family and the child. It was a tool to collect and store the memories of what had happened. The diary was used as a source of information gathering, allowing explanation, and understanding of their child's journey through critical illness and beyond.

### **7.7 Chapter Summary**

In this chapter a description of the findings from the family participants of the UPDATE study has been presented. The categories generated from the interviews have created rich insight into the usefulness of PICU diaries. The categories have grounded the understanding of how parents used the diaries to *Create Connections* with their children, other family members, and the HCPs. This greater understanding has been multi-directional, with families feeling more connected to their child, understanding the nurse's role, and explaining their child's critical illness journey to others.

The *Emotional Impact* of using the diaries was elucidated by the connectivity created through the diaries. This category explained how participants were affected psychologically by reading and the subsequent sentimental attachment they then placed on the diary. This category explored how the diary, an inanimate object, was prized by parents and the impact it had on them, both positively and adversely.



Finally, the usefulness of the diary in helping parents and children *Make Sense* of the critical illness journey was the final core category revealed from the analysis of the interviews. This category described how the participants used the diary to help them understand what had happened to their child. The diary created a tangible, permanent repository of memories and supported them in making sense of the sometimes, non-sensical.

In the following Chapter 8, findings from healthcare professional participants are reported in detail and will reveal the further grounding towards the theory of how of PICU patient diaries are used.

## Chapter 8 Grounding the Findings from the Healthcare Professionals

### 8.1 Introduction

In this chapter, the findings from the healthcare professional (HCP) participants are presented. This part of the UPDATE study aimed to explore HCP participants' perspectives on the use and usefulness of diaries during and after discharge from the PICU. The focus groups with the HCPs centred around the specific research question: *How are patient diaries used by the child, their family, and healthcare professionals during and after admission into the PICU?* The findings explored in this chapter provide the foundation of the constructivist grounded theory framework model, which will be discussed in Chapter 9.

Five focus group interviews were conducted with 95 registered or non-registered nurses to ascertain their views on using the diaries. The focus groups comprised 93 registered and two non-registered nurses. Four focus groups were comprised of HCPs from the PICU (Focus Groups A–D) and Focus Group E was comprised of nurses working on the paediatric cardiology ward (Table 6.2)

Three categories and one core category were developed from the analysis of the focus group interviews described in this chapter. The categories build upon each other, flowing onto the next, reflecting how the participants have grounded the findings through sharing their stories. This led to a greater understanding of how HCPs value the patient diary, culminating in the pivotal, core category of *Making Sense*. The categories are:

- **Creating Connections:** connecting through the diary with the child and others.
- **Impacting Emotionally:** the impact of the diary on feelings.

- **Empowering Involvement:** using the diary to empower families.

### **Core Category**

- **Making Sense:** using the diary to comprehend the journey through critical illness.

Explanations of the categories and sub-categories are supported with direct participant quotations. As a reminder, codes are used after the quotations to identify which focus groups, **FG**, the participants were in. The codes **A–D** identify the PICU focus group interviews, and focus group **E**, identifies those HCPs from the paediatric cardiology ward.

A PICU registered nurse was coded as **RNP**, and a cardiology ward nurse was coded as **RNW**. The number refers to the anonymous identifier of the HCPs, i.e., the third nurse to speak in the second PICU focus group interview would be identified as **FGB/RNP/3**. The initial written comments captured on sticky notes (Appendix 9) and further discussed during the focus group interviews are coded as **Wrt**.

### **8.2 Overview of the Categories**

The first category, *Creating Connections*, explains how HCPs used the diary to build relationships with the child and their family and, in doing so, encouraged the family to feel connected to their child. *Impacting Emotionally* explains how the diaries were a therapeutic tool for family support and offered an opportunity for the HCP to be artistically creative. *Empowering Involvement* describes how the HCPs viewed the diary as a tool which encouraged active family involvement in the care of their critically ill child and was perceived to support coping through the PICU admission. The core category, *Making Sense*, describes how the HCPs used the diaries during a time of potential uncertainty and anxiety for the families, to improve understanding during and after the PICU admission.

A summary of the categories and sub-categories from the HCP participants is depicted in Figure 8.1.

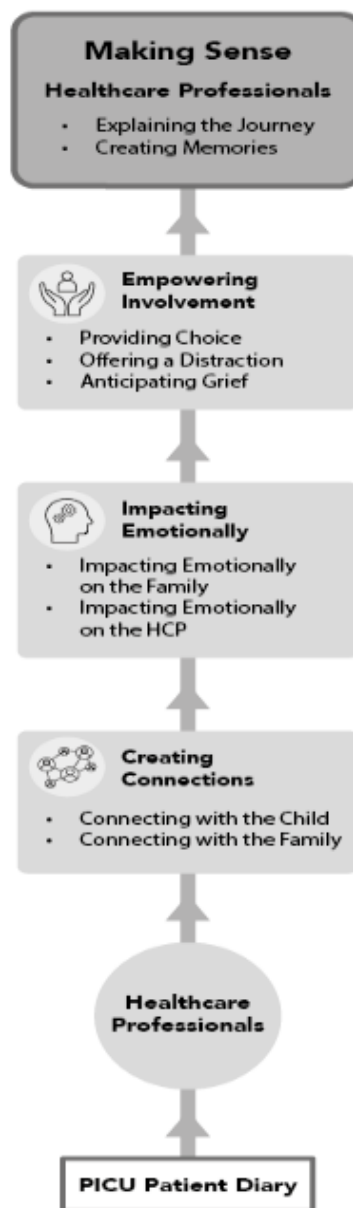


Figure 8.1 Summary of the categories and sub-categories from the HCP participants

### 8.3. Introducing Category 1: Creating Connections

The *Creating Connections* category describes how participants perceived the use of diaries to reach out and connect with the child and their family. The use of the diary to facilitate relationships between the HCP, the child, and their family was a recurring

theme in interviews. This category is mirrored in the findings of the parents in the use of the diary to promote relationships with others. The diary allowed the HCPs to present themselves to the patient in an age-appropriate way, introducing themselves to the child in a friendly manner. The diary offered an opportunity to document the nursing care the child received. The sometimes 'invisible' care that the HCP provided was captured in the diary and provided a record of the HCP's relationship to the child. The diary created an opportunity to connect with the child's family, fostering a relationship between the HCP and the family. Diaries, therefore, became a conduit through which the care the child was receiving could be re-iterated. The diary provided the ability to chronicle care activities, which was especially important if the family could not be present.

Reading diary entries made by the family provided insight for the HCPs into how the child's critical illness impacted the parents and other family members. The diary also facilitated an enhanced understanding of the nurse's role, the care delivered, compassion for the child and insight into how the family may be coping.

Therefore, *Creating Connections* explores how the diary facilitated personal relationships between the HCP, the child, and the family. Two sub-categories, *Connecting with the Child* and *Connecting with the Family*, frame this category and will now be explored in greater depth.

### **8.3.1 Connecting with the Child**

The HCPs described the diary as a tool to connect with the child, especially when a child may have limited understanding due to the complexity of their illness or cognitive development. The participants were invited to write their views on the question: '*How do I use the diaries?*' The HCPs wrote about how the diary was a means to provide information or 'tell the story' to the child in an easy-to-understand manner. When

further encouraged, the HCPs explored what was meant by the written comments.

They spoke of how it was essential to introduce themselves in the diary to personalise the relationship between the nurse and the child. The HCPs explained how they wrote the diary in an informal, conversational style 'as if the child was reading it aloud'. One HCP said:

*I might introduce myself and say my name and say things like, 'Oh, you've been a brilliant boy today. I might stick in some of the things that we used [medical equipment] and explain what they are, like ECG dots or a thermometer', and I always carry glitter pens to use [laugh] **FGD/RNP/5.***

Several HCPs spoke of how they used the diary to validate how they had come to know the child on a personal level. One HCP explained:

*I think particularly about our long-term patients; it is nice to write things like that... [personalised comments about the child], so they can see that you've got to know them **FGA/RNP/3.***

The diary allowed the HCP to explain their contribution to the child's critical illness journey. Several HCPs explained how they used the diary to communicate directly with the child whilst recognising that the child may not be able to receive these messages until later. Two nurses in Focus Group B explained this finding when they said:

*I see it as another way to show that you care, because of how it comes across at the time. They [the child] can look back and see how much we were there for them and how much we cared about what happened to them... **RNP/6.***

*...Yeah, I agree it's like the little things that you can do, to show what you actually do, like how you speak to them, read them stories, you know... and give them a bath. You can write that in the diary, but you might not write it in the notes [patient records] **RNP/7.***

The discussions illustrated the personal connection the HCPs felt towards the child and how important it was that the child was aware of the care they had received. The diaries offered a tangible legacy to chronicle care delivered by the HCPs.

In summary, this sub-category illustrated how diaries were used as a means for the HCPs to build a relationship with the child. This was particularly poignant, as it was appreciated that the child might not be able to comprehend the nurse's involvement at the time of writing the diary. Additionally, using the diary to demonstrate the personalised care delivered to the child was a crucial outcome of the diary's use. Finally, the diary was a tool to provide evidence of the child-focused and compassionate care delivered.

The focus group interviews also revealed how the diaries facilitated building a relationship with the child's family. This finding will now be explored in the *Connecting with the Family* sub-category.

### **8.3.2 Connecting with the Family**

The HCPs discussed in greater depth and incidence using the diaries to connect with the family in comparison to connecting with the child. Several written responses to the questions illustrated how the HCPs used the diary to bond with the family. The HCPs wrote comments describing how the nurses used the diary to summarise what had happened to the child during the shift. The HCPs explored how important it was to use the diary as a means of explaining in easily accessible language to families and how this, in turn, provided a means to connect. The written data generated during the focus group interviews illustrated the ability to use the diary to communicate directly with the families. Written comments to the question asking *What was the value of the diaries?* Included responses such as:

*To recap the shift and attempt to say something to the patient and family*  
**FGA/Wrt.**

*For parents to see and read how the child has progressed*  
**FGE/Wrt.**

*For parents to be able to read what has happened to their child when they are not there*  
**FGB/Wrt.**

The written statements were further discussed to understand how the diary was used to communicate and subsequently build connections with the family. The HCPs described how contributing to the diary was a way of explaining to the family what had happened to their child. This finding was elucidated as being particularly poignant if the parent was not present with their child, such as during a night shift. Two HCPs in Focus Group D explained:

*I think they [parents] like it [diary] after a night shift. We might hand over [verbally] how the night has been to the parents, but the diaries give the key things that happened overnight. Yeah, it's about being able to go over information when you might not be able to see them physically... **RNP/9.***

*...I was just thinking about that too, especially on night shifts. If you don't meet the family etc., you have a really nice way to have a bit of a connection with them even if you haven't spoken to them. They can look back and feel like their child has been looked after, so you have a bit of a relationship with them **RNP/13.***

The diary supported the HCP in demonstrating to the parents that, in their absence, their child had received care. This diary use was revealed as necessary by the HCPs, reassuring the parents in the PICU and the cardiology ward. A ward-based HCP illustrated this point:

*There's also something about telling them [family] what happened when they weren't there. Like if their baby was distressed and you cuddled them, so they know that somebody was there for them **FGE/RNW/5.***

Several HCPs explained how reading parental diary entries helped them understand the parents' perspective and how they were coping with having a critically ill child. The HCPs explained that reading these entries occasionally provided an awareness of a parent's emotional wellbeing. These insights may not have been fully appreciated if the HCP had only spoken with the parents. Reading the diary was viewed as helpful in guiding the HCP in providing additional parental support where needed. Additionally,



some HCPs acknowledged how these insights into the parents' emotional state also raised their awareness of the experiences of the critically ill child's parents and family. Three HCPs in Focus Group C discussed how reading the diary helped improve their understanding of how parents may be feeling. They explained:

*You know if they [parents] feel angry or upset and they write it down. It might make them feel better, and also, we might pick up on how they are feeling. When you read what they have written in the diary, you kind of get that feeling. You know if they want to keep the diary to themselves. But if it is a shared diary, where the nurses and family are writing in it, you might pick up something in the diary that has not been communicated directly to you... RNP/15*

*...Yeah, I had the same experience. I remember a long-term patient we had, and their parent had written something in there that worried me. I was able to say, 'I hope you don't mind me saying, but I've read this in the diary...' and it was just like opening a door, and they were able to talk about how they were feeling... RNP/13*

*...Similarly, but also, for me reading the diary has enabled me to understand the families and how they might perceive certain things. I think it teaches us something about empathy. When we read what the parents have written, I sometimes end up reading between the lines, and I feel like I've learnt a lot from it RNP/10.*

Some HCPs expressed apprehension about reading the family's diary entries if these were perceived to be private. Although it was not common for the diary to be used exclusively by the family, the HCPs respected parents' wishes if they only wanted family members to contribute. One HCP described this scenario when they said:

*I had one dad, and he would take the diary away at the end of the shift and he said that only he was going to use it. So, when dad came in, I clarified that the diary was just for him, and I checked that mum didn't want to use it. So, he took it on himself to complete FGC/RNP/16.*

A few HCPs described reading entries that raised safeguarding concerns about families. The HCPs recognised that their professional responsibilities superseded any worries about reading a personal parental diary entry. Two HCPs in Focus Group A illustrated

this point when they explored an occasion when they read a diary entry by a distressed mother expressing suicidal thoughts. They said:

*But I think they [mother] knew that we would be writing in it [the diary], so they also wrote in it knowing there was a chance we would read it. She probably thought she couldn't discuss it [her emotional distress] or didn't feel confident sharing her concerns with her mental health nurse... RNP/12*

*...Yeah, and I think you can read it [diary entry] and think it is just the parent's way of expressing and venting how they are feeling, but if it becomes a point of safety..... If they are writing things as serious as wanting to hurt themselves, it becomes much more difficult, and we have a responsibility to do something RNP/26.*

In the above incident, the HCPs discussed their concerns about the mother's safety and were able to refer her for further psychiatric assessment and support.

Several HCPs spoke of how the diaries connected parents and other families in the PICU.

They spoke of how contributing to the diary may create an opportunity for other families in the PICU to 'bond over'. The HCPs spoke of occasions when parents might speak to other families when writing or decorating the diary, such as when sharing items from the arts and crafts trolley containing pencils, stickers, and paints. One nurse said:

*I think it [the diary] gives a structure, doesn't it? A way to communicate with others. It [asking a question to another family] is like, 'Do you know where the sticker trolley is?' So, they [parents] all kind of interact with each other. You know, they might say, 'Can I have that sticker trolley?' and it is a way of talking with each other. So, I suppose, yeah, what it means is another commonality, another thing that they share FGA/RNP/2.*

The HCPs recognised that using a diary may be daunting for some parents. HCPs explained how they used a sample diary, illustrating how the diary may be used if the family were hesitant to start one. Demonstrating to parents how they could use the diary was perceived to be helpful, encouraging engagement and reducing parental

concerns. In response to a written comment: *It would be useful to show parents another diary which had already been written in FGC/Wrt*, one HCP further explained:

*Sometimes, you might mention to the parents the diary, and they think 'Oh no, I'm not so sure'. I know that they just don't want to remember it [time in PICU]. But if you can show them one [diary], then they might think 'Oh yeah, I like that'. But it's their choice at the end of the day. If they don't want to remember, it's absolutely fine. You just don't want them to regret that they didn't get one FGC/RNP/12.*

Nevertheless, the HCPs recognised that using a diary was the decision of the child's parents, and the nurse's role was to offer and inform the family of that choice.

This sub-category described how the diary connected the HCPs with the family. The diary explained to parents how nursing care had been delivered to their child, including the unwitnessed nursing aspects that may have occurred when parents were not present. The diary also offered insight into how a family may cope with their child's critical illness. This insight could be used to provide additional family support.

Concerns were raised about the voyeuristic nature of reading the family's entries in the diaries, but with a recognition of the HCPs' duty of care to address any safeguarding concerns identified. Finally, diaries created a conduit to connect parents to other parents and offered a means of introduction.

The next category, *Impacting Emotionally*, will describe how, following the opportunities to connect with others, the diaries supported the HCP in providing emotional support to families. The impact using diaries had on the HCPs' emotional wellbeing will also be examined.

#### **8.4 Introducing Category 2: Impacting Emotionally**

This category, *Impacting Emotionally*, describes how the HCPs used the diaries to understand the psychological impact having a critically ill child had on the family and the impact the diaries had on the HCPs' emotional wellbeing. The HCPs recognised

how the families' used diaries and how this enabled the expression of emotions that may have been difficult to articulate. The HCPs explained how, through this insight into the family's feelings during their child's critical illness, they were better able to offer emotional support.

Throughout the focus group interviews, participants also spoke of the personal impact they experienced when using the patient diaries. HCPs spoke of the challenges they experienced in being compassionate when writing about the problematic aspects of the child's time in the PICU or the ward. The HCPs also explored the responsibility and subsequent moral distress they felt if they could not contribute to the diary due to time constraints. Professional and legal concerns about using the diary as a patient care record will also be described. Finally, the impact of using a diary on the HCPs' personal life was also discussed.

The two sub-categories of *Impacting Emotionally on the Family* and *Impacting Emotionally on the HCP* will now be described.

#### **8.4.1 Impacting Emotionally on the Family**

The emotional impact of the patient diary was evident in the findings generated from the focus group interviews. The HCPs wrote, on the 'sticky notes', how the diaries were seen as a means for the families to express their thoughts and feelings and how this process could be perceived as therapeutic for the family. The HCPs wrote comments such as:

*It enables the parents to express what they are going through in a safe place*  
**FGD/Wrt.**

*It helps families to vent emotions in a structured way* **FGE/Wrt.**

*Offers them a place/way to express their feelings* **FGA/Wrt.**

On further exploration, the HCPs discussed how the diaries enabled the child's parents to write how they may be feeling and, therefore, offer a cathartic outlet. The beneficial

nature of using the diary and the positive impact this may have on emotions was illustrated by the discussion between two HCPs in Focus Group D when they said:

*I think it [diary] can be quite a therapeutic thing... RNP/15  
...Yeah, it is almost like self-counselling, an opportunity to debrief about what has happened RNP/2.*

Some HCPs acknowledged the value and power of writing in the patient diary as impacting family members other than parents. The use of the diaries by other family members, such as siblings and grandparents, was also recognised as helpful, as diaries were not exclusive to only the child's parents. The use of the diary to support a sibling in expressing their feelings was described by a ward nurse when she said:

*I've seen a sibling who found it [contributing to the diary] a very cathartic process. He used to just write essays in it. It was all about how he was feeling and about what was happening to his family. He wrote about some really horrible stuff that was going on FGE/RNW/13.*

In summary, this sub-category described how the HCPs viewed the families use of the diary to express the emotional impact of having a critically ill child. The diary offered the family a medium to write down their thoughts and feelings, which may have offered a therapeutic intervention. The diary was viewed as a positive tool to support the emotional wellbeing of the parents, siblings, and other family members. The emotional impact of using the diary had on the HCP was also an area of discussion with the groups. These findings will be explored in the next sub-category, *Impacting Emotionally on the HCP*.

#### **8.4.2 Impacting Emotionally on the HCP**

The emotional impact using the diaries had on the HCP was an unexpected finding from the focus group interviews. The participants described how the diary use affected themselves, professionally and personally. The focus group interviews allowed the

HCPs to reflect on the latent aspects of the diary. Some HCPs spoke of their concerns when using the diaries, and these anxieties were reflected in the written comments such as:

*Reading about my colleagues in the diary* **FGE/Wrt.**  
*Worried about writing about the negative* **FGE/Wrt.**  
*Anxiety about the legal implications of using the diary.* **FGA/Wrt.**

The HCPs expressed anguish when they discussed how they felt about reading derogatory comments about colleagues. Although these occurrences were isolated, the discussions around any episodes were animated. These concerns were illustrated in the following conversation between two nurses in Focus Group A:

*... sometimes we have parents who are passive aggressive, and they will name people and put negative comments about certain members of staff if they haven't had a good shift. That can make it very challenging for other nurses to write in the diary when there are things like that* **RNP/6.**

*...Yeah, it is difficult, isn't it? Because it just might be their [parents] way of venting. If it [comments] gets quite personal or something that you're concerned about, then you kind of have to do something about it and escalate it [report to a senior]* **RNP/2.**

Although it was acknowledged that this was a distressing situation, the HCPs stressed that it was still unusual. The HCPs reflected on their actions if inappropriate comments were written about colleagues. They spoke of feeling protective towards the named colleague and that they would address the entry directly with the family or by sharing the concern with a senior team member. Some HCPs also acknowledged that such entries allowed the opportunity to resolve parental concerns about the care their child was receiving, addressing any worries of the family in a proactive manner.

In all focus groups, HCPs spoke of the barriers they experienced when writing about a child's clinical deterioration. The participants spoke of feeling anxious, distressed, and sometimes guilty when writing perceived 'bad news' about the child. There was an

acknowledgement that only writing positively about the child and family's experiences in PICU was not helpful. Nevertheless, the burden felt by the nurse when writing something that may be upsetting for the family and child was evident. This is illustrated by the comment by a junior nurse who said:

*I have an issue about how much of the bad stuff I can write. If they [child] have had a bad day and poor diagnosis, then I try to use it [diary] to help them [family and child] understand. But yeah, it is really hard [tearful] **FGC/RNP/3.***

The HCPs recognised that reading about the child's clinical condition may add to the distress experienced by the family. HCPs were cognisant that they may remind the family of an event they may not wish to recall through their contribution to the diary. However, the participants acknowledged the importance of writing entries with honesty, compassion, and understanding.

A few HCPs spoke of how there may be a use of humour or frivolous language to lessen the emotional distress a family may experience when reading about a perceived disturbing episode. This perspective generated discussion with the HCPs, who disagreed with using humour to diminish an event. They spoke of how this approach could be counter-intuitive, adding to the family or child's distress rather than reducing it. Some spoke of how this aspect of contributing to the diaries was unhelpful and unprofessional. This point of view is illustrated by the following conversation between two nurses in Focus Group C:

*I sometimes read things that almost give the impression that the child has been naughty when they're not well. But it's not their fault **RNP/8.***

*...Yeah, I agree. You know sometimes the child had a really bad day and the chest has been cracked open and we are writing: 'you've been a little bit of a pickle today'. Sometimes I think, that doesn't help, as we might not be getting over how sick these kids really are **RNP/9.***

The HCPs also expressed concern about the professional and legal implications of what they wrote in the diaries. Participants explained how they took care to write factual entries not to be misleading, as they were apprehensive that entries might be required as evidence in a legal case. At the time of the interviews, there was a high-profile case of a child whose family disagreed with the decision to withdraw treatment, and the courts were asked to rule on the final decision. Even though this concern of the diary being used in a legal case was hypothetical, it generated significant discussion in the focus group interviews. In the context of this case, conjecture on the potential use of patient diaries as legal evidence was a worry to the HCPs. This apprehension was conveyed in the discussion between two nurses in Focus Group B when they said:

*I think you have to think very carefully about what you're writing... but I think that it is probably more important than only writing about the good days and avoiding writing about the bad..." RNP/10.*

*...Yes, I certainly think you have to be more careful now. Especially with the whole thing about C [legal case]. Like for example, if you said, 'I gave you a bath today and you enjoyed it' and the parents then turned around and said, 'well how can you say he enjoyed it and he hasn't got a good quality of life?' So, I think in some situations, you have to be really careful about what you're writing RNP/16.*

During the discussion of these concerns, the HCPs also explored ways to reduce the risk of potential professional compromise when contributing to the diary, such as using the published unit guidelines and avoiding jargon and misleading comments.

Participants also spoke of their expectations from other colleagues and families to complete the diary. Occasions when the HCP could not contribute to the diary resulted in them expressing guilt and disappointment. All focus groups had participants who expressed dissatisfaction with being unable to write in the diary. The reasons for not completing an entry were usually explained as a 'lack of time' or competing clinical priorities. Some nurses spoke of how they felt obliged to work beyond their shift end



to be able to contribute to the diary. This perceived tension to complete the diary by the end of the shift resulted in some HCPs feeling upset. This perspective is illustrated in the comments for two HCPs when they said:

*I feel guilty if I don't have time to complete the diary, like I have let them [parents] down **FGE/RNW/6**.  
Sorry, but sometimes I don't want to write a diary. I have had some parents say, 'could you write in the diary?'.... I've had a crappy day and I'd rather not write anything, but I feel that I just have to. It would be nice to have permission not to write in it [diary] sometimes! **FGD/RNP/22**.*

The HCPs acknowledged that the guilt they felt at being unable to write a diary entry was associated with recognising how much the child's family valued the diary. Some HCPs described a sense of pride in completing the diary, even if this was at the expense of finishing the shift late.

The participants described the perceived expectation of being artistically creative in the diary. This area was discussed with humour, with participants envying artistic and creative team members who set high standards to emulate. The HCPs also acknowledged using the diary to be creative and 'mindful' through their artistic submissions, such as painting and drawing. Some HCPs spoke of how they, with their own money, bought stickers, coloured pens, and pencils to decorate the diaries further, going above and beyond the expected. One nurse illustrated this point when they explained:

*I just love [stationary shop] and I love these glitter pens [laughter by other HCPs] and these [pens] smell nice! **FGD/RNP/5**.*

Some HCPs shared how they had instigated using diaries for their own loved ones when they were unwell in hospitals. These nurses spoke of how they recognised the diaries' positive impact on their children and parents. This was an unexpected finding

of the interviews and illustrated the diaries' personal impact. One nurse who started a diary for her dying mother illustrated this perspective. She said:

*When my mother was in hospital for 15 weeks, I kept a diary as it was the only way to keep track of what was going on. I actually found it a very cathartic process* **FGB/RNP/11**

In summary, this sub-category has explored the diary's emotional impact on the HCP. Some described the negative emotional impact the diary had on them. They spoke of their responsibility to contribute to the diary and the guilt they felt if they did not have the time to do this. There was low anxiety about the legal and professional implications of writing in the diary and the ambiguity about whether this document could be used as evidence in court. However, the sense of pride and value placed on using the diary was an overwhelming finding. The constructive impact the diary had on providing a process of expressing artistic creativity was also described. Finally, the adapted use of the diary in a personal capacity was also revealed as beneficial. Building on the categories *Creating Connections* and *Impacting Emotionally*, how the findings advance to the next category, *Empowering Coping*, will now be discussed.

### **8.5 Introducing Category 3: Empowering Involvement**

The category *Empowering Involvement* describes how HCPs used the diaries to support families in circumstances that could be perceived as being beyond their control. The HCPs described how the diary provided a means to foster a sense of autonomy for the families when they may have minimal choice over what was happening to them and their child. The sub-categories that comprise this category are *Providing Choice*, *Offering Distraction*, and *Anticipating Grief*.

### 8.5.1 Providing Choice

The HCPs described consistently how the diaries provided an opportunity to offer choices to parents and, therefore, were viewed as one of the approaches to empower families. Fundamental choices, such as whether to use a diary or not, were seen as the foundation for supporting parental decision-making. Associations were made between the value of using the diary and how it offered a device to provide the family with a means to decide if, how, and when it was used. In some parts, the HCPs recognised that the diary would be seen as a tool to promote autonomy in decision-making for the family, especially in a setting where several central decisions were reduced.

Written comments included statements such as:

*They [diaries] empower parents to take control of something FGE/Wrt.  
Allow parents to have an involvement in keeping track of their child FGD/Wrt.*

Further probing of these themes generated insightful discussions between the participants. The HCPs acknowledged the relative lack of power that families had. This idea is illustrated in the below discussion with two HCPs in Focus Group C:

*I agree there is something about power and control as they [families] have very little power. This [diary] is something they can control. Something they can take responsibility for. I think it gives them some control back... RNP/8.*

*...Yeah, and there's quite a variety in the way that the diaries are used, and that is very much directed by the parents RNP/6.*

The HCPs recognised that the diaries allowed parents to assert independence over their own decision-making. One of the families' first choices was whether to use the diary. If a family declined the offer of using a diary, attempts were made to explain how the diary could be used and its potential value. Informed decision-making often includes showing the family a sample diary to demonstrate how it could be used.

The HCPs discussed the agile approaches adopted when introducing the diary to families. Some HCPs described how they would wait for an appropriate time after the child's PICU admission before seeking agreement from the parents to initiate the diary. Others spoke of commencing the diary but being prepared that the family may decline and how they would respect the family's wishes and discontinue the diary. The HCPs provided parents with information on the diary use, as there was a desire to ensure the decision to decline was fully informed. Nevertheless, the reasons why a family may decline were sought, and that decision was respected as being 'their choice'.

Another assertion over parental choice focused on the basic concept of ownership of the diary. To illustrate this point, the HCPs clarified who they thought owned the diary. The consensus from the focus group interviews was that the family owned the diary. The HCPs made comments such as:

*I think they [diaries] are owned by the family* **FGE/RNW/2.**

*But it comes back to who actually owns the diary. Because if they [parents] are writing in their own diary. It is kind of up to them, isn't it?* **FGA/RNP/23**

The HCPs recognised that even though the diary's content was directed to the child, those who were benefitting from the diary during the PICU admission were the parents. Moreover, this finding is illustrated by the comment from a senior PICU nurse who said:

*Interestingly, we call it a patient diary, but it sounds more like it's a parents' diary really!* **FGD/RNP/10.**

Accepting parental ownership of the diaries affirmed for the HCPs the rights families have over the choices made around the diaries.

A few participants described stopping their contribution to the diaries after establishing that the family did not wish them to write in it. The participants explained

that as the diary belonged to the parents, they felt they could only contribute if invited. The below comment illustrates this viewpoint:

*I think they [diaries] are owned by the family, and therefore it is not my place to complete them **FGD/RNP/10.***

This negative case was raised in subsequent focus group interviews, but other HCPs did not share this perspective. The HCPs acknowledged that negotiating with the family who was to contribute to the diary was essential but that it was still unusual to seek an invitation to write in the diaries, as most parents welcomed the HCP involvement.

Nevertheless, it was essential to explore this negative case to clarify if any other HCPs had stopped contributing to the diary or if this was an isolated perspective.

Negotiating with parents' activities associated with the diaries was also an area of discussion. For example, gaining consent to take photographs of the child was explained by HCPs as a crucial action. The HCPs described that 'taking a photo' of a child was an act that should be undertaken with cultural sensitivity, respect, and courtesy. Seeking consent to take photographs also prompted the HCPs to explore how they documented this consent process in the child's healthcare records. Although there was agreement that gaining consent before photographing the child was essential, there was a lack of consistency in how consent was gained and how this process was documented. The discussion between three nurses in Focus Group A illustrates this point:

*We should be getting consent for taking photos of critically ill children. We really should be asking for consent... **RNP/3.***

*...Yes, I will write in the notes [patient medical records] and say that I have got verbal consent from the parents to take a photo **RNP/10.***

*...You are right; we do need to do this carefully and I think we all do it a bit differently **RNP/9.***

In summary, this sub-category explored several uses of the patient diary in offering a means to support parents' decision-making. The diary was adopted after a process of gaining informed consent about the impact and value of the diary. The diary offered an opportunity for autonomous decision-making in a setting in which several fundamental choices were lessened for families. Finally, the diary was viewed as being owned by the parents with proxy ownership for the child. Using the diary to provide an outlet for the parents' thoughts, feelings, and a diversion will now be explored in the sub-category, *Offering a Distraction*.

### **8.5.2 Offering a Distraction**

The use of the diary to 'give parents something to do' and therefore, offering a distraction, was expressed as a finding by several HCPs. They wrote comments such as:

*Something nice to focus on FGE/Wrt.*

*Occupies parents FGB/Wrt.*

*I give the diaries to the families to decorate and to give them something to do, to distract them FGA/Wrt.*

The use of the diary to occupy the parents' time and provide a positive outlet for them was a universally shared view by the HCPs in the PICU and the ward settings. Arts-based activities such as therapeutic act of writing, drawing, and being creative when using the diary was acknowledged by the HCPs. They discussed how they would observe families appear unsure of the 'rules of engagement' when their child was critically ill, not knowing what they could do. However, the diary provided an outlet to express their thoughts and feelings constructively. HCPs recognised the use of the diary as a wellbeing tool to support the family. Two PICU nurses in Focus Group D illustrated this point when they said:

*Yeah, so it's [diary] a distraction for them... RNP/3*

*...Yeah, it's like a mindful task, isn't it? It's like colouring books. There are lots of adult colouring books out there, and you can use them, and they are helpful to promote relaxation. I suppose the diaries are a bit like that as well* **RNP/6**

A few HCPs recognised that the diary could be used to avoid interacting with the team caring for their child. Writing the diary was described as providing an opportunity for parents to avoid the 'awkwardness' of engaging with the HCP. When asked to elaborate on what was meant by this comment, two HCPs in Focus Group C said:

*Diaries give them [parents] permission to not have to make small talk with you. They can just sit and write in the diary...* **RNP/3.**

*...Yeah, they can just sit and write in the diary. I hadn't thought of that before, but you are right as it avoids that awkwardness* **RNP/6.**

This singular comment was explored in subsequent focus groups, and others recognised the value of the diary in providing a tool to avoid interaction with HCPs but did not corroborate this point of view with further examples.

In summary, this sub-category explored how the diary was viewed to distract, occupy, and provide a positive outlet for parents. The diary was used to occupy the parents' time and focus on their activities. Finally, the diary was potentially used to provide a tool to distract the family and create a 'safety blanket' to use if they wished. Using the diary to support the dying child's family will now be explored in the following sub-category, *Anticipating Grief*.

### **8.5.3 Anticipating Grief**

Using the diary to support a bereaved family was discussed by several HCPs. They spoke of how they considered what they wrote in the diaries if they anticipated that a child might die. Although a child's death in the PICU setting is a rare occurrence, the nurses in the focus group interviews spoke of how they are conscious of diary entries when a child's prognosis is poor. Using the diary to offer choices on if, how, and what

was written supported the concept of empowering the family's decision-making.

Written responses to the posed question on the value of the diaries generated

answers such as:

*The diary is used to support the grieving parent* **FGC/Wrt.**

*We will add photographs of the child during end-of-life care* **FGA/Wrt.**

When asked to elaborate on these comments, the HCPs gave examples of using the diaries when caring for the family. The HCPs spoke of how the diary entry may support the family's grieving process by offering mementoes of the child. The collation of keepsakes and memories in the diary was discussed with additional poignancy concerning the dying child. The HCPs spoke of examples of diaries used during the six-week follow-up bereavement meeting with the medical consultant. The HCPs spoke of how a family may bring the diary to these meetings, which was used to support the recall of events:

*I spoke to one of the [medical] consultants. I think they meet families about six weeks after a child has died, and she said that they think the diary helps the family to remember the child* **FGA/RNP/7.**

HCPs also spoke of how the diary may be used to help collect items symbolic of the child's critical illness and how this collection was particularly poignant and treasured after the death of a child. One HCP explained how the diary was viewed as creating a link to the nurses who cared for the child and how this may offer comfort. She said:

*I also think that if the worst did happen [death of the child], for that family to have those photographs and those pictures and to look back on what's happened... it shows how caring we [nurses] were. They might not want to remember the hard, nitty-gritty of what was happening, but to have the diary might be a good thing as well* **FGC/RNP/10.**

The HCPs also gave examples of when families had used the nursing team to write in the diary when preparing for the death of a child. HCPs in Focus Group C recalled a child who had been born with a life-limiting condition and who was expected to die



very shortly after his birth. The HCPs were explicitly asked by the baby's mother to write about her child's personality and what had happened to him during his short life.

They said:

*From the first moment he was admitted and then we took him home to extubate him, she [mother] wanted us, everybody who looked after him, to write in the diary. She didn't necessarily want a story of his care but almost like a memento of his time... RNP/10*

*...Yes, she wanted us to write almost about what it was like and what it meant [to the nurses] to look after him... RNP/11*

*...Yes, it was really hard wasn't it RNP/10*

*...Yeah, it was really difficult as it was so difficult to put a positive spin on his time..... on his short life RNP/8.*

On further exploration of the diary used to support a dying child's family, the HCPs spoke of individual children and families they had cared for. There were examples of when the diary was used at a child's funeral. An HCP recalled when they had attended a child's funeral, and the diary was on display, and those attending the funeral were encouraged to read and further contribute to the 'child's story'. He said:

*I've been to a funeral where they've had it [diary] so the whole family and friends could read it. Some of his [child] family hadn't met him, so it was such a lovely documentation of his life FGD/RNP/8.*

The opportunity for members of the child's friends and family, who had not yet met them, to read about them in the diary was raised in other focus group interviews. Therefore, the diary was seen as a tool to provide additional insights into a child's life. In summary, this sub-category illuminated how the diary was used to provide a lasting memorial commemorating a child's life. The insights illustrated how the diary collated the child's time in the PICU. The diary was also used to enact and respond to the family's wishes. Finally, diaries offer insight into a child that may be especially important if the child has sadly died. The diary offers a permanent archive of the child

for the bereaved family. Exploration of the use of diaries in bereavement follow-up meetings is an area that warrants further exploration.

Building on the *Creating Connections*, *Impacting Emotionally*, and *Empowering Involvement* categories layers the understanding of how the diaries were used. This understanding culminates in developing the core category, *Making Sense*, and this pivotal category will now be explored.

## **8.6 Introducing the Core Category: Making Sense**

The core category, *Making Sense*, describes how the participants perceived the usefulness of the diaries in assisting the child and their family in understanding the experience of being critically ill. This category is grounded in the previous three categories, guiding understanding into how using the diary leads to this core conclusion. Moving through *Creating Connections*, *Impacting Emotionally*, and *Empowering involvement* leads to using the diary to *Make Sense*. This core category explores how the diary is used to support the family to comprehend the complexity of their child's critical illness journey. The category is developed from the two sub-categories: *Explaining the Journey* and *Creating Memories*. These two sub-categories will now be described and, in doing so, explain how these findings evolved to create the final core category.

### **8.6.1 Explaining the Journey**

The HCPs spoke of how the diary was used by themselves and the families to comprehend what had happened to the child. Notably, the HCPs also recognised that the diary retrospectively explained to the child and family what they had experienced during the critical illness journey. The HCPs wrote comments such as:

*I think it [diary] helps parents and the child to understand what has been happening, especially when looking back FGE/Wrt.*

*To explain in layman/child-friendly terms what we are doing to help make the child better* **FGA/Wrt.**

*Good for the child to have an understanding of the scars in the future* **FGC/Wrt.**

Exploring the written comments, the HCPs spoke of using the diary to chronicle a child's critical illness. The diary was seen to supplement understanding of this complex situation during a time of heightened anxiety for the family. The HCPs recognised that having the opportunity to re-read diary entries supported parents in their ability to understand what had happened to their child and additionally supported the child's understanding. Comprehension of events and the ability to prepare the child and family for any subsequent PICU admissions were explored by two nurses when they discussed how one family had used the diary. They said:

*I think it [diary] is also helpful for the children who might have surgery early in life and then come back. I looked after a Down's syndrome boy and his mum showed him the diary to explain about the chest drain and being on the ventilator. She kept that diary all those years and he looked at it before his next surgery...* **FGD/RNP/7.**

*...Yeah, I think his mum obviously went through the book with him quite a lot and he could point things out.... and he knew what certain things on the unit were because he's been shown them in his book [his diary]* **FGD/RNP/19.**

Other focus group interviews also discussed using the diary to explain the current PICU admission. The HCPs described how the written and photographic entries helped elucidate the PICU journey for the child and family post-admission and, in some cases, before any further admissions. This was particularly valuable for the children who underwent serial cardiac operations.

Acknowledging the child's cognitive development when writing in the diaries was explored by the HCPs. The nurses spoke of the importance of explicitly writing entries to the child. It was recognised that the child may not at present be able to understand what had been written for them, but that the entries were often composed in a way

that the child could comprehend as they got older. The use of plain language, although primarily directed to the child, was also considered to provide information to the family in an unpretentious way. This point is illustrated by one nurse who said:

*It might be that we use a more simple language to really help them [child] understand what's going on, but I think sometimes it allows you to explain to the parents what's going on too. They [parents] may not want to ask a question but reading what we have written in the diary for the child, helps them to understand too* **FGC/RNP/5.**

All focus groups agreed upon the ability to use the diary to explain to the child and family simultaneously. The diary provided a lasting record of the child's progress.

Explaining the child's journey in terms that were easy to understand, often supported with photographs or diagrams, was an immense benefit in explaining the PICU journey to the child and their family. The use of photographs to illustrate the environment and context in which the child was cared for was stressed as necessary in clarifying the PICU journey. The HCPs explained how they would use the diary to capture the clinical equipment, medication, and infrastructure in which the child was cared. The HCPs spoke of how they correlated the amount of medical equipment, drug treatment, and scope and nature of the healthcare team, to illustrate the clinical acuity of the child. Therefore, photographs to supplement written entries were explained to demonstrate how sick the child may have been to the child, family, and others. One of the HCPs illustrated this perspective when they said:

*I quite like a photo of the environment which shows their surroundings and things. I think that's not only useful for the child, but then for other people they might show the diary to. They can say, 'Oh yeah, there's quite a lot of equipment', and that is the place that they've been in. So, I think photos could be useful for that* **FGB/RNP/3.**

In summary, the diary was used as a source of information gathering to allow explanation and understanding of the child's journey through critical illness and

beyond. The diary was essential for the understanding of the child, their family, and others, using written, graphical, and photographic entries to support insights into the child's journey.

The use of the diary in establishing a legacy tool for supporting the child and family by building a resource for memories was also discussed by the HCPs. The following sub-category, *Creating Memories*, will now be described.

### **8.6.2 Creating Memories**

The HCPs spoke of the overriding use of the diary to capture the events, progress, and details of the child's time in the PICU. One of the written comments summarised comprehensively this finding in response to the question, '*How do I use the diary?*', stating:

*Describe the day. Chronicle care in a way the child will understand in the future. In a way that parents can relate to in the future. Pictures/diagrams of their condition inform the patient of the treatment that was delivered* **FGA/Wrt.**

This perspective was shared by many of the HCPs when discussing the value of the diary as a repository of information. It was explained that the curated data could prompt challenging memories to recall. It was also acknowledged that their age or illness may compromise the child's cognitive ability. The diary offered a permanent record that could be later referred to, providing clarification. A discussion between ward nurses in Focus Group E illustrates this point when they said:

*I think of the scarring [after cardiac surgery] and things. It [diary] would be very useful as children can look back and see... 'so that's why I've got that scar...'* **RNW/5**

*...Also, as treatment progresses, they [child] may forget where they've been ...so they can read back and think 'oh my goodness' and recognise how very sick they were* **RNW/6.**

The HCPs spoke of the techniques they used to create a memory bank of information for the child and their family. The use of photographs to chronicle the child's PICU admission was viewed as an accessible, realistic, and suitable approach to supporting memories. As previously described, HCPs stressed the importance of confirming that consent had been gained before photographing the child. There was recognition that some parents may not wish for their child to be photographed. The HCPs postulated the reasons for declining the use of photographs. The HCPs described, in the written comments, ideas such as:

*Parents do not want to be reminded of the PICU admission* **FGA/Wrt.**

*They just don't want any photos* **FGA/Wrt.**

*They [parents] might get upset when they look back on the photos* **FGE/Wrt.**

Nevertheless, the overwhelming view from the HCPs was that using photographs to supplement the written text was a powerful tool to assist in understanding and recalling events for the child and their family.

Other arts-based mediums used to capture insights for the child and family included drawings, artistic creations using medical equipment, and storytelling. The HCPs described using diagrams of the child's heart to explain a complex congenital heart defect to the family. Some HCPs spoke with humour and envy towards some of the nurses who drew anatomically correct pictures of the child's heart. Two nurses in Focus Group A explored these findings when they said:

*I think sometimes it's [drawing] a good idea especially more for the cardiac patients because some of the hearts can be so complex. Sometimes you need to draw three hearts to show which bits are wrong with their child, and how it will be repaired during the heart surgery. It helps the parents understand what's wrong with their child and they can refer back to it later* **RNP/2.**

*...Yeah, I can't draw them [hearts] but sometimes I will print pictures off and put them in the diary. I'm not a top artist like you [name of RNP2]!* **RNP/4.**

The novel use of storytelling to imaginatively explain to a child what had happened to them was discussed by a small number of HCPs. Placing the child in the centre of their own story, the HCPs spoke of writing stories that would create a lasting memory and resonate with the child. One HCP explained:

*I wrote a fairy-tale for the family, and it was like they had a Princess and she had to find a bogey monster with a very long sword, which was of course the ventilator and suction. That generated a conversation, and it brought something light-hearted, and Christmassy, to what was a difficult day. I hope she can remember this in the future and see herself as a 'Warrior Princess'! FGD/RNP/12.*

This sub-category explained how the diary was used to help the child and family make sense of their journey by providing an understanding of the PICU admission. Illustrative diary entries were a modality to enhance the narrative, offering supplementary explanations and a tool to support memories. The diaries were seen as necessary in offering a repository of the events that occurred to the child and family, accounts that were curated in inventive, child- and family-focused ways.

## **8.7 Chapter Summary**

In this chapter, findings from the HCP participants in the study were presented. The categories generated from the focus group interviews created rich insights into the usefulness of PICU patient diaries. The categories have grounded the understanding of how the HCPs used the diaries to build relationships with the child and the family.

Through the insights gained from the diary, the HCPs could better appreciate what the family understood, how they may be coping, and where additional support could be targeted.

These insights had an emotional impact on the HCPs, who described how the diary not only influenced the family's mental health but also their own emotional wellbeing. The HCPs viewed the diaries as being a therapeutic tool. Some HCPs acknowledged that the

diary impacted them negatively, creating a sense of responsibility, which in turn led to anxiety if there were completion challenges. There was low anxiety about the legal and professional implications of writing in the diary. Finally, the adapted use of the diary in a personal capacity was also revealed as a beneficial use by the HCPs.

The next category developed from the findings was using the diary to empower families in their decision-making. The HCPs described how the diary provided a means to foster a sense of autonomy for the families. Therefore, the diary offered families autonomous decision-making in a setting where several fundamental choices were reduced. The diary was viewed as being owned by the parents with proxy ownership for the child. The diary was also used to enact and respond to families' wishes. The use of the diary to collate keep-sakes and memories was discussed with additional poignancy when explored concerning the dying child.

The usefulness of the diary in helping parents and children understand their critical illness journey was revealed as the central, core category. This category described how the diaries were seen as important in offering a repository of the events that occurred to the child and family. Accounts were curated in inventive, child- and family-focused ways. Finally, the diary was a source of information gathering, allowing explanation and an understanding of their child's journey through critical illness and beyond.

In the following Chapter 9, further grounding of the theory around the usefulness of PICU patient diaries will be presented. The core category for the family and HCP participants, *Making Sense*, will be discussed in context to existing knowledge, and the contribution this category makes to theory will be described.



## Chapter 9 Making Sense: Towards the Final Conceptual Theory

### 9.1 Introduction: The Use of PICU Patient Diaries in Making Sense

In this chapter, how the categories, theoretical sampling and theoretical sensitivity led to the core category of *Making Sense* is discussed. The emergent grounded theory from all the participants is presented using the storyline developed from the abduction of the findings presented in Chapters 7 and 8. The patient diaries provided a communication tool that strengthened the relationships between the parent and their child, the healthcare professionals and other family members. The emotional impact these connections created led to an opportunity to empower the users, which resulted in the opportunity to make sense of the critical illness journey. A storyline of the findings will be used to move beyond the descriptive and into the final theory (Birks and Mills, 2023).

This chapter will present the primary storyline of the findings from the parents and the HCPs as an initial theory of how PICU patient diaries were used. The theoretical coding, the final phase in theory development, will focus on the core category of *Making Sense* and the associated sub-categories. After theoretical integration with existing literature, the conclusion of this chapter will present a refined storyline that will answer the research question: *How are patient diaries used by the child, their family, and healthcare professionals during and after admission into the PICU?*

### 9.2 Storyline: Justifying the Use in a Constructivist Grounded Theory Study

Rooted in the sociological foundation of grounded theory, the storyline is used to aid theoretical generation. The use of storyline as a technique fell out of favour with traditional grounded theorists in the 1990s after Glaser's criticism of Strauss and Corbin's perceived overreliance on this tool. In Glaser's (1992) global rebuttal of

Strauss and Corbin, he was concerned that data would be made to fit into the storyline, an approach inconsistent with grounded theory (Glaser, 1992). This criticism may explain why the use of storylines waned until the early 21<sup>st</sup> century. Charmaz's constructivist grounded theory methodology, adopted for the study, does not explicitly reference storylining as an analytical tool. Nevertheless, a chapter on the use of a storyline is included by Charmaz, suggesting an endorsement by her (Bryant and Charmaz, 2019) and therefore supports my inclusion of a storyline in this study. A *story*, in grounded theory, is explained as the descriptive narrative of the central phenomenon of the study (Strauss and Corbin, 1990). A *storyline*, therefore, is the "conceptualization of the story of the core category" (Strauss and Corbin, 1990, p. 116). Storyline is used to construct, integrate, and illuminate the final theory (Birks et al., 2009). Birks and Mills (2023) further developed the concept of storylining, explaining that through the narrative, the grounded theorist can construct and convey the final grounded theory. They also proposed guiding principles to bridge the gap between analysis and theory. These principles are that theory takes precedence, variation is allowed, gaps in the theory are identified and therefore tested and limited, the evidence is grounded, and the presentation style is accessible to the broadest audience (Birks and Mills, 2023). Using these guiding principles, the storyline explaining the theory of the UPDATE study will now be described.

### **9.3 Storyline: Narrating the findings from the UPDATE Study to Ground the Final Theory.**

Parents of critically ill children may experience uncertainty and disempowerment. These feelings may last beyond the PICU admission. If unresolved, the experience of having a critically ill child can lead to depression, anxiety and post-intensive care syndrome for the family and the child. The PICU diaries provided a tool to support the

child and family during the critical illness journey. The patient diaries built and strengthened the relationships between the parent and their child, the healthcare professionals (HCPs) and other members of the child's social circle. Through *Creating Connections*, the relationships fostered through the diaries emotionally impacted the parents and the HCPs. The diaries enhanced the relationship between the HCP, the child, and the family. PICU diaries also facilitated sharing information on episodes of unwitnessed nursing care, further connecting the HCPs with parents.

The diaries had an emotional impact, creating a sentimental attachment for the parents. Fathers conveyed how using the diary to express themselves was preferable to showing their emotions in the public context of the PICU. The diaries offered an account of the critical illness journey to other family members, reducing the emotional burden parents may have felt when relaying this information. The patient diaries also emotionally impacted the HCPs, professionally and personally. These diaries provided insights into how families cope emotionally, allowing HCPs to provide targeted support where needed.

Through the insights and understanding provided by the diaries, families were supported in decision-making. The diary empowered parental involvement, offering choices where decision-making may be complex. Parents used the diary to distract themselves, offering a positive outlet for emotions. The diaries also helped capture events and strengthen memory recall for the family and their child. As such, using these diaries enhanced the overall understanding of the critical illness journey for all.

Through the relationships built, the emotional impact this fostered, and the empowerment of parents, the diaries were used to make sense of the child's critical illness. Parental ownership of the diary directed how the HCPs and the families used the diary. Through this use, the diary offered a compendium of information about the

child's PICU journey. Providing clear insights and explanations of the child's PICU admission, the patient diary provided a resource to fill any memory gaps. It offered an easily understandable, permanent record for the child and family. Therefore, the diary was a valuable resource supporting sense-making of the complex critical illness journey for the family and child.

Using this initial storyline as the introduction to the theory generated by this study, I will now discuss how the substantive theory is formed through the theoretical integration of the core category: *Making Sense*. The emergent grounded theory is summarised using the conceptual diagram in Figure 9.1.

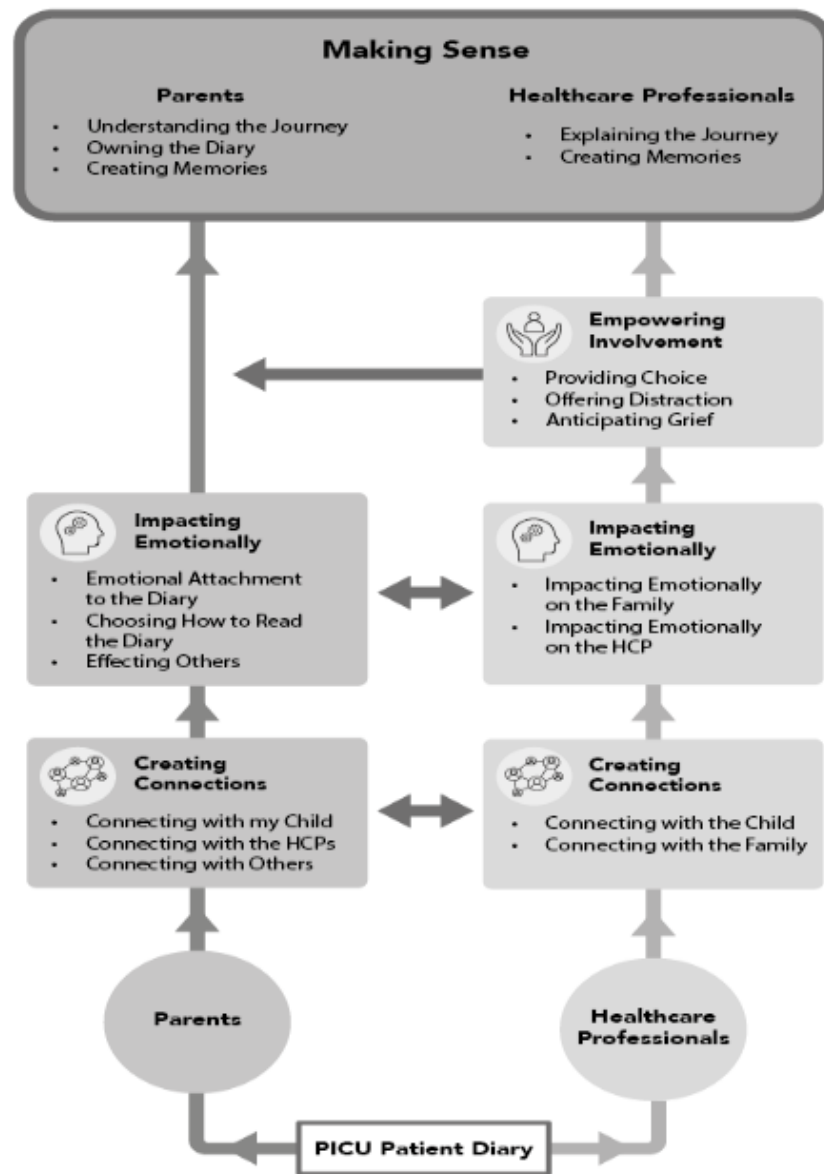


Figure 9.1 Making Sense: A constructivist grounded theory study of the use of patient diaries in the Paediatric Intensive Care Unit

#### 9.4 Owing the Diary: Leading to Making Sense

Parents in the UPDATE study described their perspectives on who owned the patient diary. The HCPs spoke more generally about diary ownership, acknowledging that it was viewed as owned by the parents with proxy ownership for their child. The notion that the parents owned the diary led to HCPs using the diary to support parents' decision-making. Therefore, the diary offered an opportunity for autonomous

decision-making in a setting in which several fundamental choices were reduced for families.

Clarifying the ownership of the diary for the HCPs is an area of debate in the literature.

The literature suggests a more significant variance in diary ownership in the adult intensive care setting. Many European countries view the diary as the hospital's property until the patient's discharge, where the diary is then 'handed over' to the patient or their relatives (Egerod and Christensen, 2009; Egerod et al., 2011). The practice of 'handing over' the diary illustrates the differences in the post-intensive care provided to the adult in comparison to the child. In the adult setting the diary is used in a structured follow-up process as part of a bundle of interventions directed to rehabilitate the patient post-ICU discharge (NICE, 2017). Currently the child and their family are not formally offered post-PICU follow-up care (Manning et al., 2018).

Danish and Norwegian nurses have regarded the diary as a 'gift' from the nurse to the patient. This means that the adult patient has assumed diary ownership, with the nurses keeping it until it can be relinquished back to the patient or their relatives (Egerod and Christensen, 2009). This perspective is reflected in the UK, as it is the usual practice that the diary is the patient's property. Some guidance from the UK even stresses that the patient owns the diary and not the hospital or relatives (Valera, 2016). This view is not shared in other adult ICU settings with a more flexible approach to diary ownership.

A qualitative study of adult ICU relatives concluded that authorship of the patient's diary gave relatives responsibility and authority, concluding that the relatives of the adult patient owned the diary (Nielsen and Angel, 2016a). However, it is clear from the studies that there remains variability in adult ICU practices on who ultimately owns the diary. Recent changes to the UK and European Law (Department for Digital Culture

Media and Sport, 2018) have influenced the approach to the rights of personal data access and have challenged societal and professional expectations on how information about patients is kept. Therefore, clarifying the ownership rights to the diary is a crucial aspect that requires an appreciation of the professional, legal, and personal implications for those who use the patient diaries, including the HCPs, patients, and their families.

The concept that the adult patient's family is the owner of the diary was discussed in Mickelson et al.'s study (2021). This qualitative study, conducted in the USA, interviewed 19 female relatives from two adult ICUs and concluded that once diary ownership was claimed by the family, relatives took control and felt responsible for contributing to the diaries. Relatives who were actively involved in the ICU diary reported that this activity positively impacted them. Conversely, those families who did not write in the ICU diary reported that they perceived the diary to be less helpful (Mickelson et al., 2021). The variation in the definition of adult ICU diary ownership was valuable to consider when exploring this concept in the PICU setting.

Consensus of who owns the patient diary is a more homogeneous concept in the PICU. The HCPs' views on the ownership of patient diaries in the PICU were explored in a qualitative study in Italy (Sansone et al., 2022). The study supported the UPDATE study's findings that parents owned the diary. Sansone et al. (2022) concluded that from the acceptance of parental diary ownership, there was a greater engagement in diary writing by both HCPs and families. In a follow-up study, Sansone et al. (2023) explored the enablers and barriers to implementing PICU patient diaries. They found that a lack of clarity and guidance on the ownership of the diary resulted in some HCPs' hesitancy to contribute. They found concerns about the professionally and legally untested aspects of diary use that were also a concern for this study's HCP

participants. Conversely, clear guidance and support using the patient diary enabled positive participation in diary writing (Lynch et al., 2020; Sansone et al., 2023), supporting the UPDATE study's findings for the creation of clear best practice guidance for PICU diary use.

A recent survey of all PICUs in the UK and Ireland included a closed question to clarify who participants thought owned the PICU patient diary (Lynch et al., 2020). The respondents stated that they viewed diary ownership as that of the family. The family (82%, n=14) and the child (12%, n=2) were cited as the owners of the diaries, with only one respondent suggesting that the PICU staff owned the diary (6%, n=1). This perspective is supported in the study as parents explained that they viewed ownership of the diary as ultimately awarded to their child. However, there was fluidity in the transfer of ownership from the HCP to the family and the child. The parents viewed their role as one of guardianship over the diary. Once accepted, this empowered them to direct, control, and take responsibility for how the diary was used.

It is reasonable to recognise that parents' or carers' ownership of the diary may reflect a child's legal, cultural, and societal status. Parental responsibility for a child is understood and accepted while acknowledging the child's rights and evolving autonomy (Alderson and Morrow, 2011). Therefore, it may be more appropriate to consider the concept of custodianship or 'looking after' the diary for the child.

Nevertheless, the view that the family owns the diary rather than the HCPs reflects and the relationships built within the PICU setting (Lynch et al., 2020).

As the number of studies exploring the impact of PICU patient diaries increases, it is envisaged that there will be a better understanding of the theory of diary ownership.

No published studies have yet investigated the child's view on who owns the diary



written about them and their critical illness journey. Therefore, future studies exploring this issue from the perspective of the child or young person are imperative. As described in the UPDATE study, the understanding and acceptance of diary ownership evolved into how participants used the diary to explain the PICU journey further. This sub-category, *Explaining the Journey*, will now be discussed.

### **9.5 Understanding and Explaining the Journey: Leading to Making Sense**

The sub-categories *Understanding the Journey* and *Explaining the Journey* explained how the parents and HCPs described how the diary was a source of information gathering, allowing understanding of the child's journey through critical illness. The diary promoted understanding of this complex experience for the HCP, the child, their family, and others. Using written, graphical, and photographic entries supported furthering insights. Therefore, the diaries were valued as offering the ability to support the processing and enhancing of understanding in what could be considered confusing situations. This was demonstrated as necessary and illustrated how the diary could be used for self-reflection. The diary was an important tool to aid understanding and, in doing so, created a sense of dependency on the diary as a source of information. Studies exploring the use of adult patient diaries by relatives support the findings of the UPDATE study. A recent systematic review and qualitative synthesis concluded that relatives used diaries in various ways (Schofield et al., 2021). Schofield et al. (2021) concluded that the family valued the diary as a means to feel connected to their loved one. The review identified three main themes: the diary was a tool to support coping; connecting other family members, HCPs, and the patient; and developing the narrative to understand what had happened. These findings were replicated in this study as the parents and HCPs described how the diary provided a tool to connect with others, support understanding and explain the journey to their child and others.

The UPDATE study has provided in-depth insights into parents' experiences and how their use of the patient diaries may differ from that of the adult patient relatives. Having a critically ill child is immensely stressful, with long-lasting and profound effects on families' physical and emotional well-being (Latour et al., 2011; Mikkelsen, 2018; Debelić et al., 2022; Jakobsen et al., 2021). The study has added to the theory that diaries enhance understanding of the critical illness experienced by demystifying the stressful journey and offering a mechanism to strengthen the ability to cope.

The findings from the study have also provided an understanding of how parents and HCPs used the diary to understand each other's perspectives. This study is one of the first to explore the perspective of parents and HCPs in using PICU patient diaries. Gawronski et al. (2022), using an observational perspective study, also explored parents' and HCPs' attitudes to the PICU diary. They reported that both groups saw the diary as beneficial for staff and families' communication. The HCPs were able to develop insights into the parental emotional response to having a critically ill child (Gawronski et al., 2022). These findings were echoed in the UPDATE study too.

The use of the diary as a bridge to facilitate connections between the parents, the HCPs, the child, and other family members, was found in the study. Parents spoke of how they gained insights into the character of the HCPs, particularly the nurses when reading the HCP entries. However, the mutual insights parents and HCPs gained from reading each other's entries, revealed in this study, were not reflected in the Gawronski et al. (2022) study. Therefore, the multi-directional impact of the diary on providing parental insights on the HCP's role and impact warrants further investigation.

The humanisation of the nurses' role was a crucial finding in this study, which has been replicated in other adult patient diary studies (Garrouste-Orgeas et al., 2014). This

grounded theory study concluded that the diary was a tool by which relatives came to see the HCPs as compassionate and empathetic. These insights provided reassurance and trust in the multi-disciplinary team, particularly the nurses. Parents of a critically ill child may be fearful for their child's survival. In a foreign and highly technical environment, parents must surrender their responsibility as protectors and primary caregivers to healthcare professionals (Gillis and Rennick, 2006). Therefore, trust in those providing care to their child is essential in empowering parents and enhancing coping (Latour et al., 2011; Gawronski et al., 2022). Therefore, the role of the PICU diary in developing and confirming trust in the HCPs is an important finding from the UPDATE study.

The HCPs recognised how they used the diary to identify how families may be coping. The HCPs described episodes when they had targeted additional support after concerns about parents' abilities to contend with traumatic experiences. The concept of the patient diary as a complex nursing intervention to aid family support and, in some cases, crisis intervention was a novel insight from this study (Ednell et al., 2017). This finding has yet to be replicated in other PICU patient diary-focused literature (Low et al., 2023). Therefore, looking at how the PICU patient diaries may be used to focus personalised support to families is an outstanding area of further research.

Using the diary to enhance the multi-directional understanding and relationship building between the parent and HCPs is vital to enhancing communication and explaining the critical care journey to the parent. Mikkelsen (2018) conducted a single-site qualitative, exploratory study to understand children's and families' experiences using PICU diaries after discharge. This Danish study interviewed five children and their families four to six months after PICU-discharge. The study concluded that diaries played an essential part in providing explanations of the 'chaotic and incoherent'

critical care journey, findings congruent with the UPDATE study. Unfortunately, the study could not elicit meaningful data from the children invited to participate.

Mikkelsen (2018) was able to offer insights into the perspective of the child's view of their diary. The study found that the diary offered the child a chronology of the PICU events and was a tool to answer some of their concerns about this experience (Mikkelsen, 2018). Exploring the child patient's perspective on the patient's diaries is an essential research question that requires further investigation.

Explaining the child's critical care journey compassionately and truthfully was a crucial finding from this study. The HCPs were, on occasion, hesitant and anxious about the impact writing about traumatic experiences may have on the family and the child.

The adult patient diary literature provides conflicting insights into the benefits of reading the diaries for relatives, with most studies supporting the use of diaries as a means of coping, a way of staying connected, a tool to understand and develop the narrative of the experiences (Barreto et al., 2021; Schofield et al., 2021). Nevertheless, it is essential to understand any negative impacts the diary may have on the patient, the family, and the HCPs (Engström et al., 2009; Ullman et al., 2014; Sansone et al., 2022) and the subsequent approaches that can be adopted to minimise the lasting psychological impact.

Professional and legal implications for the HCP when contributing to the diary were also a concern raised for the HCPs in this study. Although there have been no reported legal cases in the UK where the content of a PICU patient diary has been used in evidence, this concern has also been expressed in both adult (Barreto et al., 2019; Högvall et al., 2023) and children's critical care literature (Lynch et al., 2020; Sansone et al., 2022). Therefore, further advice and guidance are required to support the professionals using this tool.

Findings from this study ground further the theory on how recognising diary ownership directs the use of the diary in explaining the critical illness journey and then leads to the diary's use in creating a lasting memoir. The sub-category *Creating Memories* will now be discussed in relation to the emergent literature.

### **9.6 Creating Memories: Leading to Making Sense**

The sub-category *Creating Memories* explained how the diary supports the child and family in the understanding of their journey by using it to fill gaps in the memories.

Illustrative diary entries were a modality to enhance the narrative, offering

supplementary explanations and a tool to support memories. Parents stressed the diary's value in composing a record of the events during the admission to the PICU.

The diaries were a precious memento, supplementing the understanding of the events in the form of a personalised record, assisting the creation of a repository of

memories. The rationale for offering a tool to support creating memories after a period of critical illness is an area of investigation in several studies.

Factual and delusional memories of the critical care journey can deleteriously impact an ICU patient's recovery and are associated with the increased risk of developing

post-traumatic stress disorder (PTSD) (Jones et al., 2001; Storli et al., 2008). The use of patient diaries as a tool to fill any gaps in patients' and relatives' memories is not a

new concept and has been offered as one of the reasons why diaries can reduce the risk of developing PTSD (Colville et al., 2008; Åkerman et al., 2013; Barreto et al., 2019;

Pattison et al., 2019). Understanding the incidence and mechanism of PTSD in ICU patients and families and the impact that patient diaries have is important when

exploring the use of PICU diaries in creating memories.

A recent randomised control trial (RCT) of 657 adult ICU patients investigated the impact of the ICU diary on the patient and their family (Garrouste-Orgeas et al., 2019).

Symptoms of PTSD were measured in patients at three months post-discharge. The patient's family were also tested for symptoms of PTSD, anxiety, and depression. The study concluded that ICU diaries did not prevent PTSD symptoms in the patients nor reduce the incidence of anxiety and depression in family members (Garrouste-Orgeas et al., 2019). There were some limitations to this study, including a 50% loss to follow-up, which may have biased the generalisability of the results. However, the findings are important to consider when applying to the use of the PICU diary.

A recent meta-analysis of 12 RCTs concluded that ICU patient diaries did reduce the risk of depression (RR 0.41, 95% CI 0.23–0.75) and improved quality of life (10.3 points higher in SF-36 general health score, 95% CI 0.79–19.8) (Barreto et al., 2019). However, the review found that diaries did not reduce the risk of developing PTSD in patients. It is unclear if the diary, in isolation, can be targeted as the only intervention to reduce PTSD, anxiety, and depression in adult ICU patients. Placing importance on the concept of minimising memory gaps as the only indicator to reduce adverse psychological effects post-ICU may be unhelpful. Emerging evidence now looks at adopting bundles of interventions, with diaries being one, that aim to improve psychological recovery after critical care illness (Manning et al., 2018; Perry et al., 2021). Therefore, the findings from the UPDATE study provides understanding of how this tool is used in the PICU, reinforcing the need for interventions to support the child and their family's recovery post-PICU.

Parents and HCPs spoke positively of how the diaries supported the anthology of items, narratives, and photographs. Using the diaries in *Creating Memories* was seen as a complex activity for the participants in this study. Studies are beginning to explore the positive aspects, as described as post-traumatic growth, which may be experienced by parents of critically ill children (Yagiela et al., 2022). Yagiela et al. (2022) undertook

a cross-sectional survey study of 82 parents of 52 children who were discharged alive from a PICU admission. The study found that some parents experienced a positive change, called post-traumatic growth, after their child's critical illness. This growth was described as occurring in five areas, including a greater appreciation of life, improved interpersonal relationships, greater personal strength, recognition of new possibilities and spiritual or religious growth. The study supports the view of post-traumatic growth with the acknowledgement by parents and HCPs that being able to recall events was welcomed by participants as a positive outcome of the diaries in supporting the child and their family.

The use of photographs in adult ICU diaries are well-evidenced as a positive intervention, providing insight and creating memories for patients and their families (Åkerman et al., 2013; Barreto et al., 2019; Jones, 2009). However, using photographs in the PICU diary to support understanding and create memories is an under-researched area. Only a few studies have specifically explored the value of photographs in the PICU diary (Mikkelsen, 2018; Herrup et al., 2019). Mikkelsen (2018) found that photographs offered realistic insights into the child's PICU admission and were viewed by the child and family as more helpful than written words (Mikkelsen, 2018).

A qualitative study exploring the information needs of parents in the PICU concluded that a wide range of sources and mechanisms of information is needed to make sense of their child's critical illness (Laudato et al., 2020). These information sources included using photographs in diaries to serve as a personal narrative and produce explanations for their child (Laudato et al., 2020). Diaries were recognised as important as a legacy document to explain to the child what had happened, especially as the child's cognitive ability to understand may evolve over time, requiring the need to recall past events

(Gawronski et al., 2022). This perspective is supported by this study as there were examples where parents used the diary's photographs and drawings in their storytelling to explain their child's PICU journey and remember the events.

Nevertheless, the impact of photographs in the diary from the perspective of the child and other family members, the cultural significance and considerations when using photographs, and the composition of photographs remain areas that warrant further exploration.

The use of other illustrative material that supports the written word was also explored in the study. Although the literature on PICU diaries comments on the use of illustrative content such as drawings and stickers, they have yet to evaluate the impact of these artistic entries on the child, the family, and the HCP. Parents and HCPs commented positively on any significant events captured in the diaries, such as birthdays, Christmas and Mother's or Father's Days. The participants saw these entries as 'special' and 'treasured' and were anticipated to hold emotional significance for the child and wider family. The study has provided insight into this area of diary use, which has not yet been elucidated in other studies.

An understanding of how HCPs used PICU diaries in supporting bereaved families emerged from the study. The HCPs spoke of how they contributed and encouraged families to engage with the diary as they perceived that these entries might offer some comfort for a grieving family. The HCPs shared examples of when bereaved families used the diary at their child's funeral as a commemorative memento of their child's life, illustrating the value the family placed on the diary. Two children sadly died after enrolment into this study, and although invited to contribute, their families did not wish to continue participating in the follow-up interviews. Insights from these families,



understandably, could not be sought, and this was a missed opportunity to understand the diary use for this circumstance further.

No studies have explored the impact of PICU patient diaries after a child has died. A recent scoping review of memory-making approaches in the adult ICU setting found that in most studies, diaries were a positive tool used by bereaved families (Galazzi et al., 2022). However, not all grieving relatives wanted to receive the diary as they perceived it added to their distress. Therefore, relatives having the opportunity to take an informed decision on having the diary was imperative (Riegel et al., 2019). Caring for the dying child and their family is essential to critical care nursing and understanding how to support this care best is fundamental. The vital perspective of bereaved family members on the value of the diary in creating memories of a bereaved family warrants further exploration.

The sub-category *Creating Memories* was corroborated in the literature as an important aspect of patient diaries. It was recognised how the diary content, such as the written word and photographs, support the account for the critical illness period and contribute to the repository of information that can support recall of events.

In summary, the sub-categories of *Owning the Diary*, *Understanding the Journey* and *Creating Memories* have been further grounded in the core category of *Making Sense*.

To further develop the grounded theory to answer the UPDATE research question, an extant theory to integrate the core category was applied. The study has grounded the theory on using PICU diaries in the emergence of the core category *Making Sense*.

Therefore, the integration of Brenda Dervin's sense-making model and methodology (Dervin, 1998) will now be discussed and integrated when presenting the final grounded theory.

## **9.7 Sense-making Theories: Informing the Core Concept of Making Sense**

Sense-making is commonly understood as the processes people interpret and how they give meaning to their experiences (Dervin, 1998). To explain how humans understand what may be happening, several theoretical approaches have been developed. There are four main sense-making theories:

- Karl Weick's sense-making in organisations
- David Snowden's Cynefin framework
- Gary Klein's Data frame theory
- Brenda Dervin's sense-making methodology.

Each of these theories will be described with a rationale for why Dervin's Sense-Making Methodology was chosen to support the findings of the UPDATE study.

### **9.7.1 The Sense-making Theory**

The sense-making theory developed by Karl Weick (2000) examines how organisations and people experience understanding. Within his research, Weick studied how organisations can achieve sense-making by having a single reality. This framework identifies seven properties of organisational sense-making: identity, retrospect, enactment, social contact, ongoing events, cues, and plausibility (Weick, 2000).

Although this model of sense-making offers insight into how an organisation such as a PICU may be structured to support the receiving and understanding of complex information, the findings from the study were focused on the individual's use of the diaries and how these processes lead to making sense, rather than the collective experience. Therefore, this model of sense-making was not used in the theoretical development of this study.

### **9.7.2 The Cynefin Framework**

The Cynefin framework, developed by David Snowden in the early 2000s, is a conceptual framework used to aid decision-making and has been adopted in healthcare settings (Gray, 2017; Snowden, 2007). Cynefin offers five decision-making contexts or 'domains': clear, complicated, complex, chaotic, and confusion. These domains assist leaders in identifying how they perceive situations and make sense of their and other people's behaviour. However, the Cynefin model is framed around the need to decide on an identified required action. This sense-making model was not adopted as it does not reflect the study, where the diaries were used to understand the context of the critical illness experiences rather than a primary aim to be used in decision-making.

### **9.7.3 The Data Frame Theory**

The Data Frame theory was developed by the research psychologist Gary Klein, who studied naturalistic decision-making in conflict or emergency services (Klein et al., 2007; Klein et al., 2006). The Data Frame model postulates that situations are explained when fitted into a structure that links them to other situations. This model explains that sense-making is the ability or attempt to make sense of an ambiguous situation. The activities to make sense of a situation are elaborating, questioning, comparing, preserving, re-framing and seeking. Consequently, the model explains how people use sense-making to create situational awareness and to assist decision-making in situations of high complexity (Klein et al., 2007). This model helps to understand how complex decisions are made in highly pressurised environments such as conflict or time-critical situations. However, this model does not help explain how an individual's understanding is gained in an evolving situation. This theory was not perceived to help

explain how PICU diaries were used to enhance understanding, which is why it was also not adopted.

#### 9.7.4 Sense-Making Model

Brenda Dervin's Sense-Making Model (SMM), developed in the 1970s, explains how people seek information to bridge gaps in knowledge. The SMM is based on constructivist epistemological assumptions and an interpretive paradigm of human information-seeking and use. Dervin's work has evolved from a theoretical model into a communication-based valuable methodology in studying human sense-making. The SMM has been applied to various contexts, including information technology, education, and healthcare settings (Stokes and Urquhart, 2011; Urquhart et al., 2016). The SMM views sense-making as an individual's activity in information seeking, processing, recreating, and applying. After recognising a gap in their understanding, this highly complex model explains how a person is embedded in a context-laden situation bound by time and space (Naumer et al., 2008). In the sense-making process, Dervin typically explained her model using the diagrammatic metaphor of a person crossing a bridge (Figure 9.2).

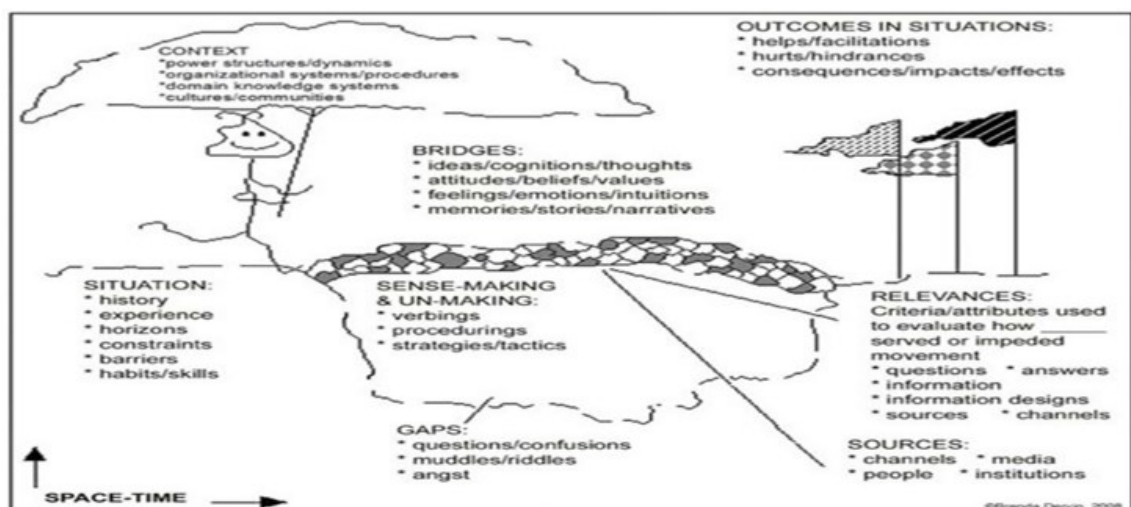


Figure 9.2 The Sense-Making Metaphor (used with permission [www.sense-making.org](http://www.sense-making.org))

The SMM's hallmark theoretical assumptions are congruent with the UPDATE study's philosophical foundations. The SMM proposes that communication praxis focuses on how participants must be free to define themselves and determine their relativity, the essence of constructivist grounded theory approach. Sense-making assumes that people move between states of certainty and uncertainty, and therefore, the epistemological assumption focuses on ordered patterns, complexity, and chaos. How people communicate focuses on the internal and external processes an individual goes through to make and unmake sense. Dervin (1998) elaborated on the importance of using verbs instead of nouns to describe the making sense processes. This supposition is fundamental to constructivist grounded theory as Charmaz (2016) stressed the importance of using gerunds when developing theory from the participants. Therefore, these foundational concepts are aligned with the study's basis and approach and support the adoption of the SMM to build the theory in this study. Finally, SMM positions human beings as central theorists in identifying their tacit and unarticulated understanding (Naumer, 2008). Placing the participant in the sense-making model's centre is in harmony with the constructivist grounded theory methodological values and the study's aims (Bryant and Charmaz, 2019; Birks and Mills, 2023). Therefore, the SMM considers the importance of theory grounded in the participants' views; social processes are used to explain a phenomenon, and how these processes are understood in the context of reality is fundamental. For these reasons, the SMM has been chosen to further explain and contribute to the *Making Sense* core category from the study.

### **9.8 Application of the Sense-Making Model to the Core Category**

Integration of the sense-making metaphor (Figure 9.2) will be discussed to ground the theory of how the diaries are used in understanding. The theory developed in the

study will apply the SMM concepts of situation in time and space, context, gaps, bridges, and sense-making outcomes (Urquhart et al., 2016).

### **9.8.1 Situation in Time and Space**

The SMM places the person in a time-space frame to explain how they understand their experiences (Dervin, 1999). The time-space milieu explains how individuals are seen as potentially static across time-space (as manifested in inflexibility, habit, rigidity, and stability) or fluid across time-space (as manifested in flexibility, randomness, innovation, and creativity). There is chaos/change, order/stability, and movement as humans move across time-space in the complex interconnections between individuals and structure. Therefore, change and stability are inherent to human sense-making (Urquhart et al., 2016).

The UPDATE study illustrated how parent participants moved from recipients to contributors and finally to the curators of the diary. This dynamic interaction within the critical illness experience changed with periods of stability and clarity within episodes of instability and uncertainty. The HCPs' contribution to making sense of the critical illness situation illustrates their dynamic relationships with the child and family. Through the interactive processes elucidated in the study, the diaries were used to capture insights into critical illness situations in the PICU's time-space continuum. The time-space contexts in which the diary was set were the PICU and the critical illness journey, and this component of the SMM will now be discussed.

### **9.8.2 The Context**

The context within the SMM metaphor describes the domain knowledge, cultures, power structures and communities (Agarwal, 2012; Dervin, 1998). Using diaries to explain the domain knowledge was an explicit finding from the study. Diaries offered explanation, insight and understanding for those who accessed them: HCP, parents,

and the child. The value of the diary in providing written and illustrative knowledge on the PICU domain was a clear outcome as it offered insights and explanations that demystified the critical care experience.

The power structures within the PICU were recognised in the study. The HCPs explained how they used the diaries to empower parents' understanding and subsequently supported informed decision-making. These findings acknowledge the power imbalance between HCPs and families. Although complex and dynamic, the part diaries played in balancing the hegemony of the HCPs was an essential factor. The HCPs actively attempted to redress this power imbalance to empower parents, a finding that has yet to be found in other studies.

Dervin (1999) wrote about how people should not be assumed to understand the jargon, vocabulary and words used in each context. This is poignant when we consider the technical terminology of the HCPs, and the familial and cultural discourse parents may use. The study also considered the importance of the diary in explaining to the child and other family members. The diary offered an insight into the understanding, interpretation, and impact of the PICU context for the family and the HCPs and, in doing so, supported the next step in the identification of any information gaps.

### **9.8.3 Information Gap**

The premise of Dervin's SMM is based on a gap in knowledge and understanding. She explained that the sense-making approach describes how people seek information to fill in the gaps in their understanding of a situation (Dervin, 1998; Naumer et al., 2008; Reinhard and Dervin, 2012). The gap is also explained as the difference between the problematic situation and the desired outcome. This gap in understanding may raise questions, confusion, and anxiety. However, once identified, the ability of the person to seek the tools to address the disparity in understanding is apparent and achievable.

The UPDATE study identified how parents used the diary to navigate their understanding of the PICU experience. Using the diary to create memories was critical in anticipating the future information gap the child and other family members may have. The diary, therefore, can be viewed as a component of the 'bridge' that reduces the information gap and leads to the sense-making of the critical illness context.

#### **9.8.4 Bridge: Relevance and Sources**

The bridge is defined as ideas, thoughts, beliefs, attitudes, emotions, feelings, memories, and values that the sense-maker turns to or constructs to bridge the gap they face (Urquhart et al., 2016). For gap-bridging, specific information sources may need to be used. The information sources include general and social media, the Internet, written information, and people or organisations. This study found that the PICU patient diaries provided information uniquely individualised to the child, their family and the team caring for them. The customisation of the diary through the processes explored in the study supports the view of the diary as an information source that supports making sense and bridges the information gap during and after the PICU admission.

#### **9.8.5 Outcome in Situations**

When bridging the knowledge gap, the individual sense-maker defines the destination outcome (Urquhart et al., 2016). Therefore, the outcome depends on how the gap is bridged. Dervin (1999) argued that some potential outcomes may not be evident initially and may only become apparent retrospectively, influencing future beliefs described as 'future horizons'. In the evolution of the SMM, Dervin also acknowledged the plurality in situations, which is reflected in the change in some components of the models, such as history changing to histories and experience to experiences (Urquhart et al., 2016). Therefore, the sense-making moment in SMM is seen as the



intersection between the situation-gap-bridge-outcome (Reinhard and Dervin, 2012). Therefore, the sense-making moment in SMM is seen as the intersection between the situation-gap-bridge-outcome (Reinhard and Dervin, 2012). This has been presented as a triangle in a simplified descriptor of the sense-making model, modified to illustrate the integration of the UPDATE theory (Figure 9.3).

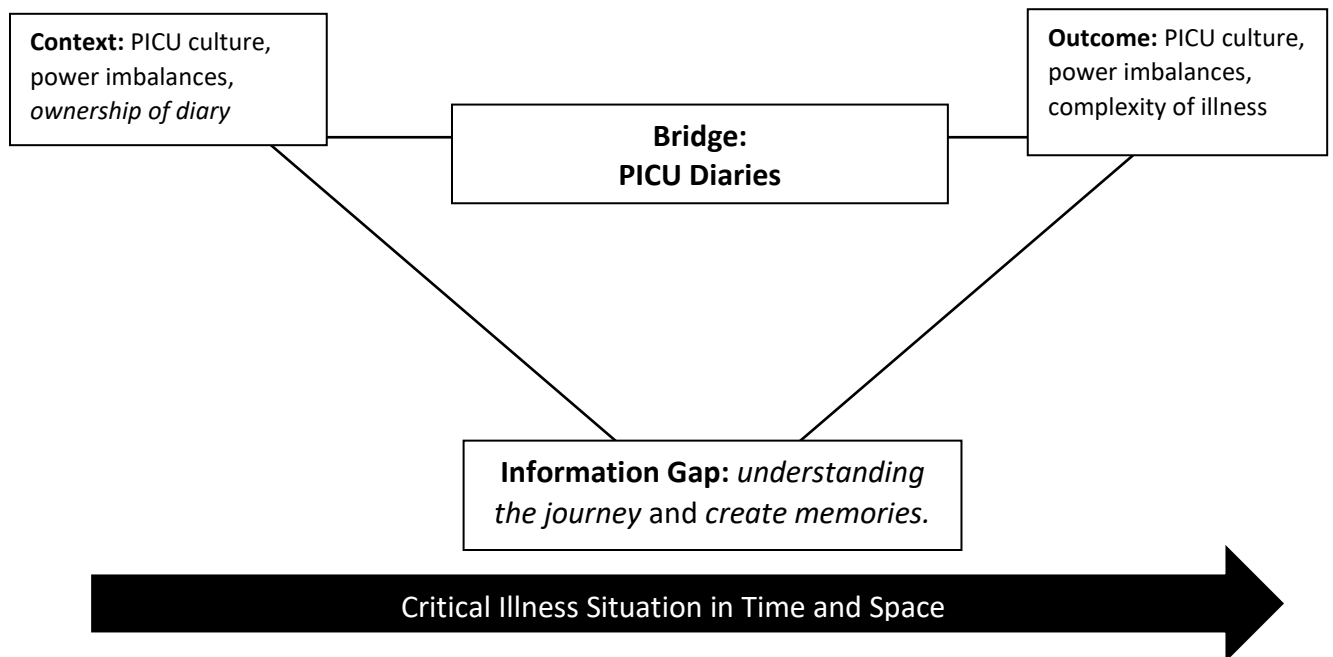


Figure 9.3 Sense-Making Process and Theory (adapted from Dervin, 2008)

The study reflected the evolving use of the diaries as the histories and experiences of the participants changed. The parent participants spoke of how they used the diary to understand the initial PICU experiences and how, over time, this changed to explain to the child what had happened to them. These findings reflected the SMM as the information outcome varied, and the diary offered an agile tool that could be modified to meet the needs of the sense-maker.

The SMM has contributed significantly to the theoretical understanding of the findings in the UPDATE study. The use of the SMM has enhanced the insights into how the diaries provided a tool to build relationships, enable understanding and bridge current

and future knowledge gaps. The study found that the participants used the diary to make sense of their critical illness experiences. Although there was a shared common outcome of *Making Sense*, the participants' experiences were unique. Using a diary to document a child's nursing care in the parents' absence provided insights and understanding for them. It offered the HCPs the ability to demonstrate the unwitnessed care they delivered. These insights may lead to the outcome of satisfying the knowledge gap or raise additional questions that may require further exploration. Therefore, the SMM provided further understanding of how individuals' knowledge gap is dynamic, unique, complex and, subsequently, how patient diaries provide an individualised tool that can be used agilely to bridge gaps and support the user in making sense of the critical illness experiences, now and in the future.

#### **9.9 Final Theory: Redefining the UPDATE Study Storyline.**

The storyline explaining the final theory grounded in the study will now be presented from the theoretical coding and integration. The evolved storyline is presented below:

Critical illness and admission to a PICU can impact the child and their family during and after the PICU admission. These experiences can lead to a constellation of effects which may be deleterious or positive, resulting in growth. To provide individualised, targeted support, identifying the knowledge gaps experienced by the child, parents and the HCPs is essential. The patient diary is a tool to bridge the knowledge gap between parents and HCPs.

The patient diaries provide a communication tool that strengthened the relationships (*Creating Connections*) between the parent and their child, the healthcare professionals and other family members. The relationships fostered through the diaries emotionally impacted the parents. From this emotional involvement, the diary

was sentimentally important to parents. Diaries provided insights into how families coped emotionally, allowing HCPs to provide individualised support where needed (*Impacting Emotionally*). In an environment with an imbalance of power, and unfamiliar organisational processes and cultures, the diary supported choices where decision-making may be complex (*Empowering Involvement*).

The diary strengthened the bridge to navigate the knowledge gaps in the child's critical illness experience. Through this use, the diary offered a compendium of information about the child's PICU journey. Providing clear insights and explanations of their child's PICU admission, the patient diary filled any gaps in memory and offered an easily understandable permanent record. Therefore, the diary was a valuable resource supporting sense-making of the child's complex critical illness journey (*Making Sense*).

### **9.10 Chapter Summary**

This chapter has described the final theory of using PICU patient diaries by parents and healthcare professionals. Theoretical integration of previous studies and the Sense-Making Methodology has enhanced the findings from the UPDATE study. Diaries are recognised to add value as an agile, long-lasting, comprehensive tool to support sense-making in an experience that can be complex, nonsensical, and traumatic.

In the following conclusion chapter, how the study has answered the research question will be presented. The significance of the final theory and subsequent implications and recommendations for clinical practice, education and research will be made. Recognition of the study's limitations will also be presented. Finally, the concluding chapter will provide the opportunity to reflect on the insights gained as a PhD student, novice researcher and nurse.

## **Chapter 10 Conclusions, Limitations and Recommendations**

### **10.1 Introduction**

In this final chapter, the UPDATE study will be drawn to a conclusion. How the research question was answered, and how the aim and objectives of the study were addressed, will be presented. While doing so, the study methods and limitations will be reflected upon. Based on the conclusion, whilst acknowledging the limitations of the study, the implications for clinical practice and education, and the recommendations for future research will be discussed. The study's original contribution to knowledge, particularly paediatric intensive care nursing, will also be defined. Finally, I will reflect on my evolution from a novice to a competent constructivist grounded theory researcher.

### **10.2 Conclusions**

#### **10.2.1 Answering the Research Question.**

The study addressed a significant gap in the evidence base regarding patient diaries used in the PICU. The research addressed the question: *How are patient diaries used by the child, the family, and the healthcare professional (HCP) during and after admission to the PICU?* This question was partially answered as findings from the 17 family interviews and five HCP focus group interviews emerged but, unfortunately, not from the child patient. Only one child patient participant was interviewed. The reasons why the child patient could not participate in this research study will be explored in the limitations section of this chapter, with recommendations on how the resulting deficit in knowledge may be addressed.

The UPDATE study addressed the research question, aims and objectives that emerged from the final conceptual model presented in Figure 9.1 and replicated in Figure 10.1

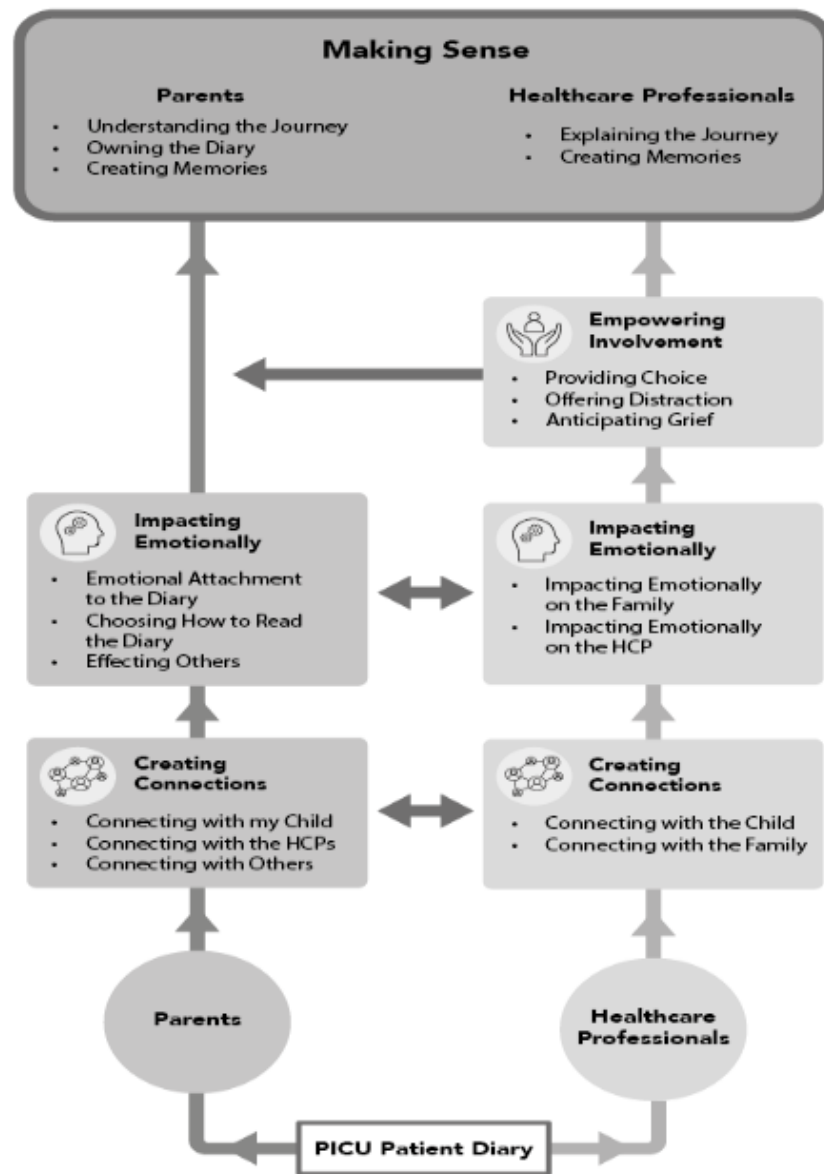


Fig 10.1 Making Sense: A constructivist grounded theory study of the use of patient diaries in the Paediatric Intensive Care Unit [replicated from Figure 9.1]

The final grounded theory, generated from the UPDATE study, concludes that through social processes, patient diaries provided a communication tool for *Creating Connections* between the parent and their child, the healthcare professionals and other family members. The resulting effect of *Impacting Emotionally* was important to the parents and the HCPs. Diaries provided insights into how families coped, allowing HCPs to provide individualised support where needed. In an environment with an

imbalance of power and unfamiliar organisational processes and cultures, the HCPs used the diary in *Empowering Involvement* of the parents, where decision-making may be complex.

The diary was perceived by parents and HCPs as a valuable resource, supporting explaining and understanding. The diary strengthened the bridge to navigate the knowledge gaps in the child's critical illness experience. Through this use, the diary offered a compendium of information about the child's PICU journey. Providing clear insights and explanations of their child's PICU admission, the patient diary filled any gaps in memory and offered an easily understandable permanent record. Therefore, the final conceptual model, grounded from the study, explained how parents and HCPs used the PICU patient diaries in *Making Sense* of the child's complex critical illness journey.

### **10.2.2 Meeting the Aim and Objectives**

The aim of the UPDATE study was to ascertain how patient diaries were used by children, families, and healthcare professionals during and after admission into the PICU. The research objectives were to explore the initial impressions, understand how the diaries were used, the value or any negative aspects, and the perceived impact of the diaries by the HCP.

The study has addressed the research aim and has illuminated how parents and HCPs used the diaries during PICU admission and, as part of the follow-up interviews, how parents and one child used them following discharge. A summary of how each objective was met will now be presented.

### **10.2.3 The Initial Impression of the Diary for the Child, their Family Members, and the HCP.**

The Parents and HCPs spoke positively about the initial impression of offering and using patient diaries. The final emergent grounded theory describes the initial impressions of the diary in the sub-categories *Owning the Diary* and *Providing Choice*. Using a diary was seen as a choice by the family, offered by the nursing team and therefore not perceived as controversial. There was an acceptance of the importance of respecting the parents' decision to adopt the diary. At the introduction of the diary, the acknowledgement of the diary ownership promoted a positive impression of the diary by all.

Only one parent recalled an initial reluctance to commence a diary, as it had been anticipated that her son might die shortly after admission. However, as his prognosis improved and she recognised hope in his recovery, she welcomed the opportunity to restart his diary. Although an isolated finding, this is an area of further exploration for future studies. Overall, the initial impressions of the diary were seen as a tool that was helpful and welcomed by parents and HCPs.

### **10.2.4 The Use of the PICU Diaries by the Child, Family Members, and the HCPs**

The final grounded theory of the study has explained the practical, social, and emotional processes involved in using the diary. Parents used the diary to understand and explain what had happened to their child during and after the critical illness journey. The diary offered a tangible, permanent record of the events during the PICU admission. The diary provided a conduit between the child, the family, and the HCPs. It was used as a tool not only to create and foster personal relationships but also to offer a compendium of information for the parents and HCPs, anticipating how it would be

used in the future for the child. Therefore, the PICU diary was used to *Make Sense* of the critical illness journey.

#### **10.2.5 The Value of the PICU Diaries and any Negative Connotations**

The findings of the study demonstrated how the diaries added value to the experiences of the parents and HCPs alike. The final conceptual model demonstrates how the diaries were a tool to improve communication, offered a distraction, and provided unseen and unheard insights that offered understanding and modification of support for parents. The sub-category *Creating Memories* explained the legacy of the diaries and how parents used the diary to support their child and family when explaining the critical illness journey. The category *Impacting Emotionally* also highlighted fathers' experiences as being different from mothers and how the adaptability of the diary provided flexibility in usage for parents.

The use of the diary after the death of a child was not an area specifically explored in depth during this study. However, the HCPs described how bereaved families used the diary in the sub-category *Anticipating Grief*. The researcher could not interview the two families whose children had sadly died. The value of the diaries after the death of a child, therefore, is an area that warrants further investigation and will be discussed in the limitations section of this chapter.

The overarching finding from parents was that diaries were highly valued. In the category *Impacting Emotionally* only the HCPs expressed any negative connotations related to using diaries. They expressed concerns about the impact contributing to the diary had on their workload, and some spoke of the guilt they felt if they were unable to write in the diary, concerned that they would disappoint the child's family. The professional and legal implications of using patient diaries were raised as an area of concern for the HCPs, who expressed anxiety about the potential negative



consequences of using the diary content in a disagreement about a child's care. The need to address these concerns and support the professional use of patient diaries is an area that the researcher is currently leading on with a group of international HCPs who are collaborating to create best-evidence standards and guidance to support patient diaries in the neonatal and paediatric critical care setting.

#### **10.2.6 The Perceived Impact of the Diary by the HCPs.**

The final theoretical model that has emerged from this study presents the perspective of how the PICU staff implemented and contributed to the diary and has been extensively discussed in this study. This study also directed and allowed the opportunity to seek the insights of the ward nurses who inherited the PICU diary when the child was transferred to the ward. The insights gained from the ward nurses complemented those of the PICU nurses, and this study is the first to gather the perspective of those non-PICU HCPs. Nurses were the main HCP contributors to the diaries. It was not possible to explore the views and experiences of other members of the HCP team, such as the doctors and allied healthcare professionals. Understanding the perspective of other HCPs would be an area of further research.

The study has met the main aims and objectives that were set to answer the research question. Prior to addressing the implications for clinical practice, education, and future research, it is important to recognise the limitations of this study. These study limitations will now be described.

#### **10.3 Limitations of the UPDATE Study.**

Several limitations are acknowledged throughout this research. Before making any comment on the implications and recommendations for future clinical practice, education, and research it is important that these are recognised and addressed.

Firstly, it is crucial to recognise that there needs to be more literature published exploring the impact, outcomes, and use of PICU patient diaries. Although not a limitation of this study, the lack of other studies did reduce the ability to direct the research question, design, and approach. Clarity around the focus of the research area needed to be improved to provide a clear direction for this study. Several other limitations of this study were also identified, including the lack of child participants, the methodological choices and methods used. These limitations will now be discussed further.

The study lacked the participation of child patients. The researcher attempted to recruit children, both the child patients and siblings, but was unsuccessful in gaining insights into a child's perspective. The researcher was cognisant of techniques to engage, support and encourage the child to participate in this study and wished to facilitate their involvement. It was always anticipated that the children's interviews would take place during the follow-up stage of this study. The recruited families consented to facilitate their children's participation, but during the follow-up interviews there were several reasons why children could not contribute. Some children were too young to participate, some families with children old enough to be interviewed were lost to follow-up, and some sibling groups could not attend the interviews. With hindsight, theoretical sampling of child participants may have addressed this gap. Nevertheless, including the child's voice in future research studies is essential.

Using constructivist grounded theory as the research methodology was the most appropriate approach to answer the research question. It is essential to recognise that this methodology was chosen to produce a depth of data, rich in explaining a social phenomenon, such as how diaries are used in a specific PICU, which this study

delivered. Consistent with the in-depth data collection processes used in constructivist grounded theory, this study was conducted in a single PICU in the UK and, therefore, the findings may not be easily applied to other PICUs with different cultural and organisational contexts. However, the qualitative approach goals are to produce conclusions that are transferable rather than generalisable to other populations or settings.

Another limitation of this study was the number of family participants lost to follow-up interviews. Attrition to follow-up is an expected phenomenon in research, and it is important to recognise that the ability to have interviewed six out of the initial 11 families was seen as a positive outcome. Two children died between the first interview and the follow-up phase. These families were contacted, and condolences for the death of their child were offered with an invitation to contribute to the follow-up interviews if they wished, but they, understandably, declined. The reasons why the remaining three families did not wish to continue with the follow-up interviews are unknown. The decision not to participate in the follow-up interviews was respected as the researcher recognised the participants' right to withdraw from the study. The reasons why the participants did not wish to be interviewed again may be surmised: that they did not wish to re-visit the PICU experience or to add any new insights. Nevertheless, it is vital to avoid making assumptions as to why some families did not wish to be interviewed again and it would be important to consider different approaches that may support follow-up participation.

Adopting focus group interviews for the HCPs and using the 'sticky notes' technique to facilitate discussions may be considered a limitation of the data collection for this study. This approach was adopted to allow those attending the focus group interviews to share their views in a non-threatening manner. The focus groups were made up of

junior and senior members of the team and, therefore, some participants may have been reluctant to contribute. Individual interviews may have overcome hesitancy to express viewpoints contradicting the majority's view. However, reflecting on the focus group interviews, the participants did express alternative viewpoints and were encouraged to share these views in an open environment of the focus group interviews.

Where more evidence is needed, implications are drawn; where the study provides a clear way forward, recommendations for future research, clinical practice and education are made. Acknowledging the limitations of this study, the implications and recommendations will now be discussed.

#### **10.4 Study Implications**

This is the first study exploring using PICU patient diaries in the UK context. However, the need remains to gather more evidence surrounding the impact of PICU patient diaries. Therefore, this study provides knowledge and insight into the PICU diaries as an intervention that can be extrapolated. The recommendations and implications for clinical practice and education will now be discussed.

##### **10.4.1 Recommendations and Implications for Clinical Practice**

The study explains how parents and HCPs in this single setting used PICU patient diaries. The theory generated explains how the diaries can positively impact communication, support relationship building and explain what has happened to the family and child. The study findings support the introduction of diaries in those units yet to be adopted and encourage the continued use of those who have already implemented them.

From the findings, the study provided insight into the experiences of parents in the PICU, and the differences expressed by fathers. Therefore, this research offers insights

into how fathers' and mothers' experiences may differ. The diary was used to support fathers in articulating their feelings. These insights could prompt the clinical teams to consider adaptation of support approaches to encourage and facilitate coping. The application of the findings of the fathers warrants further exploration, as these are not generally applicable. The unique experiences expressed by those interviewed raise the importance of considering the needs of parents and how applying an individualised approach to address differences in parental roles warrants consideration.

The study highlighted how vital the nurse's role was to the parents. The findings explained how the diaries offered an ability to explain what nurses do when caring for critically ill children. The findings provided insights into the families' value, trust, and gratitude for the nursing teams. This was particularly evident when the parents explained how much they appreciated the unwitnessed aspects of care delivered to their children. Evidence of nurses going beyond expectations was a finding in the study. The study has provided evidence of how fundamental the nurse's role is to the family of a critically ill child. How the diary provided insights that contributed to the humanisation of the nurse in a clinical environment, which is focused on technical competence, high levels of knowledge and skill, was an important finding from the study. The parental praise of the compassionate care documented was viewed as morale-boosting for the nurses and vital to recognise and disseminate, especially during this time of extreme challenge for the healthcare workforce.

The use of diaries in supporting parental choice was identified as a recurrent finding from the study. The insights gained from this study have enhanced the opportunity for HCPs to recognise further the power imbalance experienced by the family of a critically ill child. The findings acknowledge the importance of the PICU team in acknowledging and supporting the empowerment of the parents in decision-making. The role that

diaries have in some small part in enhancing the ethos of family-focused care facilitating empowerment for parents is an essential implication for practice. The study illustrated how accessible, easy to implement, and low-cost the diary intervention is. The diary can be used adaptively for all families, supporting language, literacy, and cultural needs. The study findings highlight the importance of guiding how to introduce, gain informed consent to use, and clarify the ownership of the diary. Clear guidance and policy on the professional and legal implications of diary use is an implication of the findings. The study site has a protocol for the use of patient diaries. This will be modified to include information on the value of the diary, the importance of documenting consent for introducing diaries to parents, and clarification of diary ownership. The child and family information booklet will also be updated to reflect the study findings, including suggestions of how parents could use the diary with their child and other family members. Therefore, it is recommended that any PICU considering or providing PICU patient diaries should provide guidance for the HCPs and families, providing support on diary use.

The study has explored using PICU patient diaries from a unique perspective: giving a voice to parents and nurses. The implications and recommendations for clinical practice should be disseminated and could be used to support changes locally, nationally, and internationally. The implications for education will now be discussed.

#### **10.4.2 Recommendations and Implications for Education**

Building upon the findings and conclusions of the study, a focus on the educational gaps identified will now be explored. This study offers insights into the experiences of parents of critically ill children and the support and guidance they may require making sense of the critical illness journey. Education on developing awareness and enhancing the empathy of the PICU HCPs on the family experience is advocated. The

psychological impact of being the family member of a sick child is acknowledged, and this study adds to the knowledge base. The diary was recognised as offering an additional tool to support families, especially during critical illness. Therefore, education on this area of PICU care, provided at all levels of training, including pre-registration and post-graduation, is recommended.

Specific training on the psychological impact on the child and family during and after PICU admission is an area that is only just beginning to take momentum (PICS-E 2017). Emphasis on training and education on the physical and emotional rehabilitation interventions required for the child and their family is lacking in the paediatric critical care knowledge base. Understanding and interventions to support rehabilitation in the adult ICU setting are well established in the UK, with nationally recognised guidelines. However, no guidance currently exists for the paediatric population. Although not focused on rehabilitation, this study offers insights and an intervention that will contribute to the knowledge base and support the educational approach to improving child and family outcomes.

Finally, the study illuminated the diary's impact on the HCPs' well-being. The study provided insights into how the HCPs creatively used the diary, and the positive impact the affirmations and gratitude they received from parents had. Recognising the importance of self and team well-being is essential to support the recruitment and retention of the workforce. With significant nursing vacancies in PICU, intensified after the COVID-19 pandemic and the workforce pressures currently experienced in healthcare, any interventions that improve staff well-being are greatly welcomed. A key priority is education on strategies to support nurses' and HCPs' well-being to enable resilience.

The approaches to best implementing and evaluating the patient diary require a quality improvement (QI) methodology to implement a positive change in practice. How to undertake an improvement initiative is an area that HCPs need more education and support to undertake. Successfully engaging the broader team, including patients and families, to address any barriers and enablers, and to evaluate the impact, requires training and support in change management. Therefore, training on QI strategies is essential to ensure an effective implementation of PICU patient diaries. Supporting the education and training of other HCPs who may use the diaries is essential. The nursing team in the non-PICU settings such as the ward, community, and school settings are areas where training has yet to be undertaken. Therefore, providing education on the role of the diary, the insights gained, and the use of diaries in areas other than PICU warrants further training and education.

This study has also identified several gaps in the knowledge base surrounding this intervention. Areas for further research will now be described to address the identified gaps.

## **10.5. Recommendations for Future Research**

### **10.5.1 The Child Patient's Perspective**

The perspectives of the child patients were unable to be explored in the study. This was a limitation of this study and, although ambitious, investigating how children perceive and engage with patient diaries is crucial. The child's experiences will differ from those of their family and the HCPs, so future research incorporating the child's voice and understanding is essential. Future research studies could explore the long-term impact of diaries, the perspective of specific age groups, such as the young person and how the diary may be used to support recovery, such as returning to education and integrating into friendship groups and relationships.



### **10.5.2 Impact of the Diary after the Death of a Child**

This study did not examine the use of diaries by bereaved families but heard anecdotal experiences of the diaries supporting the HCPs and family if a child had died.

Investigating how patient diaries are utilised after the death of a child would provide valuable insights into their potential benefits and any challenges in diary use in the support of bereaved family members. It is recognised that the opportunity to participate in research may be viewed positively by bereaved families. Nevertheless, consideration on the best research methodology, timing of interviews and the researchers' skills to support the participation of the bereaved family is essential to ensure no additional burden is added (Butler et al., 2018).

### **10.5.3. Long-term Benefits and Outcomes.**

This study focused on using diaries for up to six months after the PICU admission. Adult ICU diary studies have only followed-up participants beyond the first few months after discharge (Barreto et al., 2019). However, as PICU patient diaries have been reported as being in use for over ten years, future research could focus on longitudinal outcomes and the impact of using diaries. The importance of long-term investigation is essential to consider that the child patient may be too young to recall their PICU admission but may have unmet needs related to the critical illness experience as they grow.

Currently, no studies have explored the ICU diary's impact in other settings such as the ward, community, and educational contexts. Therefore, understanding the sustained effects of diary usage beyond the critical care setting would enhance the understanding and value of the diary. Research exploring the impact of diaries in other settings may require different methodological approaches to ensure that the most appropriate means to answer these research questions.

#### **10.5.4 Understanding the Broader HCP Perspective**

This study included the experiences and perspectives of nursing staff in the PICU and ward setting. Future research exploring how other HCPs, such as doctors and allied healthcare professionals, perceive and engage with the diaries would be valuable.

Exploring the perspectives of other HCPs will provide a better understanding of the different perspectives, enablers and barriers to diary implementation and use. The renewed importance in supporting the wellbeing of the healthcare workforce is imperative during this time of significant recruitment and retention concerns.

Therefore, the positive impact the diary may have on the well-being of the HCPs is also an area that warrants further investigation.

#### **10.5.5 Cultural, Familial, Language and Literacy Considerations**

This study was conducted in a single PICU in a large UK city, and participants were literate and spoke English, albeit not all were native English speakers. Exploring how patient diaries can be adapted to different cultural contexts and linguistic backgrounds is an area that requires further investigation. Cultural and linguistic sensitivities should be considered when implementing diaries to ensure the needs of the diverse PICU population are met.

Fathers' experiences were an area of focus for this study, and this exploration also raised the question of the impact of PICU diaries on other family members, such as siblings, grandparents, and other family compositions. Researching the needs of same-sex parents, single families, and looked-after children with corporate parenting is an under-represented area of study in the PICU setting. Research including the various family structures is essential and will offer insights to support empathetic and compassionate care.

Research to explore why a family may decline the offer of a patient diary would also be an interesting area of investigation. Understanding why a family may decline the diary or if there were any negative experiences with diary use would be necessary to offer adaptation or alternatives to support the child and family. Research studies exploring these unique perspectives will ensure that the diary use is diverse and inclusive, addressing any unmet child and family needs.

#### **10.5.6 Evaluation of Diary Content**

Future research could focus on exploring and analysing the content of patient diaries to identify themes. This analysis could help refine the diaries' structure, content, and guide the contributors to ensure they capture the most relevant and valuable information. Digital and online electronic diary use has grown expediently during the COVID-19 pandemic (Haakma et al., 2022). Exploring the benefits and challenges of using different mediums for the diary would also be valuable and enable choice. The role of artificial intelligence applications such as ChatGPT also warrants consideration as a future tool with consideration of the benefits and risks of using such tools.

#### **10.5.7 Cost-effectiveness Analysis**

While this study has highlighted the low cost of patient diaries, further research, including a cost-effectiveness analysis to assess the economic impact on diary implementation, would be of value. Findings from this analysis would then aid the introduction of diaries by providing information to support the budgeting of this intervention. This may be of greater importance if digital diaries are adopted as these will have higher instigation and maintenance costs.

#### **10.5.8 Replication of Adult ICU Patient Diary Studies.**

Several international, multi-centre RCTs have investigated the impact of patient diaries in adult intensive care settings. This wealth of evidence focused on the adult ICU

environment provides important support for using patient diaries. Nevertheless, recognising the differences between the PICU and the adult ICU means that extrapolation of the adult studies to the paediatric population is challenging. Therefore, adapting and replicating these studies in the PICU setting would be valuable in understanding if the outcomes for the child patient and their family were comparable to those conducted in the adult ICU.

By addressing these research recommendations, future studies can enhance the understanding of patient diaries in the PICU setting, their impact on various stakeholders, and their potential to improve care delivery and outcomes for critically ill children, their families, and the HCPs.

I will now reflect on my personal and professional development to further explore the insights gained from this study.

## **10.6 Reflecting on the PhD Journey**

### **10.6.1 Understanding the Impact of the Researcher on the UPDATE study.**

The role and influence the researcher may have on this study is essential to acknowledge. It is important to recognise the preconceived ideas of the researcher on the usefulness of patient diaries. To explore my influence on the study, I will write in the first person to be subjective and illustrate reflexivity (Davies, 2012; Webb, 1992). Charmaz (2006) wrote about the importance of the views of the researcher being explicit in the study when she explained:

...the analytic emphasis on grounded theory can lead to silent authorship replete with assumed neutrality, objectivist pretensions and an absent author. Yet completed grounded theories need not be voiceless, objectified recordings. We can weave our points of view into text and portray a sense of wonder, imagery, and drama (2006, p. 318).

Therefore, being clear on how my voice as a researcher is intertwined into the findings is vital to the authenticity of the final theory generated.

### **10.6.2 Understanding the Impact as a PICU Nurse and a Researcher**

When the UPDATE study was conducted, I had worked as a senior PICU nurse at the study site. With the PICU play specialist, I introduced diaries to the unit many years earlier. Implementing the diaries as an intervention was very straightforward; with guidance, education and support, the team positively embraced this new intervention. Once undertaking the study, I was conscious and open about my influence on the views and opinions of the children, families, and the HCP. Keeping in mind the words of Charmaz (2006), I aimed to be honest and open to the views of others without trying to deny my own, and I tried to be reflexive in my data collection and subsequent analysis.

Reflexivity recognises that the researcher implicitly and explicitly influences the research process (Guba and Lincoln, 2005). To ensure research quality, reflexivity in the research process demonstrates the rigour and creditability (Chiovitti and Piran, 2003). Schwandt (2001) described reflexivity as a process of critical self-reflection of the researcher's theoretical predispositions, biases, and preferences.

However, reflexivity differs from reflection, a means to look back, as it is a process of thoughtful, conscious awareness during research (Finlay and Gough, 2008).

To guide the reflexive process, I used several tools to bring the unconscious to consciousness. Memoing has been the primary tool to encourage free thinking and challenge my preconceptions. Structuring the memoing, and encouraging the reflexive processes, occurred by using the following questions to guide my thinking (Markham, 2017):

- How do I know that?

- What led me to that perception?
- So what?
- Why did I conclude that?

My supervisors also challenged my thinking and subsequent perspectives, opening discussions and keeping the reflexive process embedded in the study. This has shaped my understanding of my stance as an insider senior PICU nurse, and as an outsider, as the researcher. This continuous reflexive approach has been pivotal to assuring the quality of the theory generated in this study.

### **10.6.3 Understanding the Impact as a mother and a Researcher.**

The reflexive process used throughout this study has allowed me to consider my biases, and preconceptions as a researcher and as a new mother. This was especially key when interviewing families during their child's admission into the PICU. Although my son has thankfully not been critically unwell, the empathetic approach to the data collection did require consideration as to how I may influence the participants.

My son is adopted and has had life experiences before he came to our family. Some of these experiences have been documented in a life storybook: a social work intervention to recognise the adopted child's past. This book provides information about the child's birth family, often with photographs, descriptions of important life events and information such as where they were born. Therefore, the aim of the life storybooks is almost identical to that of the PICU diaries.

Explaining to an adopted child their adoption story can be very challenging and traumatic experiences must be explained with sensitivity, understanding and love.

The parallel of the life story books and the PICU diaries was not lost on me as a researcher investigating this area of interest. My experience of using my son's life

storybook is limited. He does not wish to read it yet but having this book for when he is ready is important, to aid the process of explaining how he came to his forever family. Therefore, my personal views on the use of the storybook are vital to consider and how this has influenced me as the researcher in this study.

#### **10.6.4 Looking Back and Moving Forward**

Throughout this PhD study, using the constructivist grounded theory methodology has required me to be a reflexive researcher. As I end this journey, I have re-read the numerous memos generated as part of the data analysis process required by the methodology. I recognise that these memos have formed a diary chronicling my development over the past seven years. These research diary entries have provided a framework to illustrate the insights, lessons learnt, and changes I have made as I have moved through this PhD experience.

At the beginning of the study, I was concerned that I had made the wrong choice in adopting grounded theory. I felt overwhelmed by this research approach. I was new to this method and felt that I was being forced into using it by a previous supervisor and that it did not fit my research question. The turning point came when I attended a summer school in Italy in 2015, where Professor Kathy Charmaz was teaching. I listened to her passion for the methodology, as she explained how this iterative research process valued data generation with participants. She helped me realise how constructivist grounded theory was aligned with my beliefs and values as a nurse and human being. She inspired me to persist with grounded theory and how this methodology would allow me to generate the study that would emerge, ensuring that my approach was flexible and responsive to the participants. My confidence grew as I learned more about the research processes through support from my supervisors, additional academic literature, and training.

Throughout the recruitment stage of the research, I included other members of the PICU team, creating PICU patient diary champions. These champions helped me identify families I could approach, provided introductions, and encouraged me with the study. Although I was the sole, principal researcher, I realised that one could not conduct a study of this breadth or scale unaided. Therefore, I recognised early that having a team of allies was essential in the success of a study, supporting the resilience of the researcher, especially during the longevity of the research period.

Midway through the study, after the final interviews, I left the PICU and took a leadership role in a new organisation. This change in role was a challenge, compounded by the global COVID-19 pandemic. During the pandemic, I recognised that I could not manage the demands of a new role and the operational pressures during this period of uncertainty, so I decided, with my supervisors, to suspend the PhD for one year. During this time, I worked in various settings, including the adult ICU, to support the teams working in extremis. I observed the importance of connecting with the patients and their loved ones during the restrictions placed because of the pandemic. The role of the diary became illuminated during this time and was beautifully described in the book by Michael Rosen (2021), *Many Different Kinds of Love: A Story of Life, Death, and the NHS*. During this year, I reflected on the importance of the patient diary. I returned with renewed focus to complete and disseminate this study's findings, supporting the use and value of PICU patient diaries. Undertaking a PhD whilst working full-time and partially self-funding this study has been challenging. Self-awareness of how I work best, structuring my work and home life, and learning how to be most productive, are skills I have transferred to my professional and personal life. The skills and knowledge gained as a PhD student, such as understanding the research governance, methodologies, and bioethics of nursing



research, are insights I have utilised in my nursing career as a leader. I have influenced and supported nursing colleagues to undertake research and audit, and I hope I have inspired them to consider further academic study.

Finally, my curiosity and inquisitiveness in nursing research have developed through academic learning, supervisory support, and peer review. I am immensely grateful for my growth and development during this journey. I have moved from a novice nurse researcher to a competent grounded theory researcher. I would hesitate to call myself a 'Grounded Theorist'. However, I recognise the knowledge and skills I have gained and that I could now competently and confidently undertake further study using this methodology. The learning gained has supported my professional and personal growth, and I will use this to benefit the children and their families I care for, and the teams I work with.

### **10.7 Final Words**

To my knowledge and the latest evidence, the UPDATE study is the first exploring using PICU patient diaries in the UK. For the parents and HCPs in this study, the PICU patient diary provides a tool to create connections with others, which in turn had an emotional impact on those using the diary. Empowering involvement of parents by the HCPs led to a greater understanding and finally supported the making sense of the critical illness journey through the PICU patient diary. Using a constructivist grounded theory approach, I was able to understand, through the lens of the child's parents and the nurses who cared for them, the value they placed on these 'little treasured books'. It is hoped that from this study the implications for practice and education will improve the experiences of all stakeholders in all PICU settings and lead to further enquiry and exploration.

## References

- Agarwal, N. K. (2012). *Making sense of sense-making: tracing the history and development of Dervin's Sense-Making Methodology Introduction and Motivation*. Available at <http://web.simmons.edu/~agarwal/files/Agarwal-ASIST-History-preconf-2012-author.pdf> (Accessed 10/05/2023).
- Aitken, L. M., Rattray, J., & Hull, A. M. (2017). The creation of patient diaries as a therapeutic intervention – for whom? In *Nursing in Critical Care* (Vol. 22, Issue 2, pp. 67–69). Blackwell Publishing Ltd. <https://doi.org/10.1111/nicc.12286>
- Åkerman, E., Ersson, A., Fridlund, B., & Samuelson, K. (2013). Preferred content and usefulness of a photodiary as described by ICU-patients-A mixed method analysis. *Australian Critical Care*, 26(1), 29–35. <https://doi.org/10.1016/j.aucc.2012.04.002>
- Åkerman, E., Granberg-Axell, A., Ersson, A., Fridlund, B., & Bergbom, I. (2010). Use and practice of patient diaries in Swedish intensive care units: a national survey. *Nursing in Critical Care*, 15(1), 26–33. <https://doi.org/10.1111/j.1478-5153.2009.00364.x>
- Alderson, P., & Morrow, V. (2011). *The Ethics of Research with Children and Young People: A Practical Handbook*. SAGE Publications Ltd.
- Backman, C. G., Orwelius, L., Sjoberg, F., Fredrickson, M., & Walther, S. M. (2010). Long-term effect of the ICU-diary concept on quality of life after critical illness. *Acta Anaesthesiologica Scandinavica*, 54(6), 736–743. <https://doi.org/10.1111/j.1399-6576.2010.02230.x>
- Bäckman, C. G., & Walther, S. M. (2001). Use of a personal diary written on the ICU during critical illness. *Intensive Care Medicine*, 27 (2), 426–429. <https://doi.org/10.1007/s001340000692>
- Barreto, B. B., Luz, M., Rios, M. N. D. O., Lopes, A. A., & Gusmao-Flores, D. (2019). The impact of intensive care unit diaries on patients' and relatives' outcomes: A systematic review and meta-analysis. *Critical Care*, 23(1). <https://doi.org/10.1186/s13054-019-2678-0>
- Beck, C. T. (1993). Qualitative Research: The Evaluation of Its Credibility, Fittingness, and Auditability. *Western Journal of Nursing Research*, 15(2), 263–266. <https://doi.org/10.1177/019394599301500212>
- Bergbom, I., Svensson, C., Berggren, E., & Kamsula, M. (1999). Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: pilot study. *Intensive and Critical Care Nursing*, 15(4), 185–191. [https://doi.org/10.1016/S0964-3397\(99\)80069-X](https://doi.org/10.1016/S0964-3397(99)80069-X)
- Bergin, M., Wells, J., & Owen, S. (2010). Relating realist metatheory to issues of gender and mental health. *Journal of Psychiatric and Mental Health Nursing*, 17(5), 442–451. <https://doi.org/10.1111/j.1365-2850.2010.01559.x>
- Birks, M., & Mills, J. (2023). *Grounded Theory: A Practical Guide* (3rd ed.). SAGE Publications Ltd.

- Birks, M., Mills, J., Francis, K., & Chapman, Y. (2009). A thousand words paint a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing, 14*(5), 405–417. <https://doi.org/10.1177/1744987109104675>
- Board, R. (2021). The therapeutic effects of journal writing for parents of PICU patients: A research brief. *Journal for Specialists in Pediatric Nursing, 26*(2). <https://doi.org/10.1111/jspn.12329>
- Brandao, B. B., Luz, M., Alves Valente Do Amaral Lopes, S., Goulart Rosa, R., & Gusmao-Flores, D. (2021). Exploring Patients' Perceptions on ICU Diaries: A Systematic Review and Qualitative Data Synthesis. In *Critical Care Medicine* (Vol. 49, Issue 7, pp. E707–E718). Lippincott Williams and Wilkins. <https://doi.org/10.1097/CCM.0000000000005019>
- Bronner, M. B., Knoester, H., Bos, A. P., Last, B. F., & Grootenhuis, M. A. (2008a). Follow-up after paediatric intensive care treatment: Parental posttraumatic stress. *Acta Paediatrica, International Journal of Paediatrics, 97*(2), 181–186. <https://doi.org/10.1111/j.1651-2227.2007.00600.x>
- Bronner, M. B., Knoester, H., Bos, A. P., Last, B. F., & Grootenhuis, M. A. (2008b). Posttraumatic stress disorder (PTSD) in children after paediatric intensive care treatment compared to children who survived a major fire disaster. *Child and Adolescent Psychiatry and Mental Health, 2*(1), 9. <https://doi.org/10.1186/1753-2000-2-9>
- Bryant, A., & Charmaz, K. (2019). *The SAGE Handbook of Grounded Theory* (C. K. Bryant Antony, Ed.; 3rd ed.). SAGE Publications Ltd, Ed.
- Butler, A. E., Hall, H., & Copnell, B. (2018). Bereaved parents' experiences of research participation. *BMC Palliative Care, 17* (122). <https://doi.org/10.1186/s12904-018-0375-4>
- Charmaz, K. (2000). Qualitative interviewing and grounded theory analysis. In J. Gubrium & J. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 675–694). SAGE Publications Ltd, Ed
- Charmaz, K. (2006). *Constructing Grounding Theory. A Practical Guide Through Qualitative Analysis* SAGE Publications Ltd, Ed.
- Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). SAGE Publications Ltd.
- Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing, 44*(4), 427–435. <https://doi.org/10.1046/j.0309-2402.2003.02822.x>
- Clark, A. M., MacIntyre, P. D., & Cruickshank, J. (2007). A critical realist approach to understanding and evaluating heart health programmes. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 11*(4), 513–539. <https://doi.org/10.1177/1363459307080876>
- Coad, J. (2007). Using art-based techniques in engaging children and young people in health care consultations and/or research. *Journal of Research in Nursing, 12*(5), 487–497. doi:10.1177/1744987107081250

- Coad, J., & Shaw, K. L. (2008). Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Child Health Care*, 64(4), 318–327. doi: 10.1111/j.1365-2648.2008.04801.x
- Coad, J. (2012). Involving young people as co-researchers in a photography project. *Nurse Researcher*, 19(2), 11–16. <https://doi.org/10.7748/nr2012.01.19.2.11.c8903>
- Colville, G. A., Cream, P. R., & Kerry, S. M. (2010). Do parents benefit from the offer of a follow-up appointment after their child's admission to intensive care?: an exploratory randomised controlled trial. *Intensive and Critical Care Nursing*, 26(3), 146–153. <https://doi.org/10.1016/j.iccn.2010.02.005>
- Colville, G., Kerry, S., & Pierce, C. (2008). Children's factual and delusional memories of intensive care. *American Journal of Respiratory and Critical Care Medicine*, 177(9), 976–982. <https://doi.org/10.1164/rccm.200706-8570C>
- Colville, G., & Pierce, C. (2012). Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Medicine*, 38(9), 1523–1531. <https://doi.org/10.1007/s00134-012-2612-2>
- Combe, D. (2005). The use of patient diaries in an intensive care unit. *Nursing in Critical Care*, 10(1), 31–34. <https://doi.org/10.1111/j.1362-1017.2005.00093.x>
- Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher*, 18(4), 17–22. <https://doi.org/10.7748/nr2011.07.18.4.17.c8631>
- Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research (3rd Ed.): Techniques and Procedures for Developing Grounded Theory*. SAGE Publications, Inc. <https://doi.org/10.4135/9781452230153>
- Coyne, I., & Kirwan, L. (2012). Ascertaining children's wishes and feelings about hospital life. *Journal of Child Health Care*, 16(3), 293–304. doi: 0.1177/1367493512443905
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and perspective in the research process*. SAGE Publications, Ed.
- Davies, P. (2012). 'Me', 'Me', 'Me': The Use of the First Person in Academic Writing and Some Reflections on Subjective Analyses of Personal Experiences. *Sociology*, 46(4), 744–752. <https://doi.org/10.1177/0038038512437897>
- Debelić, I., Mikolčić, A., Tihomirović, J., Barić, I., Lendić, Đ., Nikšić, Ž., Šencaj, B., & Lovrić, R. (2022). Stressful Experiences of Parents in the Paediatric Intensive Care Unit: Searching for the Most Intensive PICU Stressors. *International Journal of Environmental Research and Public Health*, 19(18). <https://doi.org/10.3390/ijerph191811450>
- Denzin, N. K., Lincoln, Y., Giardina, M., & Cannella, G. S. (2023). *The SAGE Handbook of Qualitative Research* (N. Denzin & Y. Lincoln, Eds.; 5th ed.). SAGE Publications Ltd.
- Department for Digital Culture Media & Sport. (2018). *Data Protection Act 2018*. Available at <https://www.gov.uk/government/collections/data-protection-act-2018> (Accessed 12/08/2019).

- Dervin, B. (1998). Sense-making theory and practice: an overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, 2(2), 36–46. <https://doi.org/10.1108/13673279810249369>
- DoH. (2003). *Getting the Right Start: National Service Framework for Children*. Available at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199953/Getting\\_the\\_right\\_start\\_-\\_National\\_Service\\_Framework\\_for\\_Children\\_Standard\\_for\\_Hospital\\_Services.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/199953/Getting_the_right_start_-_National_Service_Framework_for_Children_Standard_for_Hospital_Services.pdf) (Accessed 15/06/2023).
- DoH. (2013). *Compassion in Practice. Nursing, Midwifery and Care Staff. Our Vision*. Available at <https://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf> (10/04/2023).
- Doody, O., & Noonan, M. (2013). Preparing and conducting interviews to collect data. *Nurse Researcher*, 20(5), 28–32. <https://doi.org/10.7748/nr2013.05.20.5.28.e327>
- Dyer, I. (1995a). Preventing the ITU syndrome or how not to torture an ITU patient! Part 2. *Intensive and Critical Care Nursing*, 11(4), 223–232. [https://doi.org/10.1016/S0964-3397\(95\)80145-6](https://doi.org/10.1016/S0964-3397(95)80145-6)
- Dyer, I. (1995b). Preventing the ITU syndrome or how not to torture an ITU patient! Part I. *Intensive and Critical Care Nursing*, 11(3), 130–139. [https://doi.org/10.1016/S0964-3397\(95\)80618-0](https://doi.org/10.1016/S0964-3397(95)80618-0)
- Ednell, A. K., Siljegren, S., & Engström, Å. (2017). The ICU patient diary—A nursing intervention that is complicated in its simplicity: A qualitative study. *Intensive and Critical Care Nursing*, 40, 70–76. <https://doi.org/10.1016/j.iccn.2016.12.002>
- Egerod, I., & Christensen, D. (2009). Analysis of patient diaries in Danish ICUs: A narrative approach. *Intensive and Critical Care Nursing*, 25(5), 268–277. <https://doi.org/10.1016/j.iccn.2009.06.005>
- Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Ågård, A. S. (2011). Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, 39(8), 1922–1928. <https://doi.org/10.1097/CCM.0b013e31821e89c8>
- Einarsdottir, J., Dockett, S., & Perry, B. (2009). Making meaning: children's perspectives expressed through drawings. *Early Child Development and Care*, 179(2), 217–232. <https://doi.org/10.1080/03004430802666999>
- Engström, Å., Grip, K., & Hamrén, M. (2009). Experiences of intensive care unit diaries: 'touching a tender wound'. *Nursing in Critical Care*, 14(2), 61–67. <https://doi.org/10.1111/j.1478-5153.2008.00312.x>
- Ewens, B. A., Hendricks, J. M., & Sundin, D. (2015). The use, prevalence, and potential benefits of a diary as a therapeutic intervention/tool to aid recovery following critical illness in intensive care: a literature review. *Journal of Clinical Nursing*, 24(9–10), 1406–1425. <https://doi.org/10.1111/jocn.12736>

- Feinblum Donna, Gonzalez Roxana, & Clyne MaryEllen. (2016). Journaling: A Caring Initiative. *Infant Mental Health Journal*, 20(1), 15–17.  
<https://doi.org/10.1002/imhj.21424>
- Finlay, L., & Gough, B. (2008). *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Wiley.
- Flick, U. (2018). *Doing Grounded Theory*. SAGE Publications Ltd.
- Fukuda, T., Inoue, T., Kinoshita, Y., & Yukawa, T. (2015). Effectiveness of ICU Diaries: Improving “Distorted Memories” Encountered during ICU Admission. *Open Journal of Nursing*, 05(04), 313–324. <https://doi.org/10.4236/ojn.2015.54034>
- Galazzi, A., Adamini, I., Bazzano, G., Cancelli, L., Fridh, I., Laquintana, D., Lusignani, M., & Rasero, L. (2022). Intensive care unit diaries to help bereaved family members in their grieving process: a systematic review. *Intensive and Critical Care Nursing* (Vol. 68).  
<https://doi.org/10.1016/j.iccn.2021.103121>
- Garrouste-Orgeas, M., Flahault, C., Vinatier, I., Rigaud, J. P., Thieulot-Rolin, N., Mercier, E., Rouget, A., Grand, H., Lesieur, O., Tamion, F., Hamidfar, R., Renault, A., Parmentier-Decrucq, E., Monseau, Y., Argaud, L., Bretonnière, C., Lautrette, A., Badié, J., Boulet, E., ... Timsit, J. F. (2019). Effect of an ICU Diary on Posttraumatic Stress Disorder Symptoms Among Patients Receiving Mechanical Ventilation: A Randomized Clinical Trial. *JAMA - Journal of the American Medical Association*, 322(3), 229–239.  
<https://doi.org/10.1001/jama.2019.9058>
- Garrouste-Orgeas, M., Périer, A., Mouricou, P., Grégoire, C., Bruel, C., Brochon, S., Philippart, F., Max, A., & Misset, B. (2014). Writing in and reading ICU diaries: Qualitative study of families’ experience in the ICU. *PLoS ONE*, 9(10).  
<https://doi.org/10.1371/journal.pone.0110146>
- Gawronski, O., Sansone, V., Cancani, F., Di Nardo, M., Rossi, A., Gagliardi, C., De Ranieri, C., Satta, T., Dall’Oglio, I., Tiozzo, E., Alvaro, R., Raponi, M., & Cecchetti, C. (2022). Implementation of paediatric intensive care unit diaries: Feasibility and opinions of parents and healthcare providers. *Australian Critical Care*.  
<https://doi.org/10.1016/j.aucc.2022.01.011>
- Gillis, J., & Rennick, J. (2006). Affirming parental love in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, 7(2), 165–168.  
<https://doi.org/10.1097/01.PCC.0000200943.25252.4F>
- Glaser. (1978). *Theoretical Sensitivity: Advances in the methodology of grounded theory*. Sociology Press.
- Glaser, B. (1992). *Basics of grounded theory analysis: Emergence vs forcing*. Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Sociology Press.
- Gov.uk. (1989). *Children Act*. Available at  
<https://www.legislation.gov.uk/ukpga/1989/41/contents> (Accessed 12/08/2022).

- Gray, B. (2017). The Cynefin framework: Applying an understanding of complexity to medicine. *Journal of Primary Health Care*, 9(4), 258–261.  
<https://doi.org/10.1071/HC17002>
- Green, J., & Thorogood, N. (2018). *Qualitative Methods for Health Research* (4th ed.). SAGE Publications Ltd.
- Guba, E. G., & Lincoln, Y. (2005). Paradigmatic Controversies, Contradictions and Emerging Confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 191–215). SAGE Publications Ltd.
- Haakma, T., Tieben, R., Sleven, B., Buise, M., & van Mol, M. (2022). Experiences of nurses with an innovative digital diary intervention in the intensive care unit: A qualitative exploration. *Intensive and Critical Care Nursing*, 70.  
<https://doi.org/10.1016/j.iccn.2022.103197>
- Herrup, E. A., Wieczorek, B., & Kudchadkar, S. R. (2019). Feasibility and perceptions of PICU diaries. *Pediatric Critical Care Medicine*, 20(2), E83–E90.  
<https://doi.org/10.1097/PCC.0000000000001814>
- Högvall, L. M., Egerod, I., Herling, S. F., Rustøen, T., & Berntzen, H. (2023). Finding the right words: A focus group investigation of nurses' experiences of writing diaries for intensive care patients with a poor prognosis. *Australian Critical Care*.  
<https://doi.org/10.1016/j.aucc.2023.02.002>
- Houghton, C., Murphy, K., Meehan, B., Thomas, J., Brooker, D., & Casey, D. (2017). From screening to synthesis: using NVivo to enhance transparency in qualitative evidence synthesis. *Journal of Clinical Nursing*, 26(5–6), 873–881.  
<https://doi.org/10.1111/jocn.13443>
- ICUSteps. (2023). *Patient Diaries*. Patient Diaries. Available at <https://icusteps.org/professionals/news-and-updates/patient-diaries> (Accessed 29/12/2022).
- Jakobsen, L., Kristensen, K. K., & Laerkner, E. (2021). Parents' experiences during and after their child's stay in the paediatric intensive care unit – A qualitative interview study. *Intensive and Critical Care Nursing*, 67. <https://doi.org/10.1016/j.iccn.2021.103089>
- Johansson, M., Hanson, E., Runeson, I., & Wåhlin, I. (2015). Family members' experiences of keeping a diary during a sick relative's stay in the intensive care unit: A hermeneutic interview study. *Intensive and Critical Care Nursing*, 31(4), 241–249.  
<https://doi.org/10.1016/j.iccn.2014.11.002>
- Johansson, M., Wåhlin, I., Magnusson, L., & Hanson, E. (2019). Nursing staffs' experiences of intensive care unit diaries: a qualitative study. *Nursing in Critical Care*, 24(6), 407–413.  
<https://doi.org/10.1111/nicc.12416>
- Jones, C. (2009). Introducing photo diaries. *Journal of Intensive Care Society*, 10 (3): 183–185. doi:10.1177/175114370901000306
- Jones, C. (2021). Over 20 years of ICU diary research 1999–2020. *Intensive and Critical Care Nursing* (Vol. 64). Churchill Livingstone. <https://doi.org/10.1016/j.iccn.2020.102961>

- Jones, C., Backman, C., Capuzzo, M., Egerod, I., Flaatten, H., Granja, C., Rylander, C., Griffiths, R. D., & RACHEL group, T. (2010). Intensive care diaries reduce new onset post-traumatic stress disorder following critical illness: a randomised, controlled trial. *Critical Care*, 14(5), R168. <https://doi.org/10.1186/cc9260>
- Jones, C., Bäckman, C., Capuzzo, M., Flaatten, H., Rylander, C., & Griffiths, R. D. (2007). Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. *Intensive Care Medicine*, 33(6), 978–985. <https://doi.org/10.1007/s00134-007-0600-8>
- Jones, C., Griffiths, R. D., Humphris, G., Psych, C., & Skirrow, P. M. (2001). Memory, delusions, and the development of acute posttraumatic stress disorder-related symptoms after intensive care. *Critical Care Medicine* 29(3): 573-80. doi: 10.1097/00003246-200103000-00019.
- Joyce, P. (2008). Focus Groups. In R. Watson, McKenna H, A. Cowman, & Keady J (Eds.), *Nursing Research: Design and Methods*. Churchill Livingstone: Elsevier.
- Klein G, Moon B, & Hoffman R R. (2006). Making Sense of Sensemaking 2: A macrocognitive Model. *IEEE Intelligent Systems*. Vol.21, no.5 pp 88-92. doi: 10.1109/MIS.2006.100.
- Klein, G., Phillips, J. K., Rall, E. L., & Peluso, D. A. (2007). A data-frame theory of sensemaking. In R. R. Hoffman (Ed.), *Expertise out of context: Proceedings of the Sixth International Conference on Naturalistic Decision Making* (pp. 113–155). Lawrence Erlbaum Associates Publishers.
- Knowles, R. E., & Tarrier, N. (2009). Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial\*. *Critical Care Medicine*, 37(1), 184–191. <https://doi.org/10.1097/CCM.0b013e31819287f7>
- Kumpunen, S., Shipway, L., Taylor, R. M., Aldiss, S., & Gibson, F. (2012). Practical approaches to seeking assent from children. *Nurse Researcher*, 19(2), 23–27. <https://doi.org/10.7748/nr2012.01.19.2.23.c8905>
- Kvale, S. (1996). *Interview Views: An introduction to Qualitative Research Interviewing* . SAGE Publications Ltd.
- Lambert, V., Glacken, M., & McCarron, M. (2011). Employing an ethnographic approach: key characteristics. *Nurse Researcher*, 19(1), 17–24. <https://doi.org/10.7748/nr2011.10.19.1.17.c8767>
- Latour, J. M., van Goudoever, J. B., & Hazelzet, J. A. (2008). Parent Satisfaction in the Pediatric ICU. *Pediatric Clinics of North America* (Vol. 55, Issue 3, pp. 779–790). <https://doi.org/10.1016/j.pcl.2008.02.013>
- Laudato, N., Yagiela, L., Eggly, S., & Meert, K. L. (2020). Understanding parents' informational needs in the pediatric intensive care unit: A qualitative study. *Progress in Pediatric Cardiology*, 57. <https://doi.org/10.1016/j.ppedcard.2019.101172>



- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science* 5, 69. <https://doi.org/10.1186/1748-5908-5-69>
- Levers, M.-J. D. (2013). Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence. *SAGE Open*, 3(4), 215824401351724. <https://doi.org/10.1177/2158244013517243>
- López Fernández, E., Oviedo Melgares, L., Ordoñez Sáez, O., Belda Hofheinz, S., & Ramos Casado, M. V. (2022). Feasibility and acceptance of ICU diaries adapted to pediatric patients. A new tool against family post-intensive care syndrome? *Anales de Pediatría*. <https://doi.org/10.1016/j.anpedi.2022.09.007>
- Low, S. Z. Q., Kirk, A., Mok, Y. H., & Lee, J. H. (2023). The Use and Impact of Diaries in PICUs and Neonatal ICUs: A Scoping Review. *Pediatric Critical Care Medicine*, 24(2), e84–e90. <https://doi.org/10.1097/pcc.0000000000003122>
- Lynch, F. (2001). *Parental Sensory Perception of the Paediatric Intensive Care Environment* [Unpublished thesis]. King's College London.
- Lynch, F. (2003). *Listening to the Voices of Children. Exploring the Lived Experience of the Child in the PICU* [Unpublished thesis]. Imperial College London.
- Lynch, F., Endacott, R., & Latour, J. M. (2020). Patient diaries: Survey of paediatric intensive care units in the United Kingdom and Ireland. *Nursing in Critical Care*, 25(1), 31–36. <https://doi.org/10.1111/nicc.12472>
- Manning, J. C., Hemingway, P., & Redsell, S. A. (2017). Stories of survival: Children's narratives of psychosocial well-being following paediatric critical illness or injury. *Journal of Child Health Care*, 21(3), 236–252. <https://doi.org/10.1177/1367493517717078>
- Manning, J. C., Pinto, N. P., Rennick, J. E., Colville, G., & Curley, M. A. Q. (2018). Conceptualizing post intensive care syndrome in children - The PICS-p framework. *Pediatric Critical Care Medicine*, 19(4), 298–300. <https://doi.org/10.1097/PCC.0000000000001476>
- Markham, A. (2017). *Reflexivity: Some techniques for interpretive researchers*. Available at <https://Annettemarkham.Com/2017/02/Reflexivity-for-Interpretive-Researchers/> (Accessed 08/04/2023).
- Menzies, J. C., Morris, K. P., Duncan, H. P., & Marriott, J. F. (2016). Patient and public involvement in paediatric intensive care research: Considerations, challenges and facilitating factors. In *Research Involvement and Engagement* (Vol. 2, Issue 1). BioMed Central Ltd. <https://doi.org/10.1186/s40900-016-0046-7>
- Mickelson, R. S., Piras, S. E., Brown, L., Carlile, C., Drumright, K. S., & Boehm, L. (2021). The use and usefulness of ICU diaries to support family members of critically ill patients. *Journal of Critical Care*, 61, 168–176. <https://doi.org/10.1016/j.jcrc.2020.10.003>

- Mikkelsen, G. (2018). The meaning of personal diaries to children and families in the paediatric intensive care unit: A qualitative study. *Intensive and Critical Care Nursing*, 45, 25–30. <https://doi.org/10.1016/j.iccn.2017.10.001>
- Miller, S. (2003). Analysis of phenomenological data generated with children as research participants. *Nurse Researcher*, 10(4), 68–82. <https://doi.org/10.7748/nr2003.07.10.4.68.c5908>
- Ministry of Health. (1959). *Welfare of Children in Hospital: Platt Report*. Available at <https://ia800201.us.archive.org/8/items/op1266065-1001/op1266065-1001.pdf> (Accessed 10/07/2023).
- Mitchell, S. J., Slowther, A.-M., Coad, J., Akhtar, S., Hyde, E., Khan, D., & Dale, J. (2019). Ethics and patient and public involvement with children and young people. *Archives of Disease in Childhood - Education & Practice Edition*, 104(4), 195–200. <https://doi.org/10.1136/archdischild-2017-313480>
- Morse, J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research*, 25(9), 1212–1222. <https://doi.org/10.1177/1049732315588501>
- Morse, J. M., & Singleton, J. (2001). Exploring the Technical Aspects of “Fit” in Qualitative Research. *Qualitative Health Research*, 11(6), 841–847. <https://doi.org/10.1177/104973201129119424>
- Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. In *BMC Medical Research Methodology* (Vol. 18, Issue 1). BioMed Central Ltd. <https://doi.org/10.1186/s12874-017-0468-4>
- Nair, R., Mitchell, M., & Keogh, S. (2015). The extent and application of patient diaries in Australian intensive care units: A national survey. *Australian Critical Care*, 28(2), 93–102. <https://doi.org/10.1016/j.aucc.2014.09.001>
- Nakashima, H., & Gallegos, C. (2020). Journal writing by families of critically ill patients: An integrative review. *Critical Care Nurse*, 40(5), 26–37. <https://doi.org/10.4037/ccn2020293>
- Naumer, C., Fisher, K., & Dervin, B. (2008). *SenseMaking: A Methodological Perspective*. Available at <https://www.researchgate.net/publication/238691238> (Accessed 01/05/2023)
- Needham, D. M., Davidson, J., Cohen, H., Hopkins, R. O., Weinert, C., Wunsch, H., Zawistowski, C., Bemis-Dougherty, A., Berney, S. C., Bienvenu, O. J., Brady, S. L., Brodsky, M. B., Denehy, L., Elliott, D., Flatley, C., Harabin, A. L., Jones, C., Louis, D., Meltzer, W., ... Harvey, M. A. (2012). Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders’ conference. *Critical Care Medicine*, 40(2), 502–509. <https://doi.org/10.1097/CCM.0b013e318232da75>
- NICE. (2017). *Rehabilitation after critical illness in adults Rehabilitation after critical illness in adults (QS158)*. Available at [www.nice.org.uk/guidance/qs158](http://www.nice.org.uk/guidance/qs158) (Accessed 10/12/2022).

- NICE. (2018). *Post-traumatic stress disorder NICE guideline*. Available at [www.nice.org.uk/guidance/ng116](http://www.nice.org.uk/guidance/ng116) (Accessed 10/09/2022)
- Nielsen, A. H., & Angel, S. (2016a). Consolation or confrontation when interacting through an ICU diary – A phenomenological–hermeneutical study. *Intensive and Critical Care Nursing*, 37, 4–10. <https://doi.org/10.1016/j.iccn.2016.06.002>
- Nielsen, A. H., & Angel, S. (2016b). Relatives' perception of writing diaries for critically ill. A phenomenological hermeneutical study. *Nursing in Critical Care*, 21(6), 351–357. <https://doi.org/10.1111/nicc.12147>
- Nielsen, A. H., Angel, S., Egerod, I., Lund, T. H., Renberg, M., & Hansen, T. B. (2020). The effect of family-authored diaries on posttraumatic stress disorder in intensive care unit patients and their relatives: A randomised controlled trial (DRIP-study). *Australian Critical Care*, 33(2), 123–129. <https://doi.org/10.1016/j.aucc.2019.01.004>
- Nielsen, A. H., Egerod, I., Hansen, T. B., & Angel, S. (2019). Intensive care unit diaries: Developing a shared story strengthens relationships between critically ill patients and their relatives: A hermeneutic-phenomenological study. *International Journal of Nursing Studies*, 92, 90–96. <https://doi.org/10.1016/j.ijnurstu.2019.01.009>
- NMC. (2018). *The Code*. Available at [www.nmc.org.uk/code](http://www.nmc.org.uk/code) (Accessed 03/01/2023).
- NoECCN. (2022). *NoECCN-Patient Diary Guidelines (2022) Patient Diary Guidelines For use in Critical Care*. Available at [https://www.noeccn.org.uk/resources/Documents/Practice%20development/NoECCN%20Patient%20Diary%20Guideline%20\(2022\).pdf](https://www.noeccn.org.uk/resources/Documents/Practice%20development/NoECCN%20Patient%20Diary%20Guideline%20(2022).pdf) (Accessed 10/05/2023).
- Nydahl, P., Bäckman, C. G., Bereuther, J., & Thelen, M. (2014). How much time do nurses need to write an ICU diary? *Nursing in Critical Care*, 19(5), 222–227. <https://doi.org/10.1111/nicc.12046>
- Nydahl, P., Fischill, M., Deffner, T., Neudeck, V., & Heindl, P. (2019). Diaries for intensive care unit patients reduce the risk for psychological sequelae: Systematic literature review and meta-analysis. In *Medizinische Klinik - Intensivmedizin und Notfallmedizin* (Vol. 114, Issue 1, pp. 68–76). Springer-Verlag. <https://doi.org/10.1007/s00063-018-0456-4>
- Paediatric Intensive Care Society- Education (PICS-E) (2017) *Standards for Education in Paediatric Critical Care Specialist Nursing* Available at <https://pccsociety.uk/wp-content/uploads/2017/06/2-PICS-E-Standard-for-Specialist-Nurse-Education-V3.1-2017-05-31.pdf> (Accessed 15/03/2023).
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *PLOS Medicine*, 18(3), e1003583. <https://doi.org/10.1371/journal.pmed.1003583>

- Palombi, M., Boi, S., Little, A., & Matarese M. (2018). The effectiveness of the patient diary for reducing psychological disorders related to intensive care admission. Systematic literature review. *L'Infermiere* (Issue 1). Available at <https://www.infermiereonline.org/2018/05/11/> Accessed 20/12/2022.
- Parahoo, K. (2014). *Nursing Research: Principles, Process and Issues* (2nd ed.). Palgrave Macmillan.
- Pascal, C., & Bertram, T. (2014). Transformative Dialogues: The Impact of Participatory Research on Practice. In A. Clark, R. Flewitt, M. Hammersley, & M. Robb (Eds.), *Understanding Research with Children and Young People*. SAGE Publications, Inc. <https://doi.org/10.4135/9781526435637>
- Pattison, N., O'Gara, G., Lucas, C., Gull, K., Thomas, K., & Dolan, S. (2019). Filling the gaps: A mixed-methods study exploring the use of patient diaries in the critical care unit. *Intensive and Critical Care Nursing*, 51, 27–34. <https://doi.org/10.1016/j.iccn.2018.10.005>
- Patton, M. Q. (2015). *Qualitative Research & Evaluation Methods* (4th ed.). SAGE publications Ltd.
- PCCS. (2021). *Quality Standards for the Care of Critically Ill or Injured Children 6th Edition*. Available at <https://pccsociety.uk/wp-content/uploads/2021/10/PCCS-Standards-2021.pdf> (Accessed 28/03/2023).
- Perry, M. A., Dawkins-Henry, O. S., Awojoodu, R. E., Blumenthal, J., Asaro, L. A., Wypij, D., Kudchadkar, S. R., Zuppa, A. F., & Curley, M. A. Q. (2021). Study protocol for a two-center test of a nurse-implemented chronotherapeutic restoring bundle in critically ill children: RESTORE Resilience (R2). *Contemporary Clinical Trials Communications*, 23. <https://doi.org/10.1016/j.conctc.2021.100840>
- Perry-Eaddy, M. A., Dervan, L. A., Manning, J. C., Watson, R. S., & Curley, M. A. Q. (2022). Pediatric Critical Care Outcomes: State of the Science. In *Critical Care Clinics*. W.B. Saunders. <https://doi.org/10.1016/j.ccc.2022.09.007>
- Phillips, D. C., & Burbules, N. C. (2000). *Postpositivism and Educational Research*. Rowman & Littlefield.
- PICANet. (2018). *Summary Report Paediatric Intensive Care Audit Network State of the Nation Report 2015-2017*. Available at <https://www.picanet.org.uk/wp-content/uploads/sites/25/2018/11/PICANet-2018-annual-report-summary-v1.1.pdf> (Accessed 10/07/2023).
- PICANet. (2021). *Summary Report Paediatric Intensive Care Audit Network State of the Nation Report 2022*. Available at <https://www.picanet.org.uk/2022/01/13/picanet-annual-report-2021/> (Accessed 10/07/2023).
- Place, B. (2000). Constructing the Bodies of Critically Ill Children: An Ethnography of Intensive Care. In *The Body, Childhood and Society* (pp. 172–194). Palgrave Macmillan UK. [https://doi.org/10.1007/978-0-333-98363-8\\_9](https://doi.org/10.1007/978-0-333-98363-8_9)

- Polit, D., & Beck, C. (2020). *Nursing Research: Generating and Assessing Evidence for Nursing Research* (D. Polit & C. Beck, Eds.; 11th ed.). Wolters Kluwer Health.
- Pollock, D., Peters, M. D. J., Khalil, H., McInerney, P., Alexander, L., Tricco, A. C., Evans, C., de Moraes, É. B., Godfrey, C. M., Pieper, D., Saran, A., Stern, C., & Munn, Z. (2023). Recommendations for the extraction, analysis, and presentation of results in scoping reviews. *JBI Evidence Synthesis*, 21(3), 520–532. <https://doi.org/10.11124/JBIES-22-00123>
- QAA. (2021). *Advice on Doctoral Standards for Research Students and Supervisors*. Available at [www.qaa.ac.uk/covid-19](http://www.qaa.ac.uk/covid-19) (Accessed 10/08/2023).
- Rawal, G., Yadav, S., & Kumar, R. (2017). Post-intensive care syndrome: An overview. *Journal of Translational Internal Medicine*, 5(2), 90–92. <https://doi.org/10.1515/jtim-2016-0016>
- Rees, G., Gledhill, J., Garralda, M. E., & Nadel, S. (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive Care Medicine*, 30(8). <https://doi.org/10.1007/s00134-004-2310-9>
- Reinhard, C. D., & Dervin, B. (2012). Comparing situated sense-making processes in virtual worlds. *Convergence: The International Journal of Research into New Media Technologies*, 18(1), 27–48. <https://doi.org/10.1177/1354856511419914>
- Rennick, J. E., Morin, I., Kim, D., Johnston, C. C., Dougherty, G., & Platt, R. (2004). Identifying children at high risk for psychological sequelae after pediatric intensive care unit hospitalization\*. *Pediatric Critical Care Medicine*, 5(4), 358–363. <https://doi.org/10.1097/01.PCC.0000128603.20501.0D>
- Riegel, M., Randall, S., & Buckley, T. (2019). Memory making in end-of-life care in the adult intensive care unit: A scoping review of the research literature. *Australian Critical Care* (Vol. 32, Issue 5, pp. 442–447). Elsevier Ireland Ltd. <https://doi.org/10.1016/j.aucc.2018.12.002>
- Robson, W. (2008). RESEARCH CONNECTIONS: An evaluation of patient diaries in intensive care. *Connect: The World of Critical Care Nursing*, 2, 34–37. DOI: 10.1891/1748-6254.6.2.34
- Roulin, M.-J., Hurst, S., & Spirig, R. (2007). Diaries Written for ICU Patients. *Qualitative Health Research*, 17(7), 893–901. <https://doi.org/10.1177/1049732307303304>
- Sansone, V., Dall'Oglio, I., Gesualdo, F., Cancani, F., Cecchetti, C., Di Nardo, M., Rossi, A., De Ranieri, C., Alvaro, R., Tiozzo, E., & Gawronski, O. (2021). Narrative Diaries in Pediatrics: A Scoping Review. *Journal of Pediatric Nursing*, 59, e93–e105. <https://doi.org/10.1016/j.pedn.2021.02.006>
- Savage, J. (2006). Ethnographic evidence. *Journal of Research in Nursing*, 11(5), 383–393. <https://doi.org/10.1177/1744987106068297>
- Schofield, R., Dibb, B., Coles-Gale, R., & Jones, C. J. (2021). The experience of relatives using intensive care diaries: A systematic review and qualitative synthesis. In *International*

*Journal of Nursing Studies* (Vol. 119). Elsevier Ltd.  
<https://doi.org/10.1016/j.ijnurstu.2021.103927>

- Schwandt, T. (2001). *Dictionary of qualitative inquiry*. SAGE Publications, Ltd.
- Segers, E., Ockhuijsen, H., Baarendse, P., van Eerden, I., & van den Hoogen, A. (2019). The impact of family centred care interventions in a neonatal or paediatric intensive care unit on parents' satisfaction and length of stay: A systematic review. *Intensive and Critical Care Nursing*, 50, 63–70. <https://doi.org/10.1016/j.iccn.2018.08.008>
- Shields, L., Zhou, H., Taylor, M., Hunter, J., Munns, A., & Watts, R. (2012). Family-centred care for hospitalised children aged 0-12 Years: A systematic review of quasi-experimental studies. *JB Library of Systematic Reviews*, 10(39), 2559–2592. <https://doi.org/10.11124/jbisrir-2012-32>
- Snowden, D. J. (2007). *A Leader's Framework for Decision Making Anthro-complexity-various View project*. Available at <https://www.researchgate.net/publication/5689229> (Accessed 12/12/2022).
- Stajduhar, K. I., Balneaves, L., & Thorne, S. E. (2001). A case for the 'middle ground': exploring the tensions of postmodern thought in nursing. *Nursing Philosophy*, 2(1), 72–82. <https://doi.org/10.1046/j.1466-769x.2001.00033.x>
- Stokes, P., & Urquhart, C. (2011). Profiling information behaviour of nursing students: part 1: quantitative findings. *Journal of Documentation*, 67(6), 908–932. <https://doi.org/10.1108/00220411111183528>
- Storli, S. L., Lindseth, A., & Asplund, K. (2008). A journey in quest of meaning: A hermeneutic-phenomenological study on living with memories from intensive care. *Nursing in Critical Care*, 13(2), 86–96. <https://doi.org/10.1111/j.1478-5153.2007.00235.x>
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques* (1st ed.). SAGE Publications Ltd.
- Subramani, S. (2019). Practising reflexivity: Ethics, methodology and theory construction. *Methodological Innovations*, 12(2), 205979911986327. <https://doi.org/10.1177/2059799119863276>
- Sun, X., Huang, D., Zeng, F., Ye, Q., Xiao, H., Lv, D., Zhao, P., & Cui, X. (2021). Effect of intensive care unit diary on incidence of posttraumatic stress disorder, anxiety, and depression of adult intensive care unit survivors: A systematic review and meta-analysis. *Journal of Advanced Nursing* (Vol. 77, Issue 7, pp. 2929–2941). <https://doi.org/10.1111/jan.14706>
- Tavares, T., Camões, J., Carvalho, D. R., Jacinto, R., Vales, C. M., & Gomes, E. (2019). Assessment of patient satisfaction and preferences with an intensive care diary. *Revista Brasileira de Terapia Intensiva*, 31(2), 164–170. <https://doi.org/10.5935/0103-507X.20190028>
- Teece, A. (2020). An ICU diary written by relatives: Who is it really written for? *Intensive and Critical Care Nursing* (Vol. 57). <https://doi.org/10.1016/j.iccn.2020.102815>

- Teece, A., & Baker, J. (2017). Thematic Analysis: How do patient diaries affect survivors' psychological recovery? *Intensive and Critical Care Nursing* (Vol. 41, pp. 50–56). Churchill Livingstone. <https://doi.org/10.1016/j.iccn.2017.03.002>
- Tisdall, E., Davies, J., & Gallagher, M. (2009). *Researching with Children and Young People: Research Design, Methods and Analysis*. SAGE Publications Ltd.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Twycross, A. (2009). An interprofessional approach to the ethics of undertaking research with children. *Nurse Researcher*, 16(3), 7–20. <https://doi.org/10.7748/nr2009.04.16.3.7.c6942>
- Ullman, A. J., Aitken, L. M., Rattray, J., Kenardy, J., Le Brocque, R., MacGillivray, S., & Hull, A. M. (2014). Diaries for recovery from critical illness. *Cochrane Database of Systematic Reviews* (Vol. 2014, Issue 12). <https://doi.org/10.1002/14651858.CD010468.pub2>
- UNICEF. (1989). *The United Nations Convention on the Rights of the Child*. Available at <https://www.unicef.org.uk/rights-respecting-schools/wp-content/uploads/sites/4/2017/01/UNCRC-in-full.pdf> (Accessed 10/12/2022).
- Urquhart, C., Lam, L. M. C., Cheuk, B., & Dervin, B. L. (2016). Sense-Making/Sensemaking. In *Communication*. Oxford University Press. <https://doi.org/10.1093/obo/9780199756841-0112>
- Valera, J. (2016). *KEEPING PATIENT DIARIES Information for relatives*. Available at <https://www.ouh.nhs.uk/patient-guide/leaflets/files/14288Pdiaries.pdf> (Accessed 01/02/2023).
- van Manen, M. (2018). *Researching Lived Experience* (2nd ed.). Routledge. Taylor Frances Group.
- van Manen, M., & van Manen, M. (2021). Doing Phenomenological Research and Writing. *Qualitative Health Research*, 31(6), 1069–1082. <https://doi.org/10.1177/10497323211003058>
- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing* 53 (4): 459-69. doi: 10.1111/j.1365-2648.2006.03740.x.
- Webb, C. (1992). The use of the first person in academic writing: objectivity, language, and gatekeeping. *Journal of Advanced Nursing*, 17(6), 747–752. <https://doi.org/10.1111/j.1365-2648.1992.tb01974.x>
- Weick E. Karl. (2000). *Making Sense of the Organization*. Blackwell.
- Welford, C., Murphy, K., & Casey, D. (2010). Demystifying nursing research terminology. Part 1. *Nurse Researcher*, 18(4), 38–43. DOI: 10.7748/nr2011.07.18.4.38.c8635

Yagiela, L., Edgar, C. M., Harper, F. W. K., & Meert, K. L. (2022). Parent post-traumatic growth after a child's critical illness. *Frontiers in Pediatrics* 10. doi: 10.3389/fped.2022.989053

Yin, R. (2011). *Doing Qualitative Research from Start to Finish*. Guildford Press.

Zamawe, F. (2015). The Implication of Using NVivo Software in Qualitative Data Analysis: Evidence-Based Reflections. *Malawi Medical Journal*, 27(1), 13. <https://doi.org/10.4314/mmj.v27i1.4>



# Appendices

## Appendix 1 Advertising material for study

### Poster and Flier for Families

WITH PLYMOUTH UNIVERSITY  
Evelina London  
Children's Hospital

Guy's and St Thomas' NHS  
NHS Foundation Trust



photos used with kind permission of the child's family

Are you interested in taking part in a research study discussing the use of the PICU Patient Diaries?

This will involve you and your family talking about your thoughts and views on using the diaries.  
If yes, please speak to the nurse or doctor looking after your child.  
Thank you  
Fiona Lynch  
Fiona.lynch@gstt.nhs.uk

Version 1.1 Oct 2016 IRAS project ID 140655

### Poster and Flier for HCPs

WITH PLYMOUTH UNIVERSITY  
Evelina London  
Children's Hospital

Guy's and St Thomas' NHS  
NHS Foundation Trust



photos used with kind permission of the child's family

Do you think you or your patient or their family may be interested in taking part in a research study discussing the use of the PICU Patient Diaries?

If yes, please speak to me or call/email me for further information  
[fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)  
Or 0207 188 7696  
Thank you, Fiona



VERSION 1.1 OCTOBER 2016 IRAS project ID 140655

## Appendix 2 Information Sheets for Participants

### Adult Family Members

ADULT INFORMATION SHEET:



Patient Diaries in the Paediatric Intensive Care Unit (PICU)

Dear

I would like to invite you to take part in a research study. Before you decide, I would like you to have the information to understand why the research is being conducted and what it would involve for you.

**Why is this project being carried out?** I want to see if using a patient diary helps the child and their family when they are patients in PICU and once they are home. Therefore, I am interested in your thoughts and views about these diaries. This study is part of a PhD degree at the University of Plymouth.

**Did anyone else check the study is OK to do?** Before any research is allowed to happen, it has to be checked by a group called a Research Ethics Committee. They make sure that the research is of value and is fair to those participating. This project has been checked by the West London Research Ethics Committee.

As this study is part of a PhD degree at the University of Plymouth, it is therefore under very close scrutiny from my academic supervisors.

**Why have I been asked to take part?** Your relative is a patient in the PICU at the Evelina London Children's hospital and patient diaries are used in this unit.

**What does the research study involve?** The study will involve an interview with you and your family about the diary, whilst the child is in hospital and then a follow-up interviews a few months after your relative returns home.

**Do I and my family have to take part?** No, your participation in this study is purely voluntary. You and your family may refuse to take part and you do not have to explain why. Being involved or not will not affect your relative's care and treatment or their relationships with the nurses or doctors.

I am only approaching you as the patient's parent or guardian having given me their permission to do this and have agreed to be part of this study.

**What will happen to me if I say yes to take part?** If you want to take part, I will talk to you about your thoughts and views regarding the diary.

I would like to do this twice, once when your relative is still a patient on the PICU and the second time after you have been home for a few months.

The two interviews will take approximately 60-90 minutes each for adults and 20-45 minutes for any child participants, depending on their age.

These interviews will be conducted in a private area at a time and place convenient to you. I will discuss with you if you wish to be interviewed together or individually, this is of course your choice.

I will record, using a digital recorder, what you and your family tell me.

I may also ask you to share with me, parts of your diary to understand more about your experience of using it.

Once your relative has been discharged home, after 5-6 months, I will contact their parents or guardians by letter, email or phone to check if there are any reasons why you or your family would not want to participate in the follow-up interview.

**Will anyone else know I'm doing this?** No one else will be informed that you are taking part unless I am worried about your safety or that of your family. If I do need have to talk to someone else about what you tell me, I will tell you that I have to do this.

**Will joining in help me?** Taking part in the study will not help you but the information you give will help us understand how the diaries are used. Some patients and families also say it is helpful to talk about what happened.

**Will talking about the diary upset me?** Sometimes it can be upsetting to talk about the time when your relative was seriously ill. If you do get upset, you can stop or take a break from the interview. If you wish, I can put you in contact with other support resources for you and your family.

**What will happen to the recorded information?** The voice recordings will be listened to and turned into typed documents and the original recording will be

destroyed. Any typed documents will be stored securely in password protected files on computers at the Evelina London Children's Hospital. These files will be treated in the strictest confidence and only accessed by me. Each person taking part will be given a code which will replace their name and other personal details so that they will be anonymous to everyone except to me.

**What if I don't want to be part of the study anymore?** It's completely up to you as I only want you to take part if you want to. If you decide not to, do not worry. If you decide to take part and then change your mind, that is your right too and you do not have to explain your decision.

If you decide you do not want to be involved before the interview is analysed, then all of the information you have provided will be removed.

**What happens when the research stops?** When the two interviews are completed and the research stops, I will not make contact with you again unless you would like to hear about the study findings.

**What shall I do now?** Now you know more about the study you need to think about if you want to participate or not. I suggest you take some time to think and talk to your family members. I will not rush you to make a decision but will come back to speak to you in the next 48 hours to ask for your decision. If you have any further questions, please do not hesitate to talk to the nurse or doctor caring for your child or you can contact me.

**What will happen if I say yes?** If you agree to take part, I will ask you sign a consent form to agree that you understand the study and what will happen. You will be given your own copy to keep as well as this information sheet. I will then arrange, with you, a suitable time for the interviews to take place.

**What if there is a problem?** If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

Alternatively, you or your family can contact me, the principal researcher or the study's academic supervisor.

If you have a complaint, you can talk to me, the principal investigator and I will do my best to answer your questions. You can also contact the study's academic supervisor, Professor Jos Latour about your complaint. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the Guy's and St Thomas' Patient Advisory Liaison Service (PALS) on 0207 1887188, address: PALS, KIC, Ground floor, north wing, St Thomas' Hospital, Westminster Bridge Road, London, SE1 7EH.

This study is sponsored by the University of Plymouth.

The sponsors will at all times maintain adequate insurance in relation to the study independently. The University of Plymouth, through its own professional indemnity (Clinical Trials) and no-fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

**Contact details** If you have any further questions about this research, you can telephone or email me the principal researcher at:

**Fiona Lynch**

fiona.lynch@gstt.nhs.uk



Phone:0207 188 7696



Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

Professor Jos Latour



Phone: 01752 586578



jos.latour@plymouth.ac.uk

**Thank you again for taking the time to read this information sheet.**

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

Child Information Sheet Index Child 4-7 years old

CHILDREN'S INFORMATION SHEET

Patient Diaries in the Paediatric Intensive Care Unit (PICU)

(4-7-year-old)

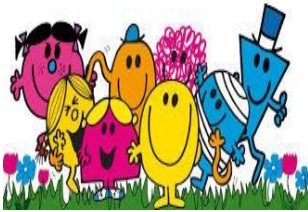


***Hello, I would like to talk to you and your family about what you thought about the diary made in the hospital.***

This sheet will help you to choose if you want to take part. Please read or ask your parents to read this sheet to you

**Why do I want to talk to you?** I want to find out more about what you and your family thought about the diary made in the hospital.

**Do I have to talk to you?** No, it is up to you.



**What will I have to do?** We can draw or play a game and you can tell me what you think about the diary. I'm interested in what you have to tell me.



You can talk to me with your family or on your own if you and your parent/s agree.

To help me remember what you said, I will make a recording of what we talk about together.

**Will anyone else know I'm doing this?** Your parents you will know you are taking part.

No-one else will know, unless I am worried about your or your family. If I do need to speak to anyone else, I will tell you I am doing this.

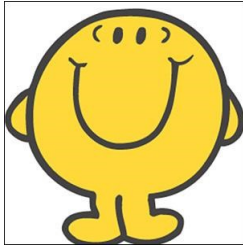


**How long will we talk for?** It is up to you but probably about 20-30 minutes.



**What if I get tired or want to take a break?** You can stop talking at any time to take a break or stop taking part. Nobody will be cross with you, and you do not need to say why.

**Could talking about the diary be difficult?** Sometimes children can find it upsetting to talk about the time when they were unwell. If you find it hard, we can stop talking at any time.



**Will talking about the diary help me?** Taking part in this study will not help you but what you tell me will help us in the way we look after other children and their families.


**Who can I ask about this?** Your parents or family know about the study. If they are not sure, the doctor or nurse who gave you this information sheet can tell you more.



**What will happen if I say yes?** I will ask you to write your name and tick the boxes to say you understand why I am talking to you and what will happen.

**Thank you!**

**Contact details** If you have any questions about this research you, your parent/guardian can telephone or email me:

Fiona Lynch  Phone: 0207188 7696 [fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Or alternatively my teacher: Professor Jos Latour



Phone: 01752 586578



[jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

## Information Sheet Index Child 8-11 years old

### CHILDREN'S INFORMATION SHEET

#### Patient Diaries in the Paediatric Intensive Care Unit (PICU)

(8–11-year-old)

***Hello, I would like to talk to you and your family about what you thought about the diary.***

This question-and-answer sheet will help you to choose if you want to take part.

Please read the sheet carefully and talk to your parents if you have any questions.



**Why am I doing this study?** I want to find out more about what children and their families thought about the diary that was started in the Paediatric Intensive Care Unit at the Evelina London Children's Hospital.

**Did anyone check that the study was OK to do?** Yes, before I am allowed to talk to you and your family, I had to check with a group of people called an ethics committee to make sure that it was ok.

I have also spoken to your parent/s or the grown up who looks after you about this study and they have allowed me to ask if you would like to take part.

When you go home, I will check with you and your family again if it is still ok to talk to you.



**Why have I been asked to take part?** I would like to talk to you as you have been a patient in the PICU. I would like to listen to what you think about the patient diary that was started when you were a patient in the PICU.

**Do I have to take part?** No, it is up to you if you take part or not.



**What will I have to do?** If you want to take part, I would like you to talk to you and your family about what are your thoughts about the diary. You can draw a picture or write a story if you think that would help you to explain to me what you think. It is not a test or quiz and there are no wrong or right answers.

I will invite you and your family to talk to me again in a few months' time. You can talk to me with your family or on your own if you and your parent/s agree.





To help me remember what you and your family say, I will record our chat, using a digital recorder.

**Will anyone else know I'm doing this?** Your parents or the grown up who looks after you will know you are taking part.

**Will anyone else hear my answers?** No, only I will listen to the recording.

I will only talk to someone else if I am worried about you or anyone in your family. If I did have to talk to someone else, I will tell you that I have to do this and why.



minutes.

**How long will we have to talk for?** It is up to you but about 20-30

**Who else will take part?** I will be talking to other families and children about what they think but this will not be at the same time as you.

**What if I get tired or want to take a break?** You can stop talking at any time to take a break or stop taking part. Nobody will be cross with you, and you do not need to say why.

**How will it help if I take part?** I hope the study will help other children and their families. I want to understand how the diaries are used by children and their families and if there is anything we can do to make these better.



**Will talking about the diary be difficult?** Sometimes children can find it upsetting to talk about the time when they were unwell.

If there are questions that you do not want to answer, you can say no. No-one will be cross with you. I will not talk to you on your own unless you want me to.

**Will joining in help me?** Taking part in the study will not help you but the information you give will help us understand how the diaries are used.

**What if I have questions or do not understand something?** Tell your parent/s or the grown up who looks after you, your questions and they will contact me or the study's academic supervisor.




**What will happen if I say yes?** If you agree to take part, I will ask you to tick the circles and write your name on the form at the end of this information sheet. This is to say you understand the study and what will happen.

I will then talk to you and your family to arrange a suitable time for to talk with me.

**Thank you!**

**Contact details** If you have any questions about this research you, your parent/guardian can telephone or email, me the principal researcher:

Fiona Lynch  Phone: 0207188 7696 [fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

Professor Jos Latour Phone: 01752 586578 [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)  
1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

## Information Sheet for the Young Person

**Hello** [add name]

you are being invited to talk about your experiences of using patient diaries. This information sheet will help you decide if you want to take part.

Please read the sheet carefully and talk to your parents/guardian if you have any questions.

**Why is this study being carried out?** I want to see how the patient diary is used by children, young people and their family when they are in the Paediatric Intensive Care Unit (PICU) and once they are at home. This study is part of a PhD degree at the University of Plymouth.

**Did anyone else check the study is OK to do?** Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the West London Research Ethics Committee.

I have also spoken to your parents/guardians, and they have agreed that I can ask you if you wish to be involved.

**Why have I been asked to take part?** Because when you were a patient in PICU at the Evelina London Children's Hospital, a patient diary was started, and I would like to find out what you think about this diary.

**Do I have to take part?** No, it is up to you to decide if you want to be take part. You do not need to explain why if you do not wish to be involved. Taking part or not, will not affect the care you or your family receive.

**What will happen to me if I say yes to take part?** If you want to take part I would like you to talk to you

about your thoughts and views about the diary. I will record, using a digital recorder, what you say.

If you find it easier to express your views/thoughts through art or story- telling, you can do this.

The interview will take approximately 30-45 minutes and you can have a break at any time if you feel tired.

You can decide if you want another family member with you or if you want to talk on your own.

When you are back at home I will then invite you to talk to me again in a few months' time.

**Will anyone else know I'm doing this?** Your parents/guardians and I will know you are taking part.

No one else will be informed unless I am worried about you.

If I do need have to talk to someone else about what you tell me, I will tell you that I have to do this.

**Will joining in help me?** Taking part in the study will not help you but the information you give will help us understand how the diaries are used. Some patients and families also say it is helpful to talk about what happened.

**Will talking about the diary and the time when I was unwell, upset me?** Sometimes it can be upsetting to talk about the time when you. If you do get upset you can stop or take a break from the interview. We can talk about what has upset you or you can talk to your family. If you wish, I can put you in contact with other support resources for you and your family.

**What will happen to the recorded information?** The voice recordings will be made into typed documents and then the voice recording will be destroyed. The typed documents will be stored securely in password protected files on computers at the Evelina London Children's Hospital and will be treated in the strictest confidence. Each person taking part will be given a code which will replace their name and other personal details so that they will be anonymous to everyone except to me.

**What happens when the research stops?** When the research stops I will not make contact with you again unless you would like to hear about what was found in the study.

The findings of the interviews will then be used to inform the way we use the diaries in PICU.

**What if I don't want to do the research anymore?** It's completely up to you. I only want you to take part if you want to. If you decide not to, it will not change how you/ or your family are looked after.

If you decide to take part and then change your mind that is OK. You can stop and don't have to say why if you don't want to.

If you decide you do not want to be involved in this study before the information is analysed, then all of the interview will be removed.



**What shall I do now?** Now you know about the study you need to think about if you want to join in or not.

**Who can I ask about this?** Your mum, dad or the adult who looks after you have been told about the study. If they are not sure, the doctor or nurse who gave you this information sheet can tell you more.



**What will happen if I say yes?** If you agree to take part, I will ask you to initial the boxes and write your name on the form at the end of this leaflet. This is to say you understand the study and what will happen. You will be given your own copy to keep as well as this leaflet. We will then arrange a time for you to talk with me. Apart from this you will not need to do anything else.

**What happens if I have any questions, concerns or a complaint?** If you have a question concern or a complaint about the study please talk to your parents and you or they can contact me.

**Contact details** If for you or your parent/guardian have any questions about this research you can telephone or email me the principal researcher at:

**Fiona Lynch**  Phone:0207 188 7696  [fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

**Professor Jos Latour**  Phone: 01752 586578  [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

**Thank you again for taking the time to read this information sheet.**

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

## **Information Sheet for Siblings**

### YOUNG PERSON'S INFORMATION SHEET:

Patient Diaries in the Paediatric Intensive Care Unit (PICU)

(12-16 yrs.)

Hello, you are being invited to talk about your experiences of using a patient diary. This information sheet will help you decide if you want to take part.

Please read the sheet carefully and talk to your parents or guardians if you have any questions.

Why is this study being carried out? I want to see how the patient diary is used by children, young people and their family when they are in the Paediatric Intensive Care Unit (PICU) and once they are at home. This study is part of a PhD degree at the University of Plymouth.

Did anyone else check the study is OK to do? Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the West London Research Ethics Committee.

I have also spoken to your parents/guardians, and they have agreed that I can ask you if you wish to be involved.

Why have I been asked to take part? Because whilst your brother or sister were a patient in PICU at the Evelina London Children's Hospital, a patient diary was started, and I would like to find out what you think about this.

Do I have to take part? No, it is up to you to decide if you want to be take part. You do not need to explain why if you do not wish to be involved. Taking part or not, will not affect the care your family receive.

What will happen to me if I say yes to take part? If you want to take part, I would like you to talk to you about your thoughts and views about the diary. I will record, using a digital recorder, what you say.

If you find it easier to express your views or thoughts through art or story- telling, you can do this.

The interview will take approximately 30-45 minutes and you can have a break at any time if you feel tired.

You can decide if you want another family member with you or if you want to talk on your own. When you are all back at home I will then invite you to talk to me again in a few months' time.

Will anyone else know I'm doing this? Your parents/guardians and I will know you are taking part. I will ask your family if it is ok to contact you for a second interview in about 5-6 months' time.

No one else will be informed unless I am worried about you. If I do need have to talk to someone else about what you tell me, I will tell you that I have to do this.

Will joining in help me? Taking part in the study will not help you but the information you give will help us understand how the diaries are used. Some patients and families also say it is helpful to talk about what happened.

Will talking about the diary and the time when my sibling was unwell, upset me? Sometimes it can be upsetting to talk about the time when your brother or sister was unwell. If you do get upset you can stop or take a break from the interview. We can talk about what has upset you or you can talk to your family. If you wish, I can put you in contact with other support resources for you and your family.

What will happen to the recorded information? The voice recordings will be made into typed documents and then the voice recording will be destroyed. The typed documents will be stored securely in password protected files on computers at the Evelina London Children's Hospital and will be treated in the strictest confidence. Each person taking part will be given a code which will replace their name and other personal details so that they will be anonymous to everyone except to me.

What happens when the research stops? When the research stops I will not make contact with you again unless you would like to hear about what was found in the study. The findings of the interviews will then be used to inform the way we use the diaries in PICU.

What if I don't want to do the research anymore? It's completely up to you. I only want you to take part if you want to. If you decide not to, it will not change how your family are looked after.

If you decide to take part and then change your mind that is OK too. You can stop and don't have to say why if you don't want to.

If you decide you do not want to be involved in this study before the information is analysed, then all of the that you have told me will be removed.

What shall I do now? Now you know about the study you need to think about if you want to join in or not.



Who can I ask about this? Your mum, dad or the adult who looks after you have been told about the study. If they are not sure, the doctor or nurse who gave you this information sheet can tell you more.

What will happen if I say yes? If you agree to take part, I will ask you to initial the boxes and write your name on the form at the end of this leaflet. This is to say you

understand the study and what will happen. You will be given your own copy to keep as well as this leaflet. We will then arrange a time for you to talk with me. Apart from this you will not need to do anything else.

What happens if I have any questions, concerns or a complaint? If you have a question concern or a complaint about the study please talk to your parents and you or they can contact me.

Contact details If for you or your parent/guardian have any questions about this research you can telephone or email me the principal researcher at:

Fiona Lynch  Phone: [0207 188 7696](tel:02071887696)  [fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

Professor Jos Latour  Phone: 01752 586578  [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

Thank you again for taking the time to read this information sheet.

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655



## Information Sheet for Child Siblings 8-11 years old

### CHILDREN'S INFORMATION SHEET:

Patient Diaries in the Paediatric Intensive Care Unit (PICU)

(8-11 year old)

*Hello, I would like to talk to you and your family about what you thought about the diary.*

This question and answer sheet will help you to choose if you want to take part.

Please read the sheet carefully and talk to your parents if you have any questions.



**Why am I doing this study?** I want to find out more about what children and their families thought about the diary that was started in the Paediatric Intensive Care Unit at the Evelina London Children's Hospital.

**Did anyone check that the study was OK to do?** Yes, before I am allowed to talk to you and your family, I had to check with a group of people called an ethics committee to make sure that it was ok. I have also spoken to your parent/s or the grown up who looks after you about this study and they have allowed me to ask if you would like to take part. When you go home, I will check with you and your family if it is still ok to talk to you.



**Why have I been asked to take part?** I would like to talk to you as or your brother or sister was a patient in the PICU. I would like to listen to what you think about the patient diary that was started when your sibling was a patient in the PICU.

**Do I have to take part?** No, it is up to you if you take part or not.



**What will I have to do?** If you want to take part I would like you to talk to you and your family about what your thoughts about the diary. You can draw a picture or write a story if you think that would help you to explain to me what you think. It is not a test or quiz and there are no wrong or right answers.

I will invite you and your family to talk to me again in a few months' time. You can talk to me with your family or on your own if you and your parent/s agree.

To help me remember what you and your family say, I will record our chat, using a digital recorder.



**Will anyone else know I'm doing this?** Your parents or the grown up who looks after you will know you are taking part.

**Will anyone else hear my answers?** No, only I will listen to the recording.

I will only talk to someone else if I am worried about you or anyone in your family. If I did have to talk to someone else, I will tell you that I have to do this and why.



minutes.

**How long will we have to talk for?** It is up to you but about 20-30

**Who else will take part?** I will be talking to other families and children about what they think but this will not be at the same time as you.

**What if I get tired or want to take a break?** You can stop talking at any time to take a break or stop taking part. Nobody will be cross with you and you do not need to say why.

**How will it help if I take part?** I hope the study will help other children and their families. I want to understand how the diaries are used by children and their families and if there is anything we can do to make these better.



**Will talking about the diary be difficult?** Sometimes children can find it upsetting to talk about the time when their brother or sister was unwell.

If there are questions that you do not want to answer, you can say no. No-one will be cross with you. I will not talk to you on your own unless you want me to.

**Will joining in help me?** Taking part in the study will not help you but the information you give will help us understand how the diaries are used.

**What if I have questions or do not understand something?** Tell your parent/s or the grown up who looks after you, your questions and they will contact me or the study's academic supervisor.



**What will happen if I say yes?** If you agree to take part, I will ask you to tick the circles and write your name on the form at the end of this information sheet. This is to say you understand the study and what will happen.

I will then talk to you and your family to arrange a suitable time for to talk.

**Thank you**

**Contact details** If you have any questions about this research you, your parent/guardian can telephone or email me the principal researcher:  
Fiona Lynch Phone: 0207188 7696 [fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

Professor Jos Latour Phone: 01752 586578 [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

## Information Sheet for Siblings 4-7 years old



Hello, I would like to talk to you and your family about what you thought about the diary.

This sheet will help you to choose if you want to take part.

Please read or ask your parents to read this sheet to you.



**Why do I want to talk to you?** I want to find out more about what you and your family thought about the diary your brother or sister had in hospital.

**Do I have to talk to you?** No, it is up to you.

**What will I have to do?** We can draw or play a game and you can tell me what you think about the diary. I'm interested in what you have to tell me.



You can talk to me with your family or on your own if you and your parent/s agree.

To help me remember what you said, I will make a recording of what we talk about together.

**Will anyone else know I'm doing this?** Your parents you will know you are taking part.

No-one else will know unless I am worried about your or your family. If I do need to speak to anyone else, I will tell you I am doing this.

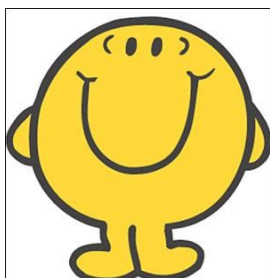


**How long will we talk for?** It is up to you but probably about 20-30 minutes.



**What if I get tired or want to take a break?** You can stop talking at any time to take a break or stop taking part. Nobody will be cross with you and you do not need to say why.

**Could talking about the diary be difficult?** Sometimes children can find it upsetting to talk about the time when their brother or sister were unwell. If you find it hard we can stop talking at any time.



**Will talking about the diary help me?** Taking part in this study will not help you but what you tell me will help us in the way we look after other children and their families.

**Who can I ask about this?** Your parents or family know about the study. If they are not sure, the doctor or nurse who gave you this information sheet can tell you more.

**What will happen if I say yes?** If you agree to take part, I will ask you to write your name and tick the boxes to say you understand why I am talking to you and what will happen.



**Thank you**

**Contact details** If you have any questions about this research you, your parent/guardian can telephone or email the me:

Fiona Lynch



Phone: 0207188 7696



[fiona.lynch@gstt.nhs.uk](mailto:fiona.lynch@gstt.nhs.uk)

Or alternatively to my teacher:

Professor Jos Latour Phone: 01752 586578 [jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

## **Appendix 3 Information Sheet and Consent for Healthcare Professionals**

### **Healthcare Professional's (HCP) Information Sheet**

#### **Patient Diaries in the Paediatric Intensive Care Unit (PICU)**

Dear

I would like to invite you to take part in a research study. Before you decide, I would like you to have the information to understand why the research is being conducted and what it would involve for you.

**Why is this study being conducted?** It is well recognised that an admission into a PICU is a stressful experience for the critically ill child and their family.

As you know, for the past few years we have offered a patient diary to the child and their family. However, the use of these diaries in PICU has not to date been studied. This research study, which is part of a PhD study at the University of Plymouth, will explore how the diaries are used; by the child, their family and by you, the healthcare professionals caring for the child and their family. I also want to explore whether these diaries have a value in patient care.

This information sheet will provide you with some more information about the study to assist you in deciding whether you wish to participate. If you do decide to take part, please sign the consent form. You will receive a copy of the consent form and information sheet to keep.

**Who has reviewed and approved this study?** This study has been approved by the West London Research Ethics Committee, GSTT Research and Development and is under close supervision from my research supervisors at the University of Plymouth.

**Why have I been approached to take part?** As you work in PICU and are familiar with and have used PICU patient diaries.

**Do I have to take part?** Your participation in this study is purely voluntary.

**What will happen to me if I say yes to take part?** If you want to take part I will invite you to one of the planned focus group interviews. These will take place in the hospital and there will be a choice of dates and times to make them convenient for staff taking part. I anticipate that there will be 6-8 other participants in each focus group and that all will be staff members from the PICU.

During these interviews, ground rules will be discussed and set to ensure that all participants have clear expectations on confidentiality and the conduct of the focus group.

The interview will be digitally recorded, and I anticipate that the interviews will take between 60-90 minutes.

**What will happen to the recorded information?** The voice recordings will be transcribed. The transcripts will be stored securely in password protected files on a computer at the Evelina London Children's Hospital and will be treated in the strictest confidence. Each person taking part will be given a code which will replace their name and other personal details so that they will be anonymous to everyone except to me, the researcher.

**What if I don't want to be part of the study anymore?** It's completely up to you as I only want you to take part if you want to. If you decide not to, do not worry. If you decide to take part and then change your mind, that is your right too and you do not have to explain your decision.

If you decide you do not want to be involved before the interview is analysed, then all the information you have provided will be removed.

**What happens when the research stops?** When the interviews are completed, I will not contact you again about the research unless you would like to hear about the study findings.

The study findings will be disseminated through publications and presentations. The findings of the study will then be used to further develop the way we use the PICU diaries.

**What shall I do now?** Now you know about the study, you need to think about whether you want to participate or not. I will not rush you to decide but will come back to speak to you in the next few hours after this initial discussion.

If you have any further questions please do not hesitate to talk to me about these.

**What will happen if I say yes?** If you agree to take part, I will ask you sign a consent form to confirm that you understand the study and what will happen. You will be given your own copy as well as this information sheet. I will then be in contact to arrange a suitable time for you to be interviewed in the focus groups. Apart from this you will not need to do anything else.

**What if there is a problem?** If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

If you have a complaint, you should talk to me, the principal researcher and I will do my best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure.

This study is sponsored by University of Plymouth. The sponsors will at all times maintain adequate insurance in relation to the study independently. University of Plymouth, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient.

**Contact details** If you have any further questions about this research, please do not hesitate to speak to me or email me.

**Fiona Lynch**



Phone:0207 188 7696



[Fiona.lynch@gstt.nhs.uk](mailto:Fiona.lynch@gstt.nhs.uk)

Alternatively, if I am not available or you wish to speak to someone else you can contact the academic supervisor for the study:

**Professor Jos Latour**



Phone: +44 (0)1752 586578



[jos.latour@plymouth.ac.uk](mailto:jos.latour@plymouth.ac.uk)

**Thank you again for your interest, time and consideration in being involved in this study.**

Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655



## Healthcare Professional Consent Form

### CONSENT FORM: Healthcare Professionals Patient Diaries in the PICU

Name of Principal Researcher: Fiona Lynch

Please initial box if you agree.

1. I confirm that I have read and understand the information sheet dated Sept 2016 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. If I withdraw my involvement prior to data analysis, I understand that any information gathered, related to my involvement, will be removed.
4. I understand that interviews will be conducted in a private place and that the information gathered will be treated confidentially and stored securely.
5. I understand that Ground Rules will be discussed and agreed by the participants of the focus group in order to respect and protect those participating.
6. I agree to take part in the above study.

**Thank You.**

_____	_____	_____
Name of HCP	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

## Appendix 4 Consent Forms

### Consent Form for Parents or Guardians

#### CONSENT FORM: Parent/Guardian

Patient Diaries in the PICU

Name of Principal Researcher: Fiona Lynch

Please initial box/es if you agree

1. I/We confirm that I/we have read and understand the information sheet dated Sept 2016 (version 1.2) for the above study. I/we have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I/we understand that mine and my family's participation is voluntary and that I/we am free to withdraw at any time, without giving any reason and without affecting medical care or legal rights.
3. If I/we withdraw my involvement prior to data analysis I/we understand that any information collected, related to my/our involvement, will be removed.
4. I/we understand that I will be contacted prior to the follow-up interview. I/we understand the reasons for this and agree to this happening.
5. I/we would like to be contacted by:
  - a. Letter
  - b. Email
  - c. Telephone call
6. I/we understand that interviews will be conducted in a private place and that the information gathered will be treated confidentially and stored securely.
7. I/we agree for my child/children to be approached to take part in the above study.
8. I/we agree to take part in the above study.

Thank You.

\_\_\_\_\_  
Name of Parent / Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Parent / Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Consent form Version 1.2 26<sup>th</sup> September 2016 IRAS project ID 140655

Consent/Assent Form for Index Child 4–7-year-old

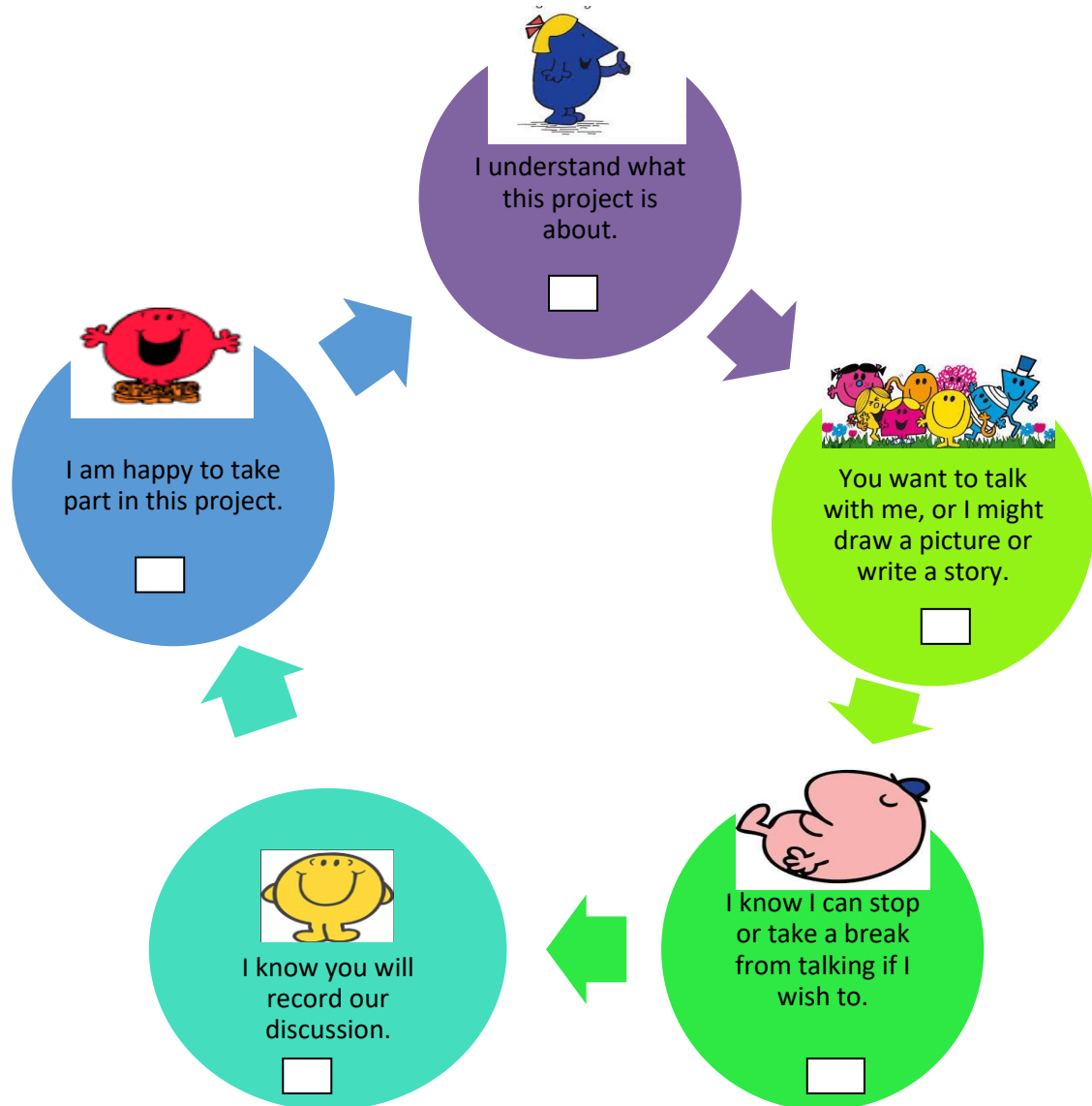
**Assent Form:**

**Patient Diaries in the PICU**

For all children aged 4 – 7 years old.



Please tick each of the small boxes if you agree.



If any answers are 'no' or you **don't** want to join in, **don't tick the boxes or write your name.**

If you do want to take part, please write your name and today's date.

Your name \_\_\_\_\_ Today's date \_\_\_\_\_

Your parent or guardian will write their name here too if they are happy for you to be part of the study.

\_\_\_\_\_  
Name of Parent / Guardian                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent                      Date                      Signature

**ASSENT/CONSENT FORM: Young Person**  
**Patient Diaries in the PICU**

Name of Principal Researcher: Fiona Lynch

**Please initial each box if you agree.**

1. I confirm that I have read and understand the information sheet dated Sept 2016 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. If I withdraw my involvement prior to data analysis I understand that any information gathered, related to my involvement, will be removed.
4. I understand that my family and I will be contacted prior to the follow-up interview. I understand the reasons for this and agree to this happening.
5. I understand that interviews will be conducted in a private place and that the information gathered will be treated confidentially and stored securely.
6. I agree to take part in the above study.

**Thank You**

\_\_\_\_\_  
Name of Young Person

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Parent / Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

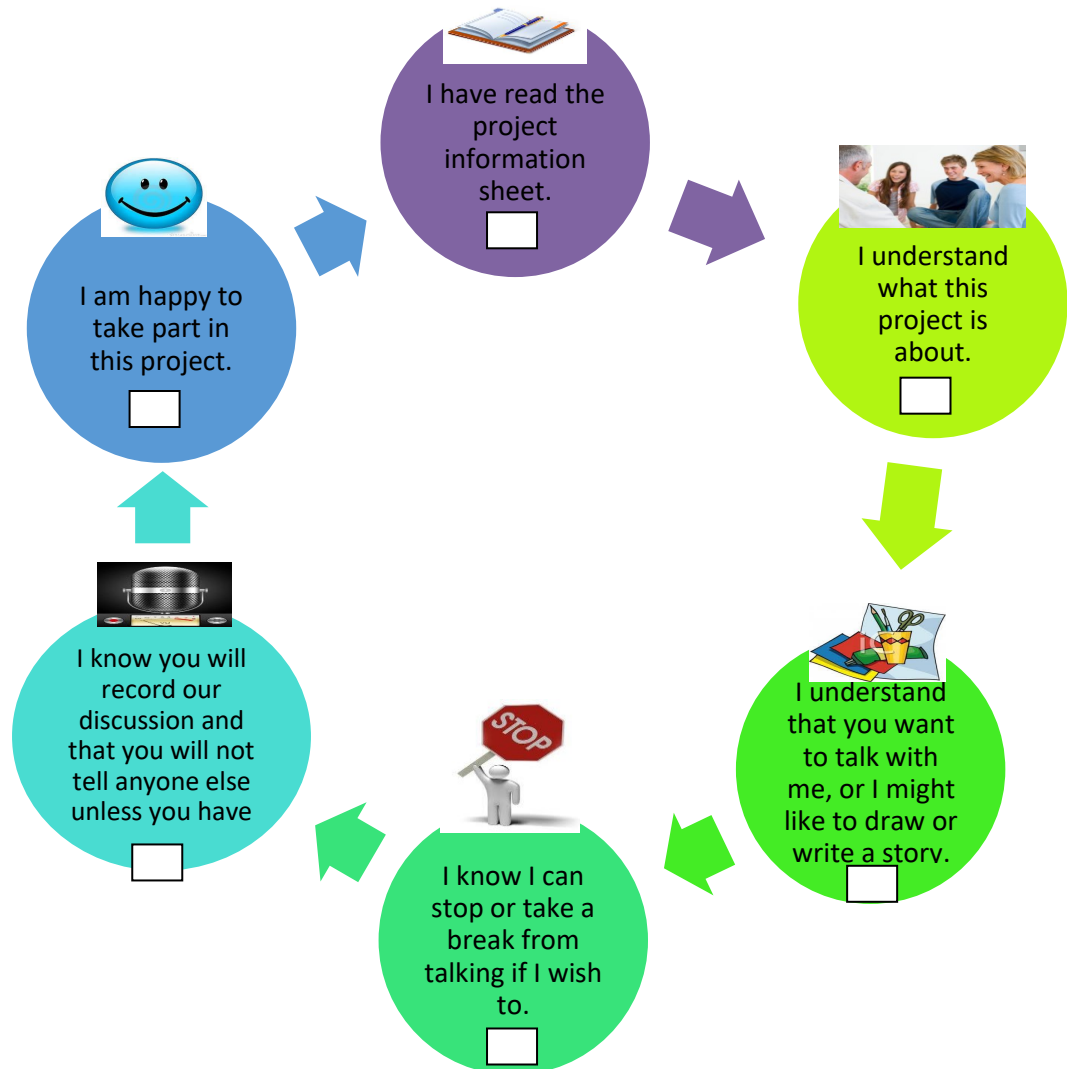
\_\_\_\_\_  
Signature

Consent/Assent Form Sibling 8-11 years old

Assent/Consent Form: Children aged 8-11 years.

Patient Diaries in the PICU

Please tick each of the small boxes if you agree.



If any answers are 'no' or you **don't** want to join in, please **don't tick the boxes or write your name**. If you **do** want to take part, please write your name and today's date:

Your name \_\_\_\_\_

Today's date \_\_\_\_\_

Your parent or guardian will write their name here too if they are happy for you to join the study.

\_\_\_\_\_  
Name of Parent / Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Appendix 5 Interview Guides for Families**

### **Interview Guide Adult Participant First Initial Interview**

#### **Interview Guide**

#### **1<sup>st</sup> Interview with adult participants**

##### **Setting**

- Quiet and private location- if possible free from distraction and noise.
- Not too far away from child/patient
- Led by participants

##### **Timing**

- At a mutually agreed time for the participants and researcher

##### **Equipment**

- Digital recording
- Consent form
- Tissues, refreshments
- Do not disturb sign
- Comfortable chairs
- Note pad and pens

##### **Opening**

- Introductions and re- iterate aims of study
- Confidentiality
- Ability to withdraw
- Additional resources

##### **Introductions**

Thank you for agreeing to take part in the study and for making the time to meet with me today.

I will introduce the study by highlighting I am interested in their views about the use of the diary for their child. I will include a statement that conveys to the participant/s that

what they say is important and relevant is what I would like to hear about. This will help me see any features that make the diary useful for children and their families during admission into the PICU.

If at any point in our discussions you wish to stop or take a break from talking please let me know.

Before we start are there any questions you would like to ask me

### **Interview Topics**

#### **Building understanding**

##### **Possible prompts;**

Could you begin by telling me about when (child's name) first came to the PICU?

Was (name child) already in hospital, what happened when you first got here?

#### **Initial Impressions of the diary**

##### **Possible prompts;**

Could you tell me about when you first heard about the diary?

Who spoke to you about the diary, what were your first thoughts?

#### **Diary use**

##### **Possible prompts:**

How have you used the diary during (name's) time here?

Have you put in any pictures/poems/stickers etc/ have you show it to family members/ the child/other family members.

Who writes in the diary?

Have you asked the staff any questions about what they have written/ how have you explained it to others?

Can you show me something from the diary?

#### **Perceived Value**

##### **Possible prompts:**

What do you think are the benefits?

How do you think the diary has been of use?

Could you show me any parts of the diary that you think are helpful?

Do you look at the diary? Some families have said.....have you found this?

Have you read any parts of the diary to others (who?)

### **Negative Connotations**

#### **Possible prompts:**

Is there anything that has not been helpful about the diary?

What reactions have you had?

What impact has reading the diary had on you?

Have you/what have you read anything that upset you?

Are there any parts of the diary that are a worry for you?

### **Diary examples/extracts**

#### **Possible prompts:**

Can we look together at a particular part of the diary?

Could show me to help me understand what you have said—i.e. tell me about any part your particularly enjoy reading/anything that means a lot to you?

### **Suggested improvements**

#### **Possible prompts:**

Is there anything else you would like to add?

### **What happens next?**

Thank you for taking part in the interview, as we discussed before I will now go away and start to write up the information from the tape and my notes.

I will be contacting you again in a few months' time for your follow up interview.

Provide the participant with:

1. My contact numbers
2. Details of further help and support
3. Next steps



## Interview Guide Child Participant

### Interview Guide

1st Interview with child participants

*This may be whilst admitted in PICU or after discharge home.*

*(5-6 months later)*

Adult/parents may also be present.

#### Setting

- Led by participants
- In an area that is location of choice for participants but where possible free from distraction and noise- may be in hospital setting and may be on PICU
- Conscious that the child/children may get tired very easily in the setting

#### Timing

- At a mutually agreed time for the participants and researcher

#### Equipment

- Digital recording
- Consent form
- Tissues, refreshments
- Drawing and writing equipment for the child
  - Toys, games, i-pad
- Comfortable chairs- patient will probably still be in on a hospital bed.
- Note pad and pens

#### Introductions

Thank you for agreeing to talk with me today.

Simply explain again the aims of the study and why I would like to hear what they think about the diaries.

If at any point in our discussions, you wish to stop or take a break from talking please let me know. You can press the stop button on the recorder or raise your hand if you want to stop or rest- we could practice that

Before we start are there any questions you would like to ask me?

#### Opening

- Introductions and re-iterate aims of study
- I will not tell anyone about what we talk about unless I'm worried about you or your family.

## Interview Topics

- **Warm up game**
  - **Have available games such as card games; pick a question**
  - **Game i.e., card game/ i-pad game**

## Topic Guide

### Initial Impressions of the diary

**Possible prompts:** Can you tell me about your diary that was made when you (your brother or sister was in hospital)?

What did it look like?

Do you remember anything about it that you could tell me about?

Could we look at the diary together?

### OR/AND

*Can you draw a picture/write me a story about the diary?*

*it can be about anything to do with the diary*

*Can you tell me about your picture/story?*

*\* May be used depending on age group*

### Perceived Value

#### **Possible prompts**

How do you think it has helped you?

What do you like about the diary?

When do you look at it?

Do you talk to your parents/siblings/family about what you have read/seen in the diary?

Can you show me something in your/your sibling's diary that is helpful?

### Negative Connotations

#### **Possible prompts**

Is there anything that has not been helpful about the diary?

What don't you like?

Is there anything that makes you sad/upset in the diary?

## **What happens next?**

Thank you for taking part in the interview, as we discussed before I will now go away and start to write up the information from the tape and my notes.

Provide the participant with:

- You can talk to your parents if you have any further questions for me.  
They have my:

Contact numbers

Details of further help and support

## **Appendix 6 Interview Guide for HCP Focus Group Interviews**

### **Interview Guide for HCP Focus Group Interviews**

## **Focus Group Guide**

### **Healthcare professionals**

#### **Setting**

- Private location
- Large enough to accommodate participants.

#### **Timing**

- At a mutually agreed time for the participants and researcher

#### **Equipment**

- Digital recording
- Consent form
- Tissues, refreshments
- Do not disturb sign.
- Comfortable chairs
- Flip charts/ sticky notes.
- Note pad and pens.

#### **Opening**

- Introductions and re-iterate aims of study
- Ground Rules
- Confidentiality
- Ability to withdraw
- Ice breaker exercise

#### **Introductions**

Thank you for agreeing to take part in the study and for making the time to meet with me today.

If at any point in our discussions, you wish to stop or take a break from talking please let me know.

Set the ground rules for the focus group

Ask the group to come up with the rules but ensure covers

- Mutual Respect
- Confidentiality
- All opinions valued

Before we start are there any questions you would like to ask me

### **Aim of Study**

The aim of this interview is to talk to them and explore their views and experiences of using the PICU patient diaries. The purpose of this study is to explore the views and experiences of the healthcare professional using patient diaries during an admission into the PICU.

- **Ice breaker exercises**

- "People Bingo"

- List of characteristics i.e., drinks tea rather than coffee etc
- Shout Bingo! - Prize for the winner

## **Interview Topics**

### **How are the diaries used by HCP?**

**Possible prompts** Who do you give the diaries to?

How and when are the diaries given out?

Is there anyone that you would not give the diary to?

What do you write in the diaries? Do you write using 1<sup>st</sup> or 3<sup>rd</sup> person?

Do you use any other methods of communication in the diaries e.g., drawings, stickers etc.?

How have they observed other staff members use the diaries? What have they observed about families when using the diaries

### **Perceived impact of diaries**

### **Perceived Value**

**Possible prompts:**

What do you think are the benefits?

Do you have any examples you can share?

What have others told you about the diaries?

How do you think the diaries might be helpful?

Do you have any examples of how you found the diary useful?

## **Negative Connotations**

Is there anything that has not been helpful when using the diaries?

**Possible prompts** Have any of you had any negative experiences using the diaries?

Have you read anything in a diary that made you concerned? Can you tell me about this?

Have you or anyone else raised any concerns about a diary/the diary? Can you tell me about this?

## **Other Factors**

**Possible prompts** Some families/staff members have told me ...(give examples)

what do you think about this?

Questions will be asked to the wider group. If the group are quiet or certain individuals dominate, then I may break the group into smaller groups and ask for group work on specific questions and then feedback to the wider group to generate ideas and discussions.

## **What happens next?**

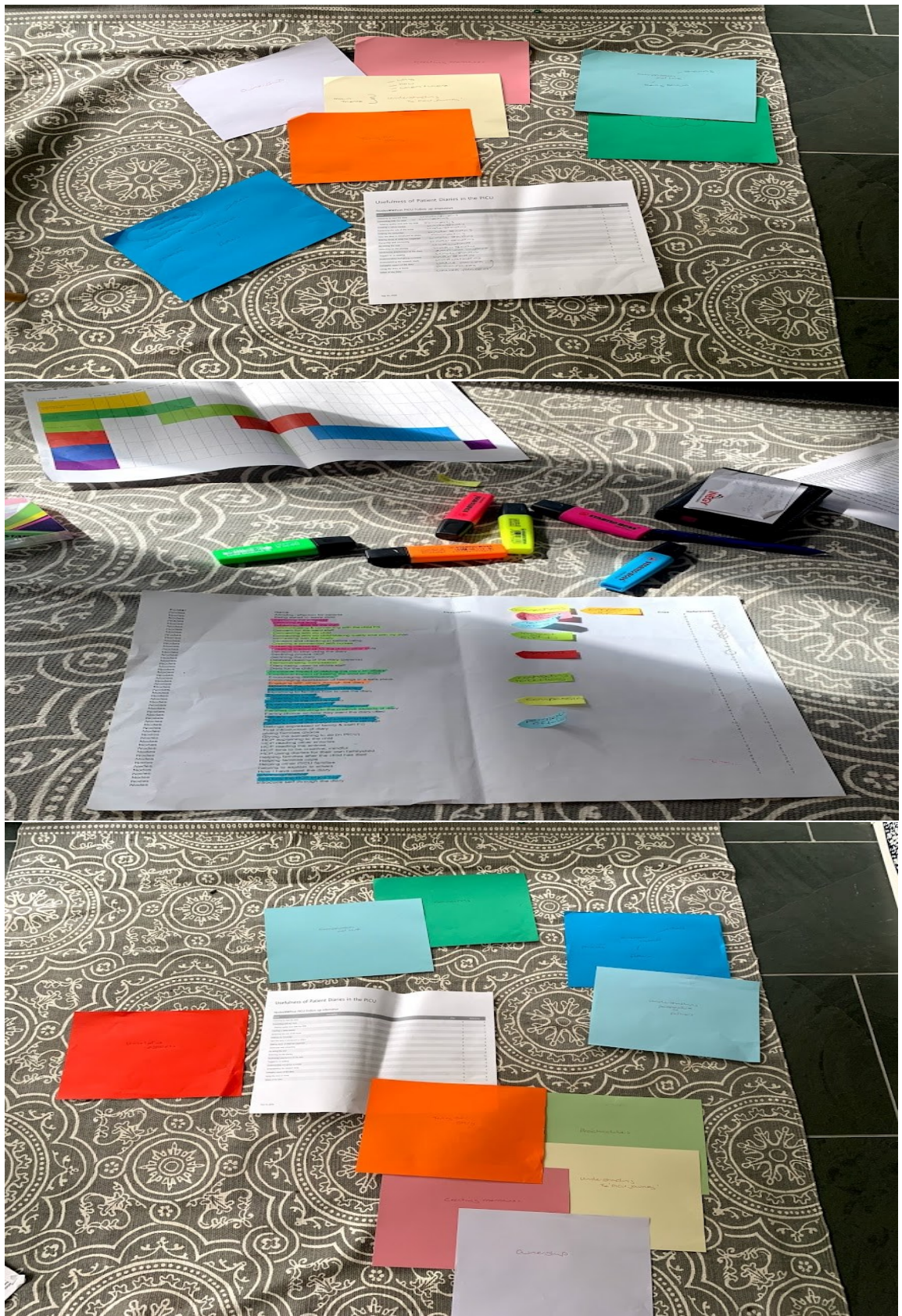
Thank you for taking part in the interview, as we discussed before I will now go away and start to write up the information from the tape and my notes.

Provide the participants with:

1. My contact numbers
2. Details of further help and support (if necessary- I will be sensitive to this and may approach individuals)
3. Next steps

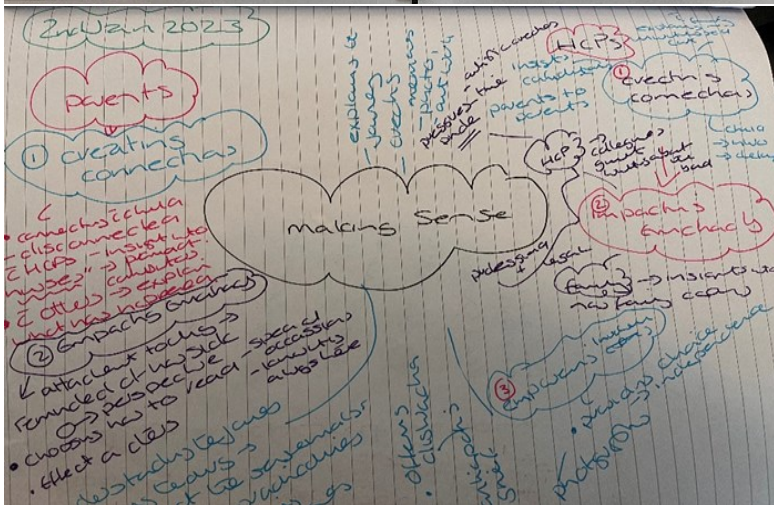
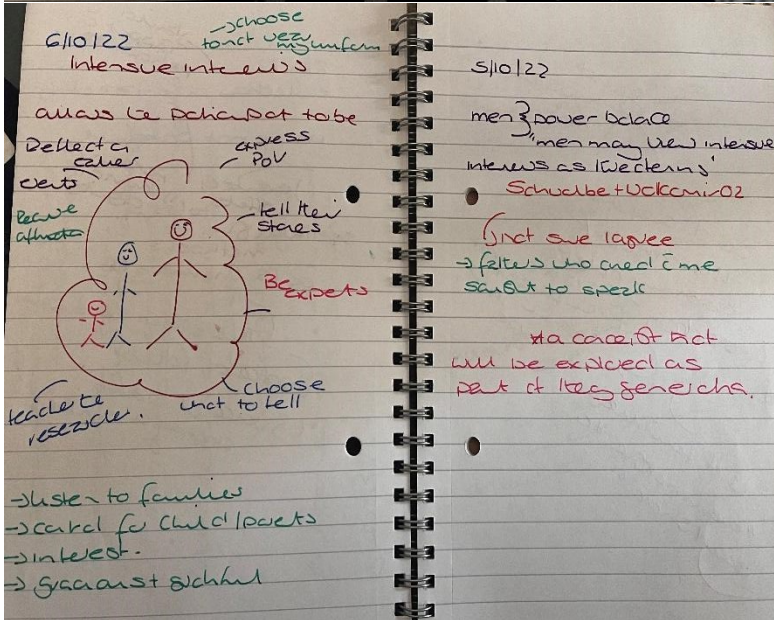
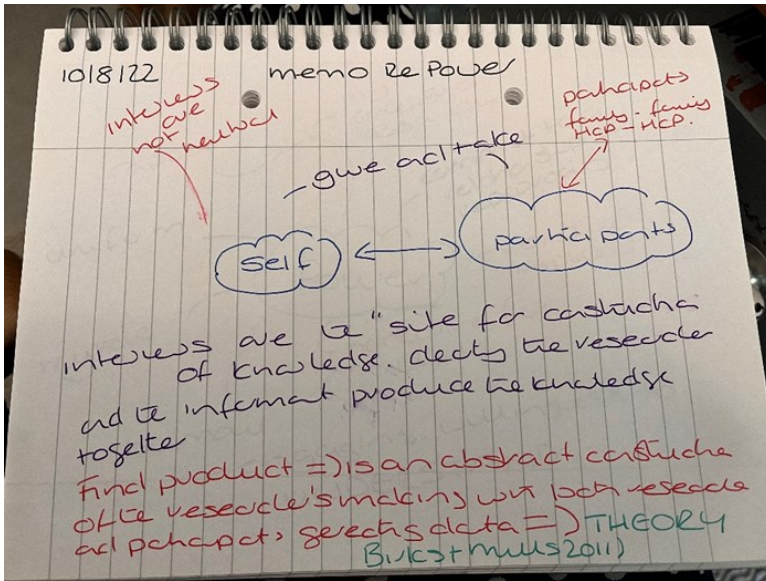
## Appendix 7 Manual Analysis Process

### Example of processes used to manually analyse data



Appendix 8 Memos

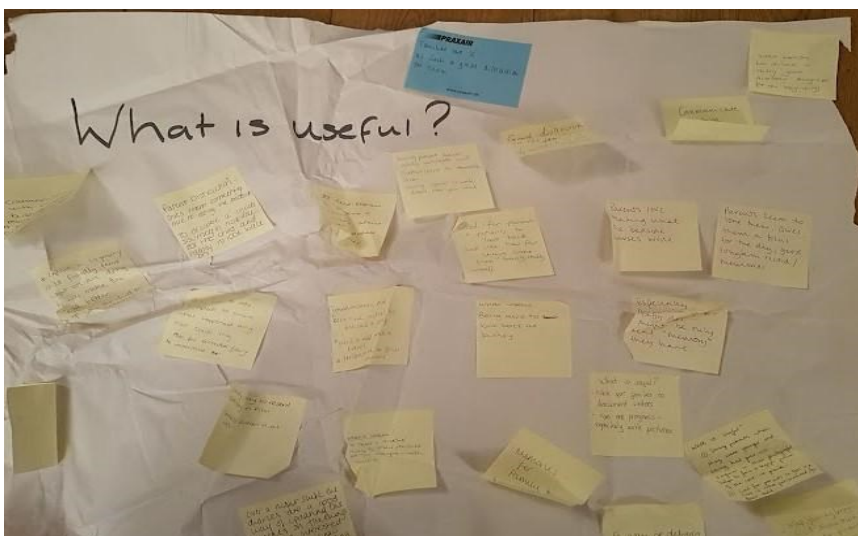
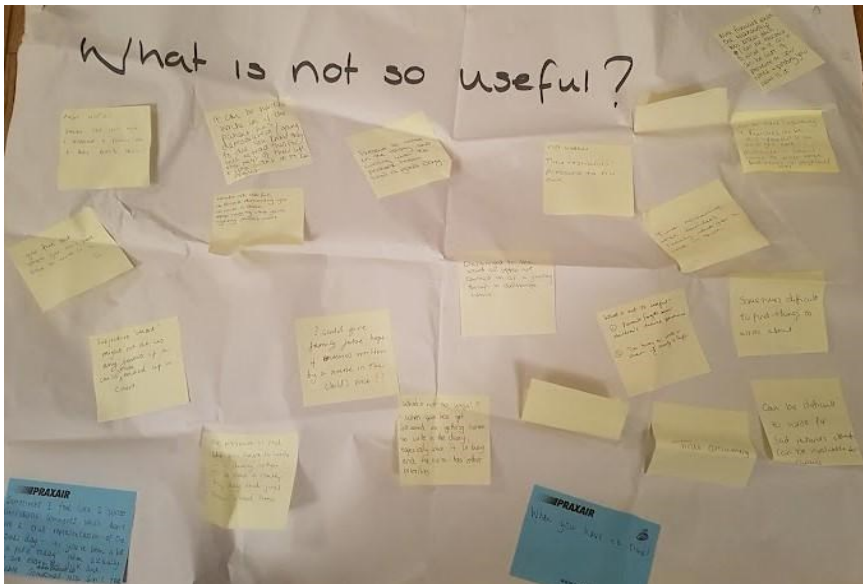
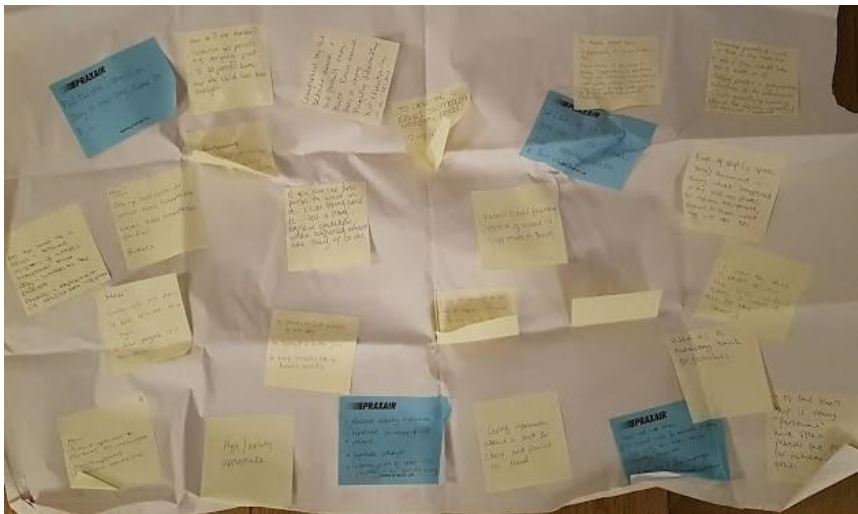
Examples of Memos Used Throughout the UPDATE Study





## Appendix 9 Focus Group Discussions

### Example of Sticky Notes Generated during the Focus Group Interviews.



## Appendix 10

### Approval Letters

#### Health Research Authority Approval Letter



## Health Research Authority

### London - West London & GTAC Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

21 December 2016

Professor Alison Metcalfe  
Florence Nightingale Faculty of Nursing and Midwifery  
57 Waterloo Road  
London  
SE1 8WA

Dear Professor Metcalfe

**Study title:** Exploration of how patient diaries are used by the the child, their family and health care professionals in the Paediatric Intensive Care Unit: A Grounded Theory Approach  
**REC reference:** 14/LO/2026  
**Amendment number:** SA#01  
**Amendment date:** 07 December 2016  
**IRAS project ID:** 140655

The above amendment was reviewed on 15 December 2016 by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Posters]	1.1	01 October 2016

Interview schedules or topic guides for participants [Adult participants interview]	1.1	29 September 2016
Interview schedules or topic guides for participants [Adult participants follow up interview]	1.1	29 September 2016
Interview schedules or topic guides for participants [Child participants 1st Interview]	1.1	29 September 2016
Interview schedules or topic guides for participants [Child participants 2nd Interview]	1.1	29 September 2016
Interview schedules or topic guides for participants [Focus group interview]	1.1	29 September 2016
Letter from sponsor [from Plymouth]		03 November 2016
Notice of Substantial Amendment (non-CTIMP)	SA#01	07 December 2016
Other [Sponsor letter]	1	03 November 2016
Other [Follow up letter]	1.1	26 September 2016
Other [CV Ruth Endacott]	1	01 October 2016
Other [CV Jos Latour]	1	01 October 2016
Other [Email from L Arnold]		
Participant consent form [Assent sibling 8-11 years]	1.1	26 September 2016
Participant consent form [Parent]	1.2	26 September 2016
Participant consent form [HCP]	1.2	26 September 2016
Participant consent form [Adult relative]	1.2	26 September 2016
Participant consent form [Assent 4-7 years sibling]	1.2	26 September 2016
Participant consent form [Assent 4-7 years index child]	1.2	26 September 2016
Participant consent form [assent young person index child]	1.2	26 September 2016
Participant information sheet (PIS) [HCP ]	1.2	26 September 2016
Participant information sheet (PIS) [Parent]	1.2	26 September 2016
Participant information sheet (PIS) [Adult relative]	1.2	26 September 2016
Participant information sheet (PIS) [8-11 years siblings]	1.1	26 September 2016
Participant information sheet (PIS) [8-11 years index child]	1.1	26 September 2016
Participant information sheet (PIS) [4-7 years index child]	1.1	26 September 2016
Participant information sheet (PIS) [4-7 years sibling]	1.1	26 September 2016
Participant information sheet (PIS) [Young persons siblings]	1.1	26 September 2016
Participant information sheet (PIS) [Young persons index child]	1.1	26 September 2016
Research protocol or project proposal	1.1	01 September 2016
Summary CV for Chief Investigator (CI) [CV Fiona Lynch]	1	16 November 2016

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>14/LO/2026:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Dr Catherine Urch**  
**Chair**

E-mail: NRESCommittee.London-WestLondon@nhs.net

*Enclosures:*                    *List of names and professions of members who took part in the review*

*Copy to:*                        *Miss Karen Ignatian, University College London Hospitals*  
*Mrs Barbara Dahill*

## Sponsor Letter from University of Plymouth

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

Ms Fiona Lynch  
Nurse Consultant  
PICU  
Elvina London Children's Hospital  
St Thomas' Hospital  
Westminster Bridge Road  
London  
SE1 7EH

Ms P Baxter  
Research Governance Specialist  
University of Plymouth  
(Peninsula Schools of Medicine and Dentistry  
And  
Faculty of Health & Human Sciences)  
The John Bull Building  
Plymouth Science Park  
PLYMOUTH  
PL6 8BU

Tel: + 44 (0) 1752 437326  
Mobile: + 44 (0) 7484869104  
Email: [pam.baxter@plymouth.ac.uk](mailto:pam.baxter@plymouth.ac.uk)

Dated: 3<sup>rd</sup> November 2016

Dear Ms Lynch

**Re: Study title: Exploration of how patient diaries are used by the child, their family and health care professionals in the Paediatric Intensive Care Unit: A Grounded Theory Approach**

**Chief Investigator:** Ms Fiona Lynch

**Collaborators:** Professor Jos Latour, Plymouth University

**IRAS Code:** 140655      **REC Ref:** 14/LO/2026

In line with the requirements of the Research & Governance Framework for Health & Social Care 2005 – and as amended to the **UK Policy Framework for Health & Social Care**, I am writing to confirm that the University of Plymouth will accept the transfer of Sponsorship for the above study, effective from 03/11/2016 subject to the terms highlighted below.

As Chief Investigator, you must ensure that you obtain the necessary ethical and regulatory amendment(s) and approval(s), to transfer the Sponsorship to the University of Plymouth before continuing the study.

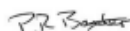
- Health Research Authority (HRA) REC Approval of Amendment (For transfer of Sponsorship)
- Pre-HRA Assessment Approval (As applicable).
- University Faculty of Health & Human Sciences Ethics Committee approval (Chairs Action).
- NHS R&D Capacity & Capability Approval (R&D Approval) for each collaborating NHS Trust site (where applicable).

Please comply with any additional requirements of the collaborating NHS Trust(s), within the remit of the Health Research Authority guidance, to enable access to the site(s) for the continuation of the study.

On full approval you are required to adhere to any monitoring and reporting conditions set within the remit of the regulatory authorities for; the University of Plymouth; NHS Trust(s); HRA and/or University collaborating sites, where applicable. On receipt of Health Research Authority REC Approval, University REC Approval and subsequent NHS Trust(s) R&D Capacity and Capability Approval(s), please send confirmation to the Sponsors Representative.

Please do not hesitate to contact me if you have any queries.

Kind Regards



**Ms Pam Baxter**  
**Research Governance Specialist**  
**And Sponsor Representative**

*For and on behalf of the Dean: Professor Trish Livsey*  
*Executive Dean Faculty of Health & Human Sciences*

Faculty of Health & Human Sciences  
403 Rolle Building  
Plymouth University  
Plymouth  
PL4 8AA

Tel: +44(0)1752 586740

Jane Newman  
Senior Personal Assistant to the Executive Dean: Professor Trish Livsey