

**Sheffield  
Hallam  
University**



## **'Marvellous Nurses'**

# **An independent evaluation of the role, impact and contribution of Roald Dahl Specialist Nurses**

**Report to**

**Roald Dahl's Marvellous Children's Charity**

**September 2021**

Sheffield Hallam University

Authors: Prof Julie Nightingale, Tanya Urquhart-Kelly,  
Lesley Saunders, Helen Monks, Dr Nancy Ali, Rachel  
Ibbotson and Dr Robin Lewis

## TABLE OF CONTENTS

EXECUTIVE SUMMARY .....	5
1. INTRODUCTION .....	9
1.1 Preface.....	9
1.2 Project Overview.....	10
1.3 Background to the Study .....	12
1.3.1 The evolution and development of the Clinical Nurse Specialist role .....	12
1.3.2 Cost-effectiveness of Clinical Nurse Specialist roles .....	13
1.3.3 The role of healthcare charities .....	14
1.3.4 Developing strategic partnerships .....	16
1.3.5 Family-centred care .....	17
1.3.6 Managing expectations in family-centred care .....	18
2. RESEARCH DESIGN .....	19
2.1 Aims .....	19
2.2 Objectives .....	19
2.3 Research Questions .....	19
2.4 Eligibility Criteria .....	20
2.5 Research Design .....	20
2.6 Ethical Approval and Research Governance.....	22
2.7 Research Methods.....	24
2.7.1 Design of semi-structured interviews.....	24
2.7.2 Design of focus groups .....	26
2.7.3 Design of lead clinician questionnaire .....	26
2.7.4 Design of parent and child surveys .....	27
3. RESULTS AND DISCUSSION .....	30
3.1 Being a Roald Dahl Specialist Nurse.....	30
3.1.1 Characterising the care need.....	30
3.1.2 Roles and responsibilities .....	34
3.1.3 Levels of practice .....	37
3.1.4 Professional values.....	40
3.2 Impact of Roald Dahl Nurses.....	41
3.2.1 Improved quality and experience of care.....	41
3.2.2 Improved efficiencies and cost-effectiveness .....	45
3.2.3 Provision of holistic family-centred care .....	47
3.2.4 Demonstrating leadership and innovation .....	50
3.3 Perceived Challenges.....	52
3.3.1 Organisational challenges .....	52
3.3.2 Achieving sustainable workloads and caseloads .....	55
3.3.3 Measuring impact .....	60

4. CONCLUSIONS AND RECOMMENDATIONS .....	64
5. REFERENCES .....	67
6. ABOUT THE AUTHORS .....	77
7. ACKNOWLEDGEMENTS.....	79

**LIST OF TABLES**

Table 2.1. Summary of the over-arching research design.....	21
Table 2.2 Ethical approval confirmations.....	22
Table 2.3 Stakeholder groups accessed within the evaluation.....	24
Table 3.1 Levels of children and young people’s agreement and disagreement with Roald Dahl nursing activities.....	43

**LIST OF FIGURES**

Figure 1.1 Locations and specialisms of the participating Roald Dahl Nurses.....	11
Figure 2.1 Mixed methods exploratory research design.....	21
Figure 2.2 Guiding research questions and topics.....	25
Figure 3.1 Discussion themes.....	30
Figure 3.2 Visual representation of parental responses to eleven statements in the Impact on Families scale (IOFS-11).....	32
Figure 3.3 Number of school days missed due to the child's condition during the last school year.....	33
Figure 3.4 How Roald Dahl Nurses transition through novice practitioner to established roles.....	35
Figure 3.5 Four zones of impact embraced by Roald Dahl Nurses.....	41
Figure 3.6 The overall satisfaction of parents with the care received from the Roald Dahl Nurse.....	43
Figure 3.7 Parents’ views of whether unscheduled contact with the Roald Dahl Nurse has previously averted the need to access emergency and urgent services for their child.....	46
Figure 3.8 How Roald Dahl nursing caseloads evolve over time.....	58

## LIST OF ABBREVIATIONS

A&E	accident and emergency	IOFS	Impact on Family Scale
ACP	advanced clinical practitioner	IRAS	Integrated Research Applications System
CNS	clinical nurse specialist	LTC	long-term conditions
CPD	continuing professional development	MDT	multi-disciplinary team
CQC	Care Quality Commission	NHS	National Health Service
CYP	children and young people	NICE	National Institute of Clinical Excellence
DoH	Department of Health	NIHR	National Institute of Health Research
EHC	Education, Health and Care plan	REC	Research Ethics Committee
ESN	epilepsy specialist nurse	RCN	Royal College of Nursing
GP	general practitioner	R&D	Research and Development department
HEE	Health Education England		
HRA	Health Research Authority		
IFNA	International Family Nursing Association		

## **EXECUTIVE SUMMARY**

### **1. Background**

The strategic aim of Roald Dahl's Marvellous Children's Charity is *“to improve the healthcare outcomes and resilience of seriously ill children and their families living with complex, lifelong, and under-funded conditions”*. The Charity has committed significant investment over the last three decades to support these children and their families, establishing 80 innovative nursing roles in 39 partner NHS Trusts and Health Boards. These specialist children's nurses are known as 'Roald Dahl Specialist Nurses'.

### **2. Project Brief**

To better understand the contribution of Roald Dahl Specialist Nurses to children's healthcare, this project has been commissioned to independently evaluate, from the perspectives of multiple stakeholder groups, the role and impact of the Roald Dahl Specialist Nurses.

### **3. Study Population**

Twenty-one Roald Dahl Specialist Nurses were included in the evaluation, representing 14 NHS Trusts and Health Boards across the UK. One third of the nurses were based in specialist children's hospitals, while the remainder worked in NHS Trusts and Foundation Trusts. The nurses worked across eight different clinical specialties with the most commonly encountered roles relating to epilepsy and non-malignant haematology. Nurses also worked in rare diseases, neurology-related specialties, gastroenterology and child to adult transition services. Regardless of the specialty, the 'golden thread' connecting the Roald Dahl Specialist Nursing roles was that the children and their families looked after within their services were living with serious lifelong conditions. These conditions included progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability.

### **4. Methodology**

The project utilised a three-phase Mixed Methods Exploratory design, combining both qualitative and quantitative data collection; these multiple approaches strengthen the study compared to using one method alone. In the first phase, data collection from healthcare staff was triggered at each hospital site when the Roald Dahl Specialist Nurse had been in post for at least 18 months. The second phase involved a survey of service users in the caseload of Roald Dahl Specialist Nurses. The data from each phase was analysed separately and then merged using a triangulation protocol process. Key findings which resonated across the phases were then discussed.

## **5. Phase 1 - Interviews with Nurses and Managers**

In-depth semi-structured interviews with Roald Dahl Specialist Nurses (n=20) and their managers (n=15) were undertaken by registered children's nurse researchers to enable deeper exploration of professional issues and challenges. Scheduled to take place at the participant's workplace, some later interviews were hosted online due to Covid-19 restrictions. Interviews were analysed using a constructivist grounded theory methodology. Four main categories were identified with nine sub-themes, which illuminate the working world of the Roald Dahl Nurse: *Becoming a Roald Dahl Nurse; Being a Roald Dahl Nurse; Impact of the Roald Dahl Nurse, and Challenges and Solutions.*

## **6. Phase 1 - Focus Groups with Nurses**

Initial findings from the interviews informed four focus groups with the nurses to explore two emerging themes. One theme related to the challenges of defining and managing patient caseloads. The second theme reviewed the diverse roles of the Roald Dahl Specialist Nurses and explored how they may fit into an advanced or specialist practice model of nursing. The focus groups were undertaken with approximately 10 participants in each group, with the findings analysed thematically. The findings provided insight into how caseloads evolve over time, strategies to maintain safe workloads, and how the nurses transition from being novices to more established practitioners. Illustrations of the impact and value of the role were also collated.

## **7. Phase 1 - Online Questionnaire with Lead Clinicians**

An online questionnaire was sent to the lead clinician for the service in which the Roald Dahl Specialist Nurses worked. Clinicians (n=17) completed the questions on behalf of the wider multi-disciplinary team, articulating how and why the business case for the role had emerged, and what difference the role had made to children and their families. Clinicians were overwhelmingly positive about the impact that the Roald Dahl Specialist Nurse had made to their service, and suggested other areas of care that could benefit from a similar role. Many clinicians confirmed that the nurse's caseload had expanded since appointment to the role, and some felt this was unsustainable in the longer term. While many could not see how their service could function effectively without the nurse in place, a few had concerns regarding the impact of financial austerity now and in the future.

## **8. Phase 2 - Survey of Parents and Carers**

Findings from Phase 1 informed the development of an online parental survey in Phase 2. The aim was to understand, from the perspective of parents and families, the nature of their child's condition and its impact on the family, to explore the nature of the care received and the potential impact of having access to a Roald Dahl Specialist Nurse. The survey incorporated the validated Impact on Family Scale (IOFS-11) designed to measure the impact of non-specific childhood chronic illness on the family.

One hundred and fifty-nine parents completed the survey, with 86.8% indicating they were the child's mother; 36 children and young people also completed a survey. Many of the children had complex conditions with over one quarter requiring 'round-the-clock' care. The child's condition had a marked impact on the daily lives of the family, including impacts on work, finances and daily life. The Roald Dahl Specialist Nurses had a significant impact on the families; nearly three quarters of the parents had needed to contact them at least three times in the last year in addition to scheduled appointments. Timely contact with the Roald Dahl Specialist Nurse had averted visits to A&E on at least one occasion for 42.3% of parents, with at least one emergency admission to hospital averted for 37.5% of parents. This contact had also averted the need for urgent GP appointments on several occasions (40%), with over half of parents (52.7%) indicating that consultant appointments had also been avoided. Particularly valued services were '*being a point of contact and coordinating my child's care across hospital services*' and '*providing advice regarding changes in my child's health status*'. However non-clinical aspects of care were even more highly praised, including '*providing emotional support for myself or my family*' and '*advocating to other authorities or individuals*'. Parents described the huge difference that the nurses made to their own, their child's and their family's lives, rating 9.47/10 in overall satisfaction of the care they received. Many commented that their nurse was "amazing", "appreciated", "a godsend", "invaluable", "incredible", and "worth their weight in gold". Children were also positive about engaging with their Roald Dahl Specialist Nurse, with 88% stating that their nurse was friendly and two thirds (66.7%) 'agreeing a lot' that they liked visiting their nurse. Older children and young people recognised that their nurse included them in treatment decisions and helped them to be more accepting and independent in managing their condition.

## **9. Phase 3 - Mixed Methods Integration and Discussion**

The findings were integrated into three sections: *A profile of Roald Dahl Specialist Nurses*; *The impact of Roald Dahl Specialist Nurses*, and *Perceived Challenges*. The role was shown to have a number of unique features, more akin to an Advanced Clinical Practice descriptor than a Clinical Nurse Specialist role. The nurses, regardless of their specialty or setting, demonstrated a clear family-centred care philosophical approach to their work, forging networks across inter-agency boundaries to safeguard the child and family and to enhance the family experience of care. Helping families to be safe and supported in these other aspects of their lives ensures that the healthcare that is delivered has the maximum impact. Impact was further categorised into four sections: *Improving quality and experience of care*; *Improved efficiencies and cost-effectiveness*; *Provision of holistic family-centred care*; *Demonstrating leadership and innovation*. Stakeholders provided examples of impact including improved patient and family experience, more responsive and flexible services, new service initiatives such as helplines, nurse-led clinics and improved transition pathways, and safeguarding children and families by improved inter-agency working.

Many services identified improvement in metrics such as reduced waiting times, A&E visits, hospital admissions and duration of stay, with some evidence of cost efficiencies.

## **10. Conclusions and Recommendations**

This research has categorised the depth and breadth of the role played by the Roald Dahl Specialist Nurses; a unique role that goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for patients and their families. The Roald Dahl Specialist Nurses require a particular skill set beyond their clinical expertise to equip them for this role, including the core attributes of being passionate, empathetic and motivational, and having professional excellence, patient advocacy, empathy, proactivity, enthusiasm, resilience and team spirit. Innovation was a key driver for all of the nurses and this yielded new ways of working to improve patient experience and outcomes. It is evident throughout this research that the Roald Dahl Specialist Nurses, regardless of their specialty, location, organisation or service focus, have a profoundly positive impact on the stakeholders around them.



## 1. INTRODUCTION

### 1.1 Preface

Roald Dahl believed in the importance of children and in helping them overcome life's toughest challenges. He was one of the world's most imaginative and loved storytellers and he left a marvellous legacy - Roald Dahl's Marvellous Children's Charity.

Roald Dahl's Marvellous Children's Charity, which provides specialist nurses and support to seriously ill children, was established in 1991 by Roald Dahl's widow Felicity, shortly after his death. Today, there are 80 Roald Dahl Specialist Nurses caring for over 21,000 seriously ill children across the UK<sup>1</sup>.

Roald Dahl Specialist Nurses are a vital lifeline to the children and their families, supporting them clinically and emotionally. The Charity supports children and young people affected by complex, lifelong illnesses that are under-funded, under-resourced and under-recognised including rare diseases, sickle cell anaemia, neuro-muscular conditions and epilepsy. The Charity also supports children and young people as they move from children's to adult services<sup>2</sup>.

Following a rigorous application and interview process, successful NHS Trusts and Health Boards can secure a Roald Dahl nursing post. Roald Dahl's Marvellous Children's Charity uses a pump-priming model and fundraises for the first two years of the Roald Dahl Specialist Nurse's salary and the NHS funds thereafter. This has been a successful model with almost all Roald Dahl Specialist Nurse posts retained since the Charity started establishing nurses in 1992.

Local service evaluations and audits have demonstrated the roles to be innovative, effective and well-received by various stakeholders, but by their nature such evaluations are designed primarily for local dissemination, rather than sharing on a wider scale. In order to better understand the contribution of Roald Dahl Specialist Nurses to children's healthcare, thus informing future investment strategies, this project was initiated to independently evaluate the impact and contribution of Roald Dahl Specialist Nurses. Sheffield Hallam University was commissioned in late 2018 as the Higher Education Institution partner to undertake this mixed methodologies research project on behalf of the Charity, and this report presents analyses of the study findings.

---

<sup>1</sup> Eighty per cent of the nursing posts are located in NHS Trusts in England, with several posts located in health boards within Scotland (10%), Wales (9%) and Northern Ireland (1%).

<sup>2</sup> Just over half of these posts are focused on assisting children living with epilepsy, with approximately 18% of posts in haematology and 18% in the neurology field. Posts have also been supported in other specialties including gastroenterology, rare diseases, palliative care as well as a play specialist. More recently a commitment has been made by the Charity to support investment into posts related to 'transition of care', the often complex challenges associated with moving children with chronic and serious conditions from children's to adult services.

## 1.2 Project Overview

This project provides an independent assessment of the role and impact of Roald Dahl Specialist Nurses on both the teams that they work with, and on the children, young people and families on their caseload. The project was led by Prof Julie Nightingale and was supported by a field research team of experienced educators who are registered children's nurses (Helen Monks, Tanya Urquhart-Kelly and Lesley Saunders). Dr Nancy Ali and Rachel Ibbotson have also both supported data collection and analysis, and Dr Robin Lewis has supported study design, data analysis and report writing.

The aim of this project was to explore, from the perspectives of multiple stakeholder groups, the role and impact of Roald Dahl Specialist Nurses. Twenty-two services delivered by Roald Dahl Specialist Nurses were eligible to take part in the research, however one NHS Trust subsequently declined to participate due to the impact of the Covid-19 pandemic.

The locations and clinical specialties of the remaining 21 Roald Dahl Specialist Nursing services included in the study are shown in Figure 1.1. The nurses represented 12 NHS Trusts in England, one in Wales and one Health Board in Northern Ireland. Seven out of the 12 English Trusts were based in Greater London and the South East. Seven of the nurses were located at renowned specialist children's hospitals, including Alder Hey (Liverpool), Birmingham Women and Children's Hospital, and Belfast Hospital for Sick Children, while the remainder worked in mixed adult / paediatric NHS Trusts and Foundation Trusts.

The nurses worked across eight different clinical specialties with the most commonly encountered roles related to epilepsy (n=5) and non-malignant haematology including sickle cell and thalassaemia (n=6). Nurses were also delivering services related to: rare diseases (n=3), neurology (neuro-disability=1; neuromuscular=2; neurosurgery=1), gastroenterology (n=1) and child to adult transition services (n=2).



**Figure 1.1 Locations and specialisms of the participating Roald Dahl Specialist Nurses**

The role and impact on the clinical service provided by the 21 Roald Dahl Specialist Nurses was investigated via a three-phase mixed methods research approach (containing both qualitative and quantitative methods). The methods are outlined in Chapter 2. Phase 1 data collection (healthcare staff) was primarily undertaken via semi-structured interviews with nurses and managers. This was supplemented by focus groups to explore emerging topics with the nurses, and online questionnaires with the lead clinicians (generally consultant paediatricians) for each service, to provide a multi-disciplinary team perspective. Phase 2 data collection (service users) was via an online survey of parents and children in the caseload of the Roald Dahl Nurses. The detailed findings from both phases are detailed in the Appendices. The findings from each phase of the research were compared and contrasted in phase 3 and the merged results are discussed in Chapter 3. Conclusions and recommendations are outlined in Chapter 4.

### **1.3 Background to the Study**

It is acknowledged in the literature that there are a number of key determinants that impact the health of children and young people (CYP) in the United Kingdom (UK). Due to advances in obstetric and paediatric medicine, increasing numbers of CYP are now surviving previously unsurvivable or significantly life-limiting conditions. The way that health services are organised is therefore a crucial aspect of ensuring a good quality of life for these CYP and their families.

The Kennedy Report *Getting it right for children and young people*, published in 2010, highlighted that there were a number of specific issues that needed to be addressed to improve the health outcomes for all CYP. One of the key issues that Sir Ian Kennedy identified in his report was the need for improved co-ordination and integration of children's services. The subsequent *Report of the Children and Young People's Outcomes Forum*, published in 2012 by the Department of Health (DH), built upon the findings from the Kennedy report, outlining a number of key priorities and introducing the establishment and implementation of family-centred care. In response to this, one of the priority recommendations was an emphasis on the importance of the Clinical Nurse Specialist (CNS) role in the delivery of high-quality care for CYP.

#### **1.3.1 The evolution and development of the Clinical Nurse Specialist role**

The CNS role has been in existence in various guises since the 1950s. The first reference to a paediatric CNS is found in the 1960s in the United States (US). Since then, the role has evolved and developed in the US, Canada, Australia, and the UK. Confusion exists in the UK literature over where the CNS role resides (Leary et al., 2017), particularly due to a degree of ambiguity in relation to the Advanced Clinical Practitioner (ACP) role. There is significant overlap between the two roles in terms of the type of clinical activity and the level at which this activity takes place, although there is an expectation that a CNS will have more disease-specific specialist knowledge than an ACP. Paradoxically, the ACP role requires master's level education whereas the CNS role does not. There is an ongoing debate over the relative benefits of the ACP and CNS roles in patient care, and this will inevitably form part of the discussion within this study.

For the purposes of this introduction, the term CNS will be used in relation to the Roald Dahl Specialist Nurses. There have been numerous systematic reviews over the years (Kilpatrick et al., 2014; Watts et al., 2014; Caird et al., 2010; Campbell et al., 2019; Randall et al., 2017) that have looked at the contribution of the CNS role to patient care, concluding that the CNS role provides high levels of patient satisfaction, quality care, and a reduction in length of hospital stay. Having reviewed the available evidence, the importance of the CNS role in the care of CYP is clear and unambiguous, providing safe, effective, and high-quality patient care. With complex conditions, care is often disjointed and fragmented, involving the input of a variety of health professionals with different roles and in different contexts. Evidence shows that the CNS role can

save resources, leading to greater efficiency and better outcomes (RCN, 2010). This may be achieved through improved coordination of services (Vidal et al., 2011), the provision of information and emotional and psychological support, as well as providing expert clinical and technical input. The benefit of the CNS role to the NHS (and CYP in particular) is that they are highly skilled in these higher-level, more strategic activities and are therefore able to coordinate the different parts of the system to enable them to work together, better (Read, 2015). The fact that the CNS works strategically across different teams means that their experience may be invaluable to senior management as they can advise on the specific nature of service provision to inform service redesign.

### **1.3.2 Cost-effectiveness of Clinical Nurse Specialist roles**

CNS roles come at a significant cost, and it is clear that the current healthcare system has faced significant challenges in supporting and justifying the CNS role. While it may be an attractive proposition, the evidence base for the cost-effectiveness of the CNS role is limited. The care typically provided by the CNS for their patients is complex in nature, which makes it difficult to objectively measure empirical outcomes and impact, or make comparisons between CNS roles in different organisations. Most evidence is therefore related to a single service operating within a single centre, indeed CNS efficiency savings of four Roald Dahl Specialist Nurses working in children's epilepsy services have previously been showcased via individual case studies (Roald Dahl's Marvellous Children's Charity, 2021).

A systematic review of the cost-effectiveness of CNS interventions in outpatient care settings (Kilpatrick et al., 2014), shows reduced costs and resource use compared to usual care, together with consistent evidence of improved patient reported outcomes and largely similar healthcare system outcomes. However there is little published evidence related to the long-term cost implications of the CNS role, or objective assessments of cost benefits.

In the short term, pay costs often increase due to the establishment of a CNS role, yet healthcare costs could be off-set over a longer period of time due to interventions leading to a decrease in preventable adverse events such as unscheduled admissions. Unfortunately the methodology used to calculate costs in many reviewed studies is variable and not clearly described, which will inevitably affect the final conclusions being drawn (Lopatina et al., 2017). Although seven out of 13 economic analyses reported some level of cost-effectiveness, four were inconclusive and two concluded that the intervention was actually more expensive. Overall, the evidence regarding the cost-effectiveness of CNS interventions 'across the board' is inconclusive (Lopatina et al., 2017; Kilpatrick et al., 2014).

Macmillan Cancer Support, one of the largest charities currently funding CNS posts in the UK, estimated in 2012 that sustaining the CNS role in adult cancer care cost the NHS an additional £20 million per year in staff time costs alone. In the current challenging economic climate, due to the impact of Covid-19, there is a real danger that care providers as well as NHS Trusts and Health Boards will reduce 'higher end' staffing costs by freezing CNS vacancies in order to achieve short-term savings, without consideration of the risk to patient care and the longer-term cost implications of their actions.

The voluntary or third (charity) sector will undoubtedly continue to play a vital part in supporting the delivery of public services, particularly in implementing innovative business models to fund activity that would otherwise be considered 'desirable but not essential' by senior NHS management (King's Fund 2017). Eftekhari et al. (2015) described the development of their business model for funding new CNS posts. Working in partnership with British Heart Foundation (BHF), they noted that even with the success of similar, already established posts, gaining approval for further posts was difficult. The authors described the need for engagement with business and finance managers. They captured data on income generation and cost benefits, clinic attendance numbers and patient satisfaction over the two-year period of BHF funding. The number of outpatient appointments was used to calculate outpatient department income. The authors were able to demonstrate a significant increase in service provision and therefore income as a result of the deployment of a CNS post; sufficient to cover the cost of the post.

### **1.3.3 The role of healthcare charities**

In recent years, several common factors have played a role in influencing the context in which charities work and the contribution they make. These factors include:

- The impact of economic recession and subsequent periods of austerity
- Health and social care reforms
- Changes in how charities are represented in public policy
- Social and demographic changes in the population.

As the King's Fund (2017) note, the way in which charities have historically adapted to these changes, and led responses to them, has given them an increasingly pivotal role in supporting and maintaining the health and social care system. Establishing a CNS role has become one identifiable and practical way in which health charities can play a role in supporting healthcare delivery. Many high-profile healthcare charities establish CNS posts (e.g. Macmillan Cancer Support, Marie Curie, BHF, Diabetes UK) however, the impact of the COVID 19 pandemic upon charitable incomes and the ability to deliver the necessary investment required is yet to be fully realised.

If we use Macmillan Cancer Support as an exemplar for the successful financial support and implementation of their CNS posts, the evidence identifies that there are several key characteristics that any successful, long-lasting implementation will possess. These characteristics are primarily concerned with the formation and maintenance of partnerships between the charity and the healthcare organisation. The formation of partnerships provides a number of advantages to both the charity and the organisation with which it works. At a basic level, their pump-priming model for establishing CNS posts may be seen in terms of (1) establishing trust, (2) spreading the financial risk by offsetting the need for the NHS to provide any up-front financial commitment. When reviewing the work of other charities, however, there is little empirical evidence of the relative effectiveness of different approaches to the provision of investment. The vast majority of successful UK charities now establish a CNS type role in their particular sphere of healthcare activity. Most, if not all, appear to use the 'pump-priming' model of support.

For example, Macmillan Cancer Support provide funding for both new posts and 'adopt' existing posts under threat; the most up-to-date figures suggest that Macmillan have funded in excess of 3,500 CNS posts. Macmillan typically fund the posts for three years (or less) before the partner organisation takes responsibility for the continuing support of the role. The adopted CNS is still referred to as a 'Macmillan Nurse' and they retain this title even when all charitable funding ends. In effect, there is a two or three year period in which the NHS or other care provider (and by extension the patient) are able to benefit from the role without any additional outlay. Since the charity funds the start-up period, and any costs incurred during the development of the role, the NHS will benefit from a CNS that is already embedded within a team and 'up and running' by the time the NHS is required to take over financial responsibility. In addition, the partner organisation benefits from the kudos of having a 'Macmillan Nurse' in its team and the resultant goodwill that is generated.

These successful partnerships have a number of additional, 'value-added' benefits for both the charity and the organisations with which they work, for example, supporting a successful 'outreach' approach, in which charities support and develop existing services designed to engage with marginalised populations. There is also evidence of partnerships being formed in relation to specific projects, for example where a charity proactively sought to work with another organisation as a means of directly or indirectly fulfilling the aim of the charity, and addressing the needs of the population it supports.

Charitable organisations are able to successfully mobilise (and coordinate) expertise in their own particular area; the clinical and professional workforce in the NHS and social care are often featured as a key stakeholder group with which to influence and network (King's Fund, 2017). There is some evidence that successful charities develop partnerships with academic organisations both to support the evaluation of programmes and projects, and to test and disseminate novel approaches developed within the academic sector that may be beneficial to the populations they serve.

#### ***1.3.4 Developing strategic partnerships***

The King's Fund (2017) identified that successful charities operating at a local level often also contributed to a wide range of strategic bodies at national level, particularly those focused upon marginalised groups. It was apparent that these successful charities were increasingly playing a higher-profile leadership role within their spheres of influence; for example, by bringing together organisations with a common interest to share good practice, coordinating action to drive change and developing joint bids for funding. Successful charities that operated at a UK level demonstrated a proactive approach to strategic leadership. Typically, they were involved in partnerships aspiring to raise awareness and advocate changes to policy, including:

- Providing insights to policymakers and government
- Sharing best practice with partners and stakeholders
- Enabling engagement with target populations and hard-to-reach communities.

As a high-profile charity, Macmillan Cancer Support demonstrate this through their work in strategic partnership with the Department of Health and Social Care (and its equivalents in Scotland, Wales, and Northern Ireland). Their aims include developing and improving the current cancer CNS workforce, to make the role more fit for purpose and to increase cancer CNS skills through the provision of CPD education and training. Part of this work is strategic, in that it is focused upon enabling (and therefore influencing) clinical teams, commissioners and health and social care providers to understand and evaluate the contribution and impact of the CNS role in cancer, as they plan their local workforce and service improvement strategies. This is clearly demonstrated by the fact that Macmillan also contributed to a UK-wide economic analysis of CNS posts required to meet the needs of all cancer patients. The results showed significant potential savings for the NHS if workforce gaps were filled (Department of Health, 2010).



It is clear from the evidence that the CNS role is particularly suited to the care of patients with long-term conditions (LTC) such as sickle cell disease or epilepsy. The ability to form longstanding and therapeutic relationships with the patient and their support network is invaluable in enabling the patient to deal with an often complex set of circumstances. Managing LTCs depends on the negotiation of a mutually beneficial partnership between the patient (and families as appropriate) and health professionals (Collins et al., 2007; Entwistle, 2010; Smith et al., 2015) that fosters collaborative decisions and care management (Kitson et al., 2013; O'Grady & Jadad, 2010).

### **1.3.5 Family-centred care**

Where the patient with a long-term condition is a CYP, the partnership with health professionals needs to be family focused. While children clearly have the right to be involved in all decisions that affect them (United Nations, 1989), parents/carers are likely to be both advocates and the primary care giver for their child and will play a key role in negotiating their child's care needs (Boshoff et al., 2016). Family-centred care may be conceptualised as the delivery of care that supports individuals within their family unit. The core components of family-centred care are developing an effective relationship with the family and health professionals working collaboratively with them when planning and delivering care for the CYP (Kuo et al., 2011). However the findings from two systematic reviews on family-centred care have highlighted a lack of evidence in terms of measurable outcomes to support its practice (Shields et al., 2012; Watts et al., 2014).

The Institute for Patient and Family-Centered Care (IPFCC) has proposed a widely accepted definition of patient and family-centred care as an *'approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families'*.

The IPFCC definition consists of four precepts:

- **Dignity and Respect:** health professionals listen to and value patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing:** health professionals communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation:** patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration:** patients, families, health professionals, and hospital leaders collaborate in policy/program development, implementation, and evaluation of healthcare service design and in professional education, as well as in the delivery of care (Johnson et al., 2008).

Family-centred care has significance for child health because it moves patient care beyond the care of the child by also considering the needs of the family as well (Carter et al., 2014; Kuo et al., 2012). In the context of working with children with long-term conditions and their families, this type of collaboration is particularly relevant as these children are primarily cared for at home, with parents often taking significant responsibility for care decisions and delivering treatments (Kish et al., 2018; Smith et al., 2013). Research that focuses on adult patients highlights that when collaboration works well it can increase a patient's involvement in care and treatment decisions. This can result in improved treatment adherence and increased satisfaction with and trust in health professionals.

### ***1.3.6 Managing expectations in family-centred care***

Although there is a paucity of evidence in the child health setting (Shields et al., 2012), parents report wide variations in the quality of parent/health professional relationships, with some parents perceiving that their expertise and contribution to care is not valued (Smith et al., 2015a; Swallow et al., 2013). Family-centred care brings many challenges, since health professionals and families may have widely varying expectations, experiences, expertise, and motivation to work collaboratively (Moore et al., 2017). Furthermore, collaborative practice will require health professionals to shift from a paternalistic approach to care delivery, to one where the differing perspectives of parents and professionals are integrated, to develop a joint understanding of the child's condition that informs care planning and delivery (Smith et al., 2015b). In the context of childhood long-term conditions, it is likely that as parents become skilled and experienced in providing care for their child, they shift from a passive to more active position when collaborating with health professionals.

## 2. RESEARCH DESIGN

### 2.1 Aims

The aim of this project is to explore, from the perspectives of stakeholder groups, the role and impact of the Roald Dahl Specialist Nurses.

### 2.2 Objectives

- To review the current literature to ascertain how Roald Dahl Specialist Nurse roles align with published evidence related to clinical nurses specialists, advanced clinical practitioners, and other charity funded healthcare roles.
- To identify, from the perspective of lead clinicians for the service, the initial drivers for the creation of the Roald Dahl Specialist Nursing role, its impact on the wider service and plans for expansion.
- To explore in detail the strategic and operational 'day-to-day' aspects of the Roald Dahl nursing roles and their impact from the perspective of the nurses and their line managers.
- To revisit specific operational challenges identified in early data collection in a collective forum with Roald Dahl Specialist Nurses.
- To discover the nature of interactions between parents, children and the Roald Dahl Specialist Nurses, the value parents place on the service, and the impacts the nurses may have upon children and their families.

### 2.3 Research Questions

Primary question:

*What is the role and impact of Roald Dahl Specialist Nurses from the perspectives of multiple stakeholders?*

Secondary questions, from the perspectives of the stakeholder groups:

- *What are the similarities and differences between the roles performed by the different Roald Dahl Specialist Nurses?*
- *What are the impacts of the role of the Roald Dahl Specialist Nurses on their employing Trust or Health Board?*
- *What are the impacts of the role of the Roald Dahl Specialist Nurses on the multi-disciplinary team in the clinical service in which they work?*
- *What are the impacts of the role of the Roald Dahl Specialist Nurses on the children and families that they care for?*

## 2.4 Eligibility Criteria

Roald Dahl Specialist Nurses were invited to participate in the study if their nursing post had been established between 1st April 2016 and 1st April 2019. Twenty-two Roald Dahl Specialist Nurses were eligible for inclusion, 20 from NHS Trusts in England, one based in Wales and one in Northern Ireland; one NHS Trust declined to participate due to the impact of the Covid-19 pandemic. Data collection commenced at each participating site when the nurses (n=21) had been in post for a minimum of 18 months.

## 2.5 Research Design

Since we consider this study to be an evaluation of a complex intervention, we are guided by the Medical Research Council framework for evaluating complex interventions. A **pragmatic** methodological approach was selected which employed a **mixed methods research design**. A **triangulation protocol** was used to integrate data and findings from each element of the project.

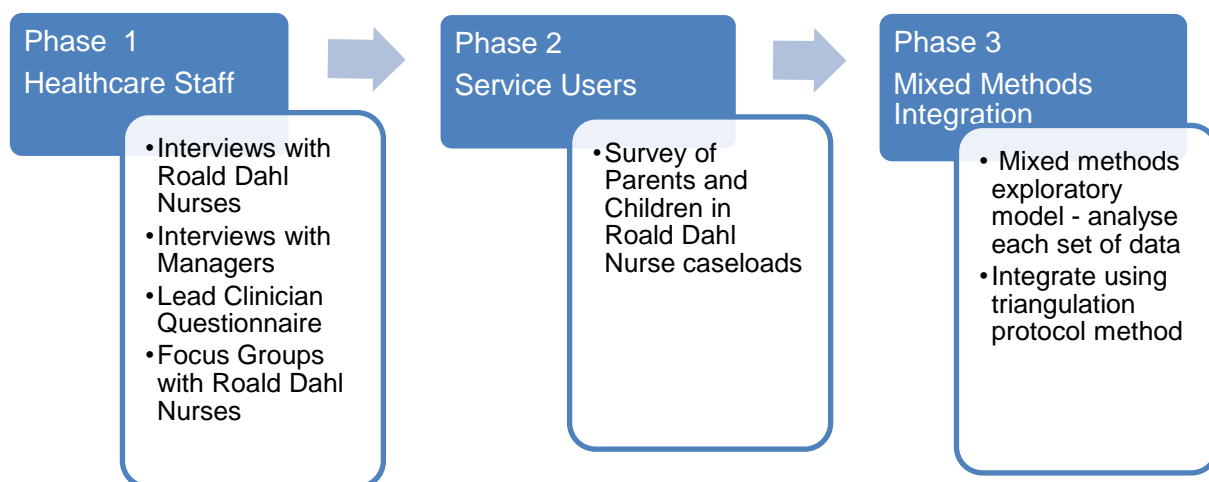
Pragmatism is a modern research paradigm suitable for addressing 'real world' issues, that supports the use of any well-established quantitative and qualitative methods to optimally explore the research question (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2003). Mixed method research designs typically incorporate elements of quantitative and qualitative data in sequential or concurrent data collection (Creswell, 2009). **Qualitative methods** such as interviews and focus groups are suitable for generating rich, detailed information on subjective experiences, decision-making and individual or group perspectives, and may be useful for studying small samples. In contrast, **quantitative methods** such as surveys are an empirical method of inquiry that involve generating numeric data through standardized processes in order to numerically draw statistical conclusions (Creswell, 2009).

Mixed method studies combine multiple approaches to strengthen the study compared to using one method alone (Creswell & Plano Clark, 2011), and this approach has rapidly gained in popularity and acceptance within healthcare research, as more systematic and rigorous frameworks have been developed. This study aligns with the definition of Tashakkori and Creswell (2007, p4), who defines the method as:

*Research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry.*

The research design follows a **mixed methods exploratory model** which is a sequential dual phase design (Figure 2.1). In the **first phase**, both qualitative and quantitative data collection from healthcare staff was triggered at each hospital site when the Roald Dahl Specialist Nurse had been in post for at least 18 months, and permission was received to proceed from the site

R&D department. The ongoing analysis of the data from the first phase informed the design of the second phase tools. The **second phase** involved a survey of service users (parents and children in the caseload of Roald Dahl Nurses). Each set of data is analysed separately and then merged during the **third phase** (interpretation). The triangulation protocol method was adopted for integrating the data (O’Cathain et al., 2010), based on the six step approach developed by Farmer et al. (2006). This approach builds upon the individual analyses of components by yielding additional findings related to areas of agreement and dissonance across the data collected.



**Figure 2.1 Mixed methods exploratory research design**

In summary, the overarching research design for this study is outlined in Table 2.1.

Research Approaches	This Study	Comments
Philosophical Paradigm	Pragmatic Approach	Supports merging qualitative and quantitative methods
Methodological Approach	Mixed Methods	Enables a triangulation approach to make sense of and merge data
Research Design	Mixed Methods Exploratory Research Design	Two phases, qualitative followed by quantitative
Research Methods Phase 1	Interviews	Individual semi-structured interviews with Roald Dahl Nurses and Managers
	Focus Groups	Four focus groups with Roald Dahl Nurses
	Questionnaire	Lead Clinicians for each Roald Dahl Nurse
Research Methods Phase 2	Survey	Parents and children in the caseload of Roald Dahl Nurses
Integration Phase	Triangulation Protocol 6-step Process (Farmer et al., 2006)	Synthesised findings integrated with literature

**Table 2.1 Summary of the overarching research design**

## 2.6 Ethical Approval and Research Governance

The project was approved by Sheffield Hallam University Ethics Committee, the North East Research Ethics Committee (specialising in research involving children) and the Health Research Authority which governs research within NHS sites in England and Wales. Additional applications were made for the research to proceed in Northern Ireland. Subsequently two amendments were submitted and approved, enabling a move to online data collection to comply with Covid-19 restrictions, and a request to extend the study end date to accommodate the 'downtime' for NHS research between March and August 2020 (Table 2.2). Participant information leaflets and consent forms were developed and participants were asked to provide written consent prior to data collection. Audio recordings and anonymised transcripts from interviews and focus groups were password protected and accessible only to the research team. All participants were assured of anonymity, confidentiality and right to withdraw.

Submission	Committee	Date granted	Review ID
1	Sheffield Hallam University Research Ethics Committee	19.12.18	ER10500163
2	North East - Newcastle & North Tyneside 2 Research Ethics Committee (specialist paediatric ethics committee)	20.12.18	18/NE/0383 IRAS no. N255882
3	Health Research Authority and Health and Care Research Wales	29.01.19	As above
4	IRAS Amendment 1	14.07.20	10000001
5	IRAS amendment 2	02.11.20	10000003

**Table 2.2 Ethical approval confirmations**

Research governance requirements dictated that following the receipt of the approvals and amendments above, the employing organisation for each participating Roald Dahl Specialist Nurse was required to give approval to enable the research to proceed. Fifteen NHS Trusts were approached to participate (including two additional Trusts requested by the Charity to be part of the study at a later stage), however the impact of Covid-19 on this process was significant. In early March 2020, combined guidance from the Department of Health and Social Care, the HRA and the NIHR recommended that NHS Trusts prioritise research related to Covid-19 over all other 'non Covid-19' research. NHS Trust R&D departments suspended the review of new studies, and

many Trusts suspended all existing research for several months, unless it was in patients' best interests for it to continue.

The main impact on this research project was as follows:

1. NHS data collection was suspended for several months. Several interviews therefore took place at a later date than originally scheduled (to coincide with the 18 months in employment window), and the parent survey was delivered several months later than intended. An IRAS amendment was submitted to enable the end date of the project to be extended (Table 2.2).
2. All data collection had to be transferred online - this affected later staff interviews which were moved to zoom videoconferencing. IRAS amendment 1 was submitted to facilitate this.
3. All Trusts that suspended research required further permissions to enable the research to 're-start' which was time-consuming and further delayed data collection.
4. Five NHS Trusts had not yet given permission for the parent survey to take place by March 2020 when research was suspended; there was a 6-month window where they were not reviewing new applications, and/or not responding to requests. One Trust subsequently declined to participate.

## 2.7 Research Methods

The research team investigated each of the clinical services delivered by the participating Roald Dahl Specialist Nurses by capturing the perspectives of a range of stakeholders as seen in Table 2.3.

Stakeholder Group	Research Method	Justification for Inclusion
Roald Dahl Specialist Nurses	Semi-Structured Interviews  Focus Groups	Roald Dahl Nurses were pre-selected by the Charity for inclusion if they commenced their role between April 2016 and April 2019. Interviews were cross-sectional and scheduled to take place at a minimum of 18 months post appointment. Focus groups were scheduled to coincide with the Roald Dahl Nurses' Conference (May 2019), and enabled an opportunity to explore early findings from the initial interviews in more depth.
Line Managers	Semi-Structured Interviews	Nurse managers or heads of children's nursing services with line management responsibility and a good understanding of the service provided by the Roald Dahl Nurse.
Lead Clinicians	Online Questionnaire	The lead clinician is clinically responsible for the multi-disciplinary team and the service in which the Roald Dahl Nurse works. They may have been involved in commissioning of the service.
Service Users (Families and Children and Young People)	Online Questionnaire Survey	Survey distributed by Roald Dahl Nurses to parents/carers and (via parents) to children and young people.

**Table 2.3 Stakeholder groups accessed within the evaluation**

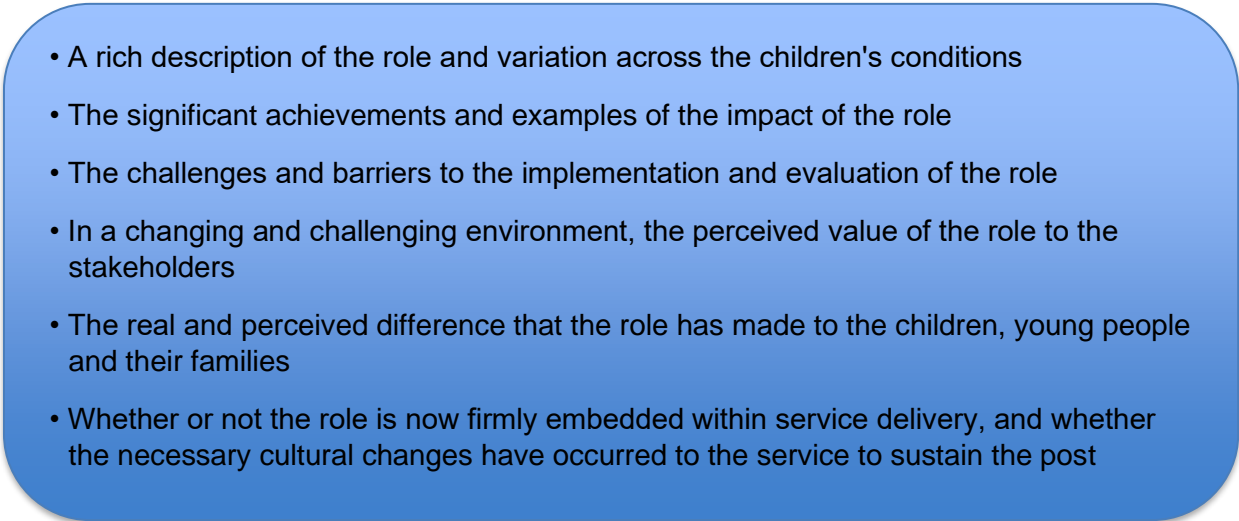
### 2.7.1 Design of semi-structured interviews

This Phase 1 study utilised semi-structured interviews to capture the perspectives of Roald Dahl Specialist Nurses and their managers. A qualitative study design was adopted to allow in-depth exploration of varied, complex and potentially unexpected dimensions of the research questions (Hennink et al., 2020). Adopting a qualitative approach is most suitable for understanding people's subjective views, and it has been recommended and widely used to explore the perceptions and experiences of nurses specialised in the management of children with chronic conditions (Beacham and Deatricks, 2015; Maytum et al., 2004; Silva et al., 2016). This qualitative study was undertaken from an interpretivist theoretical perspective; interpretivism argues that reality is co-constructed through interactions between individuals and their social world (Potrac et al., 2014). Data analysis was guided by the methods of constructivist grounded theory methodology, which is founded upon the co-construction of knowledge between the researchers and participants, and the interpretive re-construction of data by researchers to form meaningful categories



(Charmaz, 2006). This methodology considers participants as researchers and vice-versa, and thus it enables the generation of research knowledge from participants' viewpoints (Charmaz, 2000).

Roald Dahl Specialist Nurses were invited to participate if they had been appointed between 1<sup>st</sup> April 2016 and 1<sup>st</sup> April 2019. Nurse Managers or Directors of Children's Nursing services were selected to participate if they were overseeing the work of at least one of the participating Roald Dahl Nurses. A topic guide consisting of a few open-ended questions and discussion points covering the research objectives was employed to facilitate conversation during interviews (Figure 2.2). This meant that the interviews were non-directive and allowed each participant's ideas to inform subsequent questions.

- 
- A rich description of the role and variation across the children's conditions
  - The significant achievements and examples of the impact of the role
  - The challenges and barriers to the implementation and evaluation of the role
  - In a changing and challenging environment, the perceived value of the role to the stakeholders
  - The real and perceived difference that the role has made to the children, young people and their families
  - Whether or not the role is now firmly embedded within service delivery, and whether the necessary cultural changes have occurred to the service to sustain the post

**Figure 2.2 Guiding research questions and topics**

The timing of the visit to each of the NHS Trusts or Health Boards where Roald Dahl Specialist Nurses were employed was scheduled to be, wherever possible, 18 months after their initial appointment. Three researchers who were registered with the NMC as children's nurses collected the data between March 2019 and December 2020. This professional insight into the working world of the nurses and their managers was considered essential to enable the researcher-practitioner conversations to extract high level information in the short timeframe, with appropriate use of prompting to 'dive deeper' where appropriate. The interviews were intended to be conducted face-to-face at the participant's place of work, however in response to Covid-19 restrictions, several later interviews were conducted via Zoom videoconferencing technology.

The analysis used three key methods of constructivist grounded theory as described by Charmaz (2006), namely two-step coding, memo-writing and the constant comparative method. Throughout the analysis rigour was assured by following the constant comparative method, whereby codes were compared across transcripts, and to subcategories, categories and new data (Charmaz, 2003). The research team regularly discussed the analysis to ensure that the generated interpretations were supported by participants' narratives. These discussions increased the validity of the analysis which was gradually refined to ensure that the final categories were exhaustive.

### **2.7.2 *Design of focus groups***

An initial analysis of the early manager and nurse interviews highlighted two themes which required further exploration. One theme related to the challenges of defining and managing patient caseloads which appeared to expand over time. The other theme described the diverse roles of the Roald Dahl Nurses and questioned how they may fit into an advanced or specialist practice model of nursing.

These two themes were explored in greater detail with the nurse participants by bringing them together to participate in qualitative focus groups at a Roald Dahl Nurses' Conference in May 2019. The cohort of nurses was divided into two sub-groups (approx. 10 in each group) who discussed each of the two themes in turn (a total of four focus group discussions). A member of the research team facilitated the groups, with a second team member taking notes and contributing to 'prompting' the group where necessary. The focus groups were recorded with each group's permission and later transcribed. Thematic analysis following a method outlined by Braun and Clark (2006) was undertaken to identify key themes within and between the groups - both sub-groups highlighted similar themes.

### **2.7.3 *Design of lead clinician questionnaire***

An online survey was sent to the lead clinicians for the service in which the Roald Dahl Specialist Nurses worked. The decision to employ a specialist nurse is complex and based upon a number of different factors. When developing the successful business cases it is important to understand these factors and their relative importance to the decision-making process. We hypothesised that the decision making was hierarchical and therefore the most senior clinicians would be involved together with senior financial managers from the various organisations. The nurses do not operate in a vacuum and it is important to understand how they are understood and regarded by the wider clinical team and how they fit into the existing clinical infrastructure.

An online survey was considered to be the most effective way of gathering data from busy clinicians. The questions were elicited from the initial analysis of the nurse and manager interviews and focus groups and from discussions with Roald Dahl's Marvellous Children's Charity's team. The survey was split into a number of sections relating to: demographic details; the business case; the perceived challenges; the Roald Dahl Specialist Nurse and their caseload; the impact of the nurse on children and young people. It was hosted on an online survey platform (Qualtrics) and an email invitation with a link to the survey was sent to the lead clinician for each participating Roald Dahl Nurse. The clinicians were requested to represent the wider multi-disciplinary team where appropriate when answering the survey questions, and to forward on to other colleagues if relevant.

#### **2.7.4 Design of parent and child surveys**

Increasingly, researchers understand the importance of investigating the impact of disease on the lives of the families of patients. A review by Golics et al. (2013) showed that many aspects of family members' lives may be affected by the illness of a loved one, including emotional and financial aspects, family relationships, education and work, leisure time, and social activities. The impact of disease on the families of patients is often unrecognised and underestimated. Golics et al. argue that taking into account the quality of life of families as well as patients can offer the clinician a unique insight into issues such as family relationships and the effect of treatment decisions on the patient's close social group. The aim of this survey was to understand, from the perspective of parents and families, the nature of their child's condition and its impact on the family. Placing the Roald Dahl Specialist Nurse as an 'intervention' at the heart of the child's care, the survey also explored the nature of the care received and the potential impact of having access to a Roald Dahl Specialist Nurse.

A questionnaire survey was developed with questions drawn initially from published literature and from the themes developed from the nurse and manager interviews. The survey was divided into the following sections:

- a) Participant demographics
- b) The participant's household
- c) The child under the care of the Roald Dahl Nurse
- d) The impact on the family of managing the child's condition
- e) Interactions with the Roald Dahl Nurse.

The questions comprised a range of question types including Likert scales (e.g. numerical scale indicating completely agree to completely disagree), sliding scales, forced responses (yes/no) and the opportunity to provide open text responses.

Several research instruments exist to measure the impact of illness on the family, although many are disease (e.g. epilepsy) or specialty (e.g. dermatology) specific, or are focused on illness affecting adults. However the Impact on Family Scale (IOFS) was designed to measure the impact of non-specific childhood chronic illness on the family, and has been incorporated into this survey. Originally developed by Stein and Reissman in 1980, this validated (triallyed and tested) psychometric scale has been widely used in healthcare research, with a shortened version (IOFS-15) launched by Stein and Jessop in 2003. Williams et al. (2006) independently assessed the revised scale and concluded that:

*This scale is a promising, easy-to-use instrument for the measurement of impact of illness and disability on families of children with chronic illness or disability.*

They also identified that a few items remaining on the scale may not be needed and that it may be possible to shorten the scale to 11 or fewer items to create a scale that is “*even friendlier to clinic settings*”. Subsequently, the 11-point scale has been tested successfully in several clinical settings including epilepsy (Dehn et al., 2014). With the permission of the original authors (Stein, personal correspondence) this shortened scale (IOFS-11) has been incorporated into this study, enabling findings from this study to be compared to previous research in similar settings.

The draft surveys were discussed and tested within the research team, steering group and with representatives of the Charity. They were also 'field tested' (piloted) with three parents. The survey was hosted on an online platform (Qualtrics survey tool). It was designed to be distributed by clinical teams to potential parent participants via an email containing a link to the survey, with participant information sheets as an attachment. In the invitation email, parents were also invited to ask their child to complete a brief children's survey (with parental assistance if necessary). This simple children's survey explored what children and young people liked to do most with their Roald Dahl Specialist Nurse, using 'faces' to ascertain whether children agreed or disagreed with statements.

Distribution by this method ensured that the research team did not have access to any sensitive or private data; parents could complete the survey without leaving any name, address or contact details. Additionally by the responses going directly to the independent research team, it gave parents assurance of confidentiality and anonymity should they wish to leave any negative comments regarding the service they received from the NHS Trust or Health Board.

Independent research nurses, administrators and/or the Roald Dahl Specialist Nurses were asked to gather parent email addresses for their caseload, and then send out the pre-prepared email with the link to the survey. The Trusts were asked to secure parental participant responses from the caseload of each participating Roald Dahl Specialist Nurse, although the Covid-19 pandemic meant that this was a very challenging task for many services that were at full stretch.

An ethics amendment was granted to extend the study for an additional four months until 1st March 2021 in order to capture as many responses as possible.

Each participating service had a bespoke survey link to enable data to be captured and fed back to the nurses following the study. At the end of the study the data from each service's survey was merged into a single survey and the data was analysed via descriptive statistics to enable easily accessible visual displays to be created.

### 3. RESULTS AND DISCUSSION

A detailed description of the findings are displayed in the accompanying Appendices document; Phase 1 (healthcare stakeholders) findings are detailed in Appendix 1-3 and Phase 2 (service users) findings are found in Appendix 4-5. The findings from each stakeholder group have been analysed, reviewed, compared and contrasted following the mixed methods 6-step process outlined by Farmer et al.,(2006). Appendix 6 reviews the level of convergence (degree of similarity in the findings) between the different phases of the research. Each stakeholder group corroborated the evidence from the other groups and added new information for analysis; there were no significant divergent findings identified. Topics where a high degree of convergence was seen across the studies (Figure 3.1) are presented in this section for further exploration and analysis alongside relevant literature.

The results and discussion are presented in the following sections (Figure 3.1):

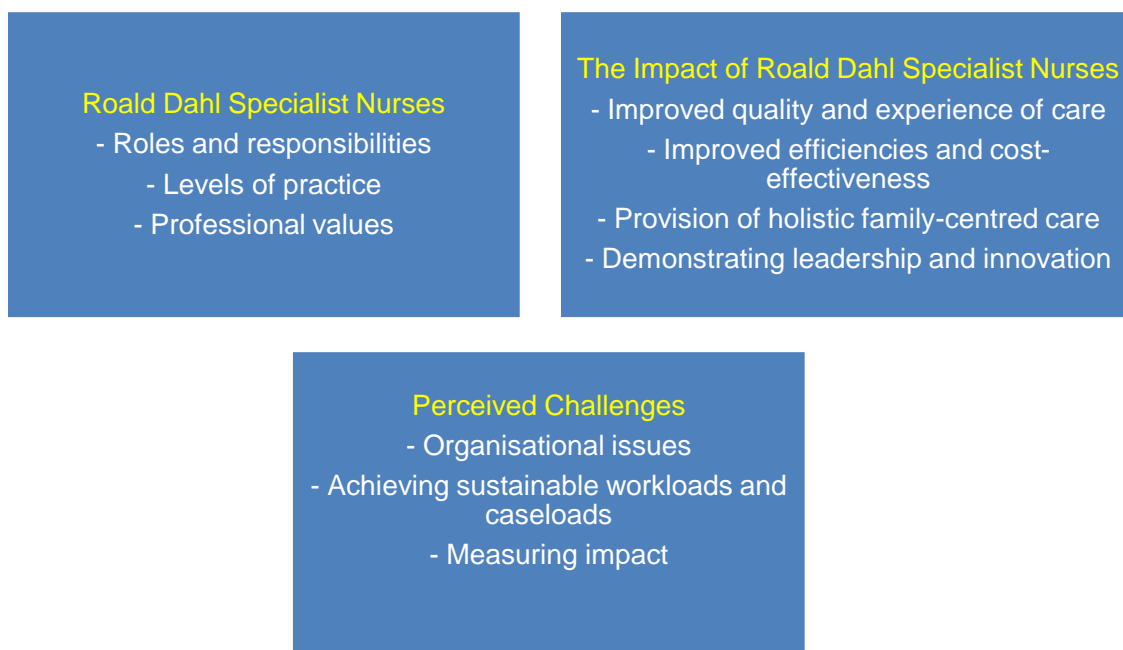


Figure 3.1 Discussion themes

#### 3.1 Being a Roald Dahl Specialist Nurse

##### 3.1.1 *Characterising the care need*

The 21 nurses who participated in this study represent 12 NHS Trusts in England, one in Wales and one Health Board in Northern Ireland. Seven nurses were located at renowned specialist

children's hospitals, with the remainder working in secondary care (mixed adult and child NHS Trusts).

The nurses worked across eight clinical specialties with the most commonly encountered roles related to children's epilepsy (n=5) and non-malignant haematology including sickle cell and thalassaemia (n=6). Nurses were also specialists in rare and genetic diseases (n=3), neurology (neuro-disability=1; neuromuscular=2; neurosurgery=1), gastroenterology (n=1) and child to adult transition services (n=2).

While the specialties appear to be extremely diverse, the common thread is that the children and young people looked after within these services are all living with complex lifelong conditions. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability. While some of these children may be living fairly normal lives for most of the time (e.g. those with milder forms of epilepsy and sickle cell disease), others require higher levels of care including support for activities of daily living; some are frequently hospitalised.

In this study, 41 parents (27.9%) said their children were unstable and required round-the-clock care, with 17 of the children (11.6%) requiring at least five A&E visits in the last year. The consequences of caring for these children had an impact on the wider family who experienced stress, anxiety and in some cases poor mental health. Completing the Impact on Family Scale (IOFS), many parents in this study strongly identified with their lives being on a 'roller coaster', needing to give up normal family things or change plans at the last minute due to changes in their child's condition (Figure 3.2). This uncertainty and worry was exacerbated when liaising with healthcare services, particularly in emergency or urgent care situations. The Roald Dahl Specialist Nurses provided much-needed emotional support for the family:

*“She provides us with emotional and practical support when no one else is available. It's really a lifeline sometimes when you feel lost and confused and sad” [Parent].*

*“They have been brilliant in every way, I don't know what I would do without them, really helps with my mental health to know that someone is there for me, for support for my ill child and family” [Parent].*

*“It is definitely supportive and sometimes it is just a case of that emotional support in terms of just a phone call. I have one family that mum rings me every day that I am at work and it's just a two-minute phone call and it's just checking in and it's just what mum needs so that's what we do” [Nurse].*

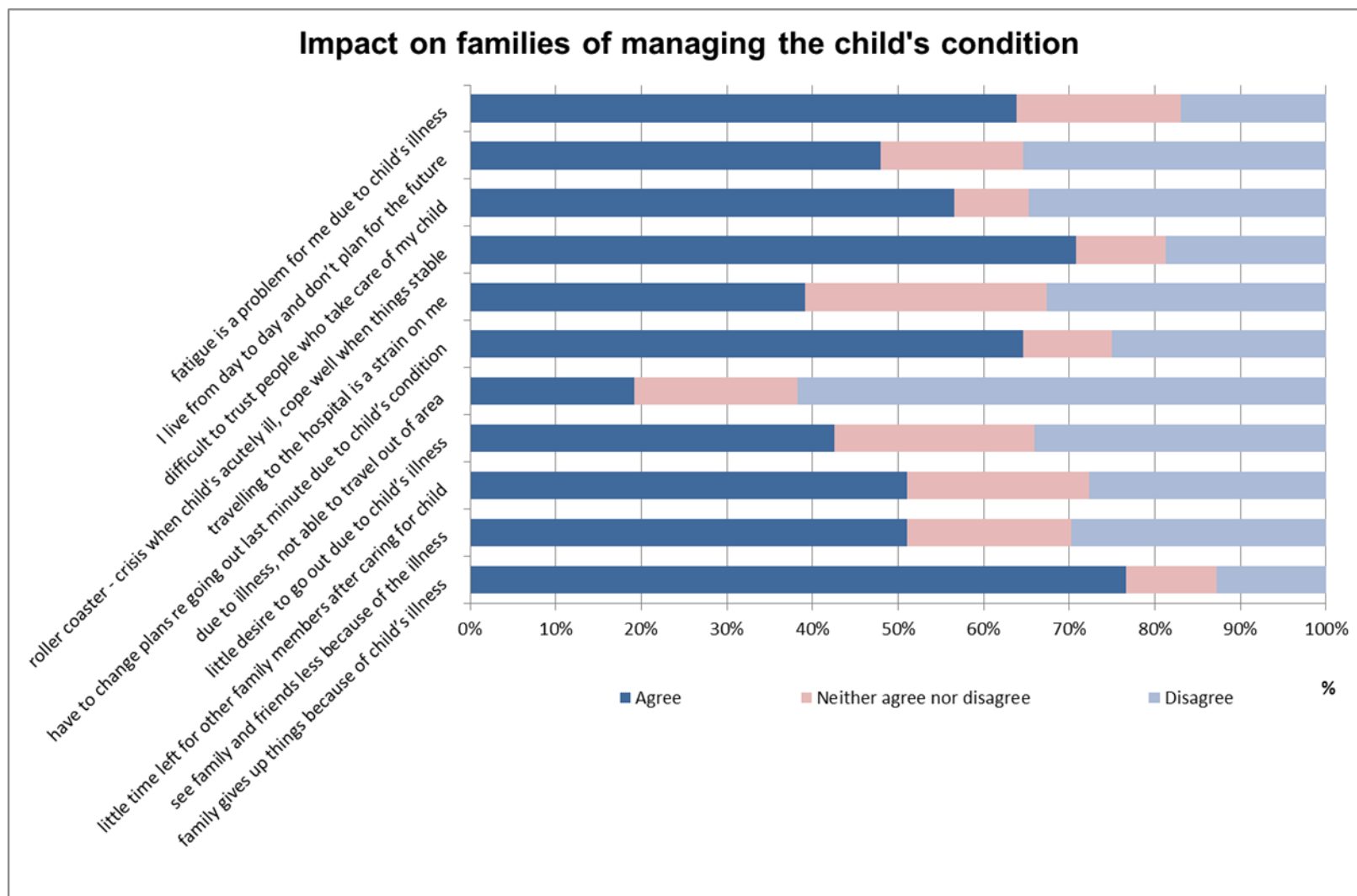


Figure 3.2 Visual representation of parental responses to eleven statements in the Impact on Family Scale (IOFS-11). The darker colours indicate a stronger agreement.

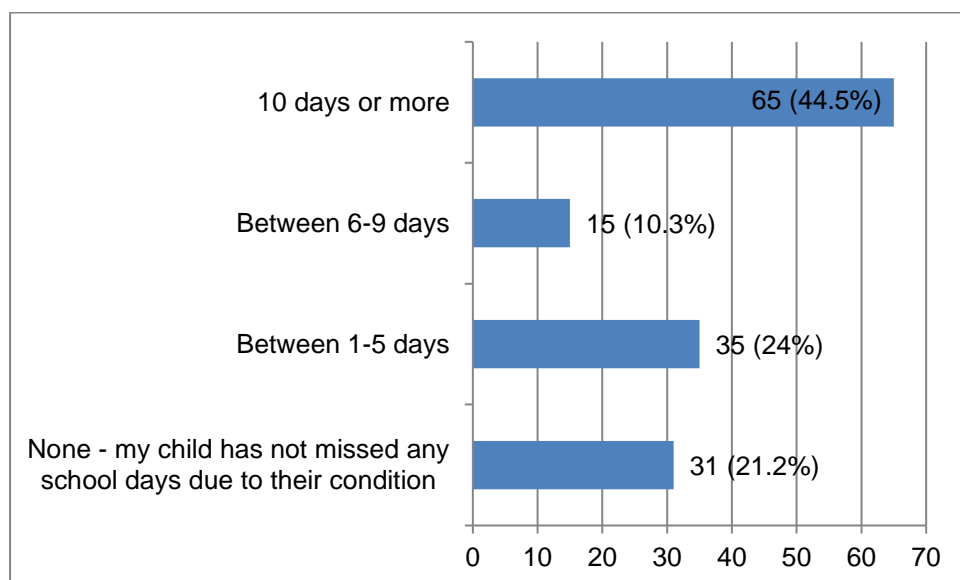


Several parents indicated that their children had very complex conditions exhibiting multiple organ system disorders (for example cardiac, gastrointestinal and neurological), and consequently they were under the care of several different consultants, often associated with different Trusts and healthcare organisations. The co-ordination of their child's healthcare was highly complex and often exhausting for the parents, however, many children had significant needs beyond healthcare that added to the complexity:

*“She [Roald Dahl Nurse] has been an amazing support to my family and our little boy, he is extremely complex so therefore has a lot of doctors involved in his care. She has been great at helping them to all work and communicate together... it is hard when so many professionals are involved” [Parent].*

*“With so many medical professionals involved in our daughter's care, it has been great to have a person whom we can turn to to liaise between them when we are not sure who to contact. It has been MUCH appreciated” [Parent].*

All children in this study were in some form of education, with one third of children (29.9%,n=44/147) attending a school catering for special educational needs. Many of the children required complex Education Health and Care (EHC) plans to be created, approved and regularly updated, but their schooling was a challenge. As shown in Figure 3.3, many of these children had missed at least 10 days in the last year due to their condition (44.5%, n=65/146).



**Figure 3.3 Number of school days missed due to the child's condition during the last school year**

In addition, the child's condition sometimes required adjustments to housing (such as wheelchair access) and the support of formal carers, requiring regular liaison with social services and city councils.

*“We’ve got families who have very difficult social circumstances, where we’ve had to go and help and write letters to the council and support them from that perspective to try and get them a cleaner house, a better housing and safer housing for the children” [Manager].*

These factors all put added strain on parents who had multiple responsibilities. While most parents in this study were married or in steady relationships, 21 (13.2%) were single parents and many were juggling work commitments as well as looking after other children. Sixteen parents (10.7%) indicated that they were suffering a great deal of financial hardship, with one third of parents (36.9%, n=55/149) occasionally experiencing hardship. Forty percent of parents (40.1%, n=61/152) in this study stated that their child's illness has had a significant impact on their employment or financial status.

There is a large body of existing evidence that has explored the lived experiences of parents whose children have chronic health problems (George et al., 2007; Madrigal and Walter, 2019; Shudy et al., 2006). Unfortunately, these experiences are often dominated by social isolation and significant struggles in coping with work and parental responsibilities on top of looking after a sick child (Wright-Sexton et al., 2020; Yagiela and Meert, 2020). Feelings of despair and helplessness were particularly heightened in young, deprived or ethnic minority families as they often did not know how to navigate the system to get medical, financial and emotional support (Cabizuca et al., 2009; McClellan and Cohen, 2007; Suurmond et al.2020). Some parents in our study experienced particular issues due to financial hardship, lack of family support or being a migrant family with little knowledge of national or local systems and processes. Many expressed similar concerns regarding navigation of the different systems within and beyond healthcare; these confusing systems need to be mastered in order to ensure even basic care for their child and their wider family.

The context in which the Roald Dahl Specialist Nurses are working is clearly complex and requires professional approaches which go beyond traditional patient-centred nursing. The following sections will explore the range of roles and responsibilities and professional values adopted by the nurses in this study.

### **3.1.2 Roles and responsibilities**

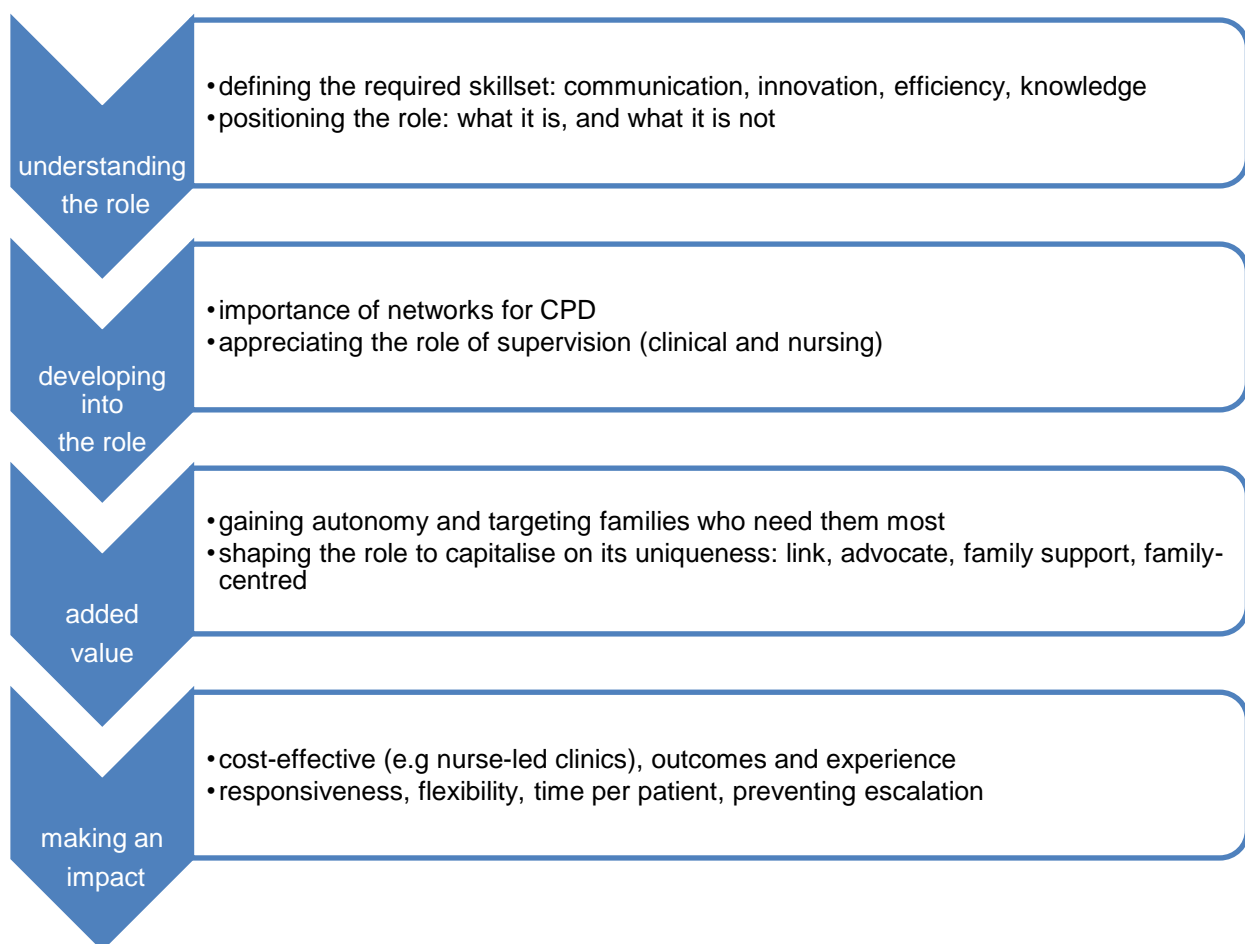
The nurses described a number of routes through to their Roald Dahl post, with some already being employed in the organisation and service, and others entering the role as a new member of staff. However, their journeys through the early stages of the role, in terms of exploration of role boundaries, priorities and support networks, were similar.

Role descriptions for each nursing post inevitably varied to suit the client caseload and the required duties, however these duties were unclear in the early stages of the role and required some time for the nurses to 'carve out' a niche for themselves:

*“There is a lot of work to be done and knowing where to start / what to prioritise. We have had our Roald Dahl Nurse in post for almost 18 months and they have been developing the post from scratch. The families have high levels of need and social deprivation so there is a lot of work to be done” [Clinician].*

*“Coming into a new role, dealing with a group of rare disorders, and joining a well-established team can be challenging. As the only nurse on the team, it took time to build up links across our regional network and these have been very effective in supporting local care and monitoring” [Clinician].*

The evolution from novice to established Roald Dahl Nurse is shown in Figure 3.4.



**Figure 3.4 How Roald Dahl Nurses transition from being novice practitioners to established roles**

Both nurses and managers in this study emphasised the importance of the liaison role which, for many, takes up a significant part of their working week. The nurses work across healthcare, social

services, education and housing boundaries to mobilise resources, striving to secure *“the right services involved at the right time”*. The focus group narratives also discussed liaison alongside sign-posting and networking as key aspects of the role, highlighting that they were not only the *“missing link”* between families and the medical staff, but were also a *“link between families and the rest of the world”*. Parents also highly appreciated this *“co-ordination of care”*, with advice and liaison undertaken both within and outside healthcare boundaries.

The term 'care navigation' perhaps better describes the complexity of the role from the parents' perspective. Clinicians also recognised the importance of this cross-boundary role, with nurses providing a single point of access and contact for the service:

*“A key role across the entire pathway, helping to ensure continuity between settings, educating service providers and users. Networking with other health professionals and across healthcare boundaries” [Clinician].*

*“There was a significant need to bridge community, outpatient, and inpatient services...” [Clinician].*

*“A perceived need to support and educate other clinical staff including community children’s nurses, school nurses, teachers, learning disability nurses and medical colleagues” [Clinician].*

In some settings such as epilepsy care, this work beyond healthcare is seen as an essential role from a national perspective. Epilepsy services have the most comprehensive national NICE guidance (2012, updated 2020) which recommends that Epilepsy Specialist Nurses (ESNs) should be an integral part of the network of care of children, young people and adults with epilepsy. The NICE guidance states that the key role of ESNs is to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services, and to provide information, training and support to the child and their family and to others involved in the child's education, welfare and well-being.

This 'link' or 'liaison' role across service boundaries has been previously described by While et al.(2006), who identified a five level spectrum of collaboration in nursing:

- intra-professional (nurses working with other nurses)
- inter-professional (nurses working with other professionals)
- intra-organisational (nurses working across different components of the health service)
- inter-agency (nurses working across and between different agencies)
- trans-disciplinary (nurses working within integrated services involving different agencies).

Many of the Roald Dahl Specialist Nurses were working routinely at *inter-professional* and *inter-organisational* levels, however a major component of their work was situated at the *inter-agency* level. While a wide variety of examples of inter-agency working can be seen in adult nursing roles

which cross agency boundaries, in Roald Dahl Specialist Nursing this appears to be a significant part of their role and is often ongoing, rather than a time-limited process as in many other 'care navigator' roles (Gilbert, 2016). Although their roles may lie within individual organisations (the NHS Trusts), their remit appears to be to actively create connections and facilitate care across organisational boundaries, similar to integrative care roles previously described for HIV specialist nursing (Panton, 2014).

*"She [Roald Dahl Nurse] has forged links with other organisations and services to develop 'alert' systems for our patients and with other specialty teams across the region to develop evidence-based emergency care plans for all patients... She is balancing many competing needs... the safeguarding of an individual child against the importance of dealing with a teenager having a 'crisis' against a planned clinic and this requires levels of competence, leadership and initiative that can be daunting" [Clinician].*

Gilbert (2016), in a review of integrated (cross boundary) roles for the King's Fund, identified that the capacity of individual roles to support integration is always a key issue. Gilbert suggests that many roles which are developed to support co-ordination of an individual's care and unmet needs (such as the Roald Dahl Specialist Nursing role), can lead to high caseloads with increasing complexity (Kendall-Raynor, 2012). Gilbert also identifies that integrated care is 'process-heavy', dependent on building and supporting inter-agency working to achieve successful boundary-spanning (Erens et al., 2015). These cross-boundary roles are characterised by negotiation with stakeholders on a daily basis, an element that is not readily reflected in role descriptors. Furthermore, these roles often demand post-holders to develop new systems and, importantly, networks (Kessler and Bach, 2007). These demands are often time-consuming and difficult to maintain (McEvoy et al., 2011), and may add to the frustrations by working across different systems. Gilbert suggests that all of this places additional demands on those in roles that span those boundaries. The Roald Dahl Specialist Nurses and their managers all articulated challenges of working inter-agency, particularly at the start of their role when systems and networks had to be constructed, often from scratch. One of the problems highlighted by the nurses regarding crossing the boundaries of care, is that this is often time-consuming and challenging, particularly with an expanding caseload.

### **3.1.3 Levels of practice**

The majority of the nurses self-identify with the role descriptor 'Clinical Nurse Specialist' (CNS) or specialist nurse, with a few having 'advanced' in their title. Inconsistency in job titles is not unusual in charity-established roles, with one study identifying almost 50 different job titles in use for nurse specialists working in the field of urological cancers alone (Macmillan, no date). This inconsistency may be related to confusion in the requirements and duties of both the CNS role and 'advanced

practice'. While the specialist practitioner is well established and clearly defined, there is a degree of ambiguity in relation to the Advanced Clinical Practitioner (ACP) role, making differentiation between specialist and advanced nurses potentially challenging (Leary et al., 2017). Further clarification to better standardise these roles has been offered by Health Education England (2017):

*Advanced clinical practice is delivered by experienced, registered health and care practitioners. It is a level of practice characterised by a high degree of autonomy and complex decision making. This is underpinned by a master's level award or equivalent that encompasses the four pillars of clinical practice, leadership and management, education and research, with demonstration of core capabilities and area specific clinical competence...Advanced clinical practice embodies the ability to manage clinical care in partnership with individuals, families and carers. It includes the analysis and synthesis of complex problems across a range of settings, enabling innovative solutions to enhance people's experience and improve outcomes.*

While there is significant overlap between the two roles, there is an expectation that the CNS will have a more disease-specific specialist knowledge than an ACP whose focus is often wider. In this study the nurse participants have developed highly specialist knowledge regarding particular conditions or specialisms, for example epilepsy or sickle cell disease. However some of the nurses who focus on 'general' transition could arguably be better aligned with the ACP definition, and indeed some nurses have a title which includes the word 'advanced'. The ACP role comprises four components of practice as illustrated in the definition above; the CNS role, in contrast, often includes more direct clinical contact. In this study, however, the nurses' clinical practice (direct patient care) appeared to be a less significant component in terms of the working week; the Roald Dahl Specialist Nurses displayed effective mastery of leadership, management and education expertise more aligned to ACP role descriptions than a Clinical Nurse Specialist role. This model of practice which emphasises the non-clinical roles, alongside the multi-agency nature of the work undertaken, presents a relatively unique model of nursing practice.

*"It's all about coordinating care, being able to support families, encouraging research, to be empathetic and compassionate, all that... you've got to be multifaceted to do this role, really, it's unique" [Nurse].*

Many examples of the work of the Roald Dahl Specialist Nurses are synonymous with practice at an advanced level. The complex conditions and high levels of clinical uncertainty mean that the nurses are not always able to follow standard pathways of care or clinical protocols; they regularly have to use their ingenuity and innovation. Service development represents a significant aspect of their role, including: restructuring care pathways; facilitating access to available resources; designing and implementing new services by formulating business cases; putting in bids and drawing upon the expertise of different professionals from various fields. The Roald Dahl

Specialist Nurses used their creativity and innovation to question the status quo, drive forwards change and address service issues, such as “*filling in the gap*” between hospital and community settings to create “*cohesive care*”, and creating smooth transition pathways for teenagers and young adults.

*“Transition is everybody’s business, so what are people, what are they doing about it? And to think about when they’re talking about transition, are they actually talking about transition or are they talking about transfer of care?” [Nurse].*

*“We’re looking at the pathways across sites, how can we make it so it’s a standardised pathway because we know that in some areas there’s really good examples of transition, but in others not so great or it’s just not really happening, it’s more of a transfer of care” [Manager].*

These numerous examples of autonomous practice, high-level clinical reasoning, decision making and critical analysis provided by the nurses and managers are recognised as master’s level academic skills (Level 7). While the ACP role is expected to be underpinned by master’s level education (HEE, 2017), there is no expectation for this level of education to underpin CNS roles:

*Specialist practitioners should be educated to degree level, with additional clinically-based educational preparation within the specialty; advanced practitioners should be educated to master’s level (RCN, 2014).*

Lack of investment in academic development to master’s or PhD level can affect the potential for impact of specialist nurses (Redwood et al., 2007) as well as harm their career progression. Few of the nurses within this study had undertaken master’s level education, although some had studied post-registration modules focussed on their specialist area. Nurse-prescribing courses were seen as challenging, intense and complex for practitioners but were considered to have a positive effect on patient care. However, one or two nurses explained that following completion of these demanding courses, they were subsequently prevented from applying their new skills in practice as they were “*not an ACP*”. This suggests that some NHS Trusts may be re-visiting role demarcations, perhaps reflecting Health Education England’s increasing advocacy for Advanced Clinical Practice (HEE, 2017). The lack of a requirement for master’s level education to underpin the Roald Dahl Specialist Nurses’ practice arguably devalues the role and reduces credibility. Clearly the nurses are working at an advanced level and their stakeholder-identified skillset is synonymous with master’s level. While only a few carry the ‘advanced’ role title, for many their employment grade is also commensurate with advanced practice (Agenda for Change Band 7). At the start of the study two thirds of the nurses were employed at Band 7 (n=14), with two at Grade 8 and five at Grade 6. Of those at Grade 6, three were supporting a more experienced Roald Dahl Nurse in the same specialty.

There is clearly an ongoing debate over the relative benefits of the ACP and CNS role in patient care, and arguably the role title is not of importance. However many nurses identified the highly stressful transition into the role, and this was consistently expressed whether they were a newcomer to the service or were transitioning from an existing role. The preparation of the nurses for this highly challenging role may be better served with educational underpinning at master's level, instilling the core values of leadership, management and education, as well as providing expertise in clinical reasoning, critical appraisal and decision making.

### **3.1.4 Professional values**

Four clinical philosophies (guiding frameworks) were outlined repeatedly within the interviews with the Roald Dahl Nurses, and these reinforced the work of the nurses and defined their role-based responsibilities. *Family-centred care* was the over-arching philosophy, underpinned by *holistic management approaches, evidence-based practice* and *empowerment*.

Roald Dahl Nurses require a set of core values and a professional and personal skillset to enable them to deliver care sustainably. Parents express these qualities as “*a willingness to go the extra mile*”, a friendly and impartial person, providing emotional support and advocating for the parent and child. They describe a helpful and caring person who is a good listener, with one parent noting that her Roald Dahl Nurse was “*a credit to her profession*”. Children and young people (CYP) also recognise how the Roald Dahl Specialist Nurses focus not only on their physical health, but also on their emotional wellbeing:

*“Talk a lot about my meds and how I feel and how things are at school and home” [CYP].*

*“Talk about my medication. Answers any questions I have. Always asks me how I have been or if I am worried about anything” [CYP].*

*“Talks about how I am feeling and how I am coping” [CYP].*

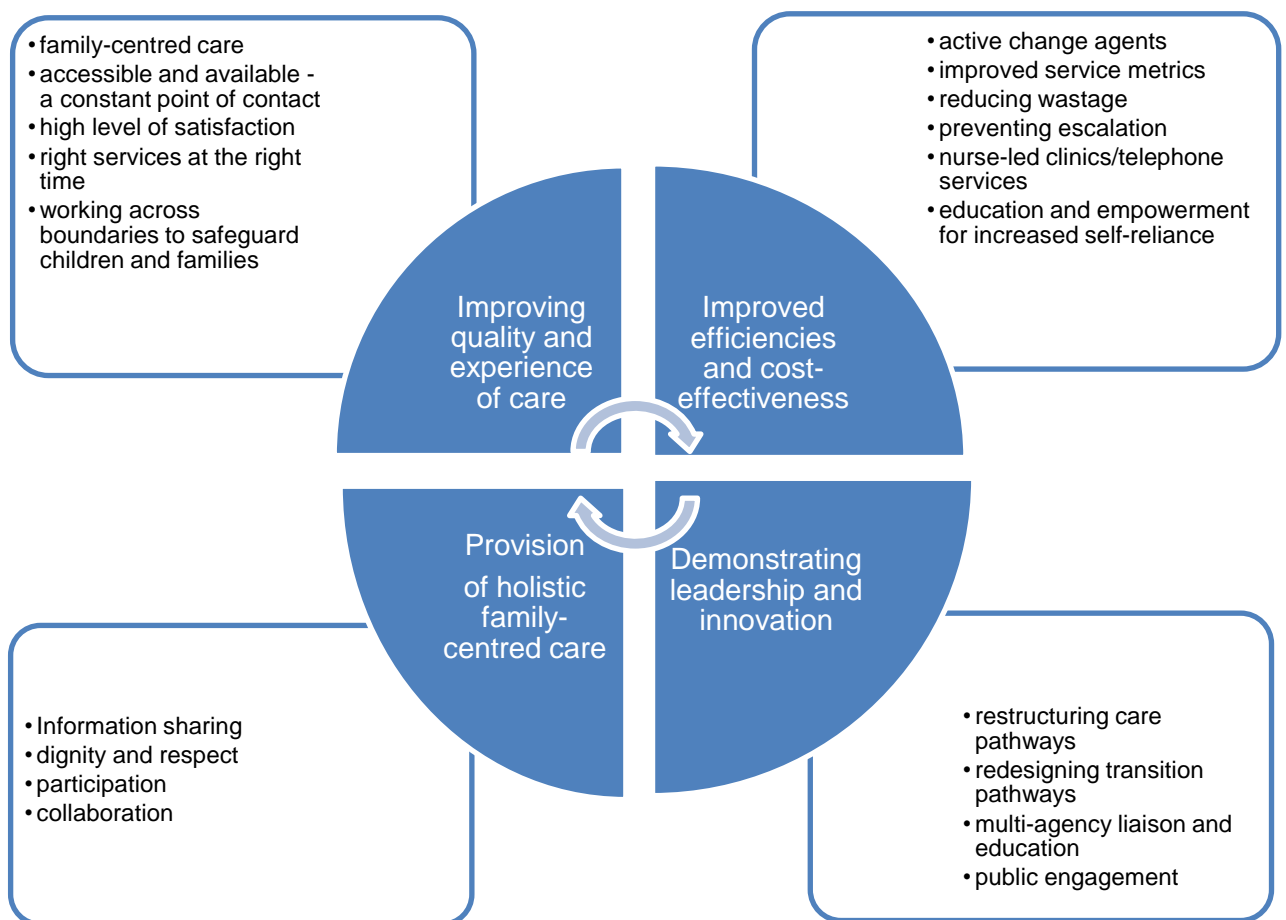
Individually the nurses, who by the time of data collection were well-established in post, rarely mentioned clinical skills as they felt this was often the pre-requisite for the role. Nurses expressed their core attributes as patient advocacy, being passionate, empathetic and motivational, while both managers and the lead clinicians identified qualities of their Roald Dahl Nurses as professional excellence, empathy, proactivity, enthusiasm, resilience and team spirit. Many of these attributes are exhibited by professionals in high responsibility posts compared to those previously reported for specialist nurses such as: adaptability, assertiveness, flexibility, negotiating skills, conflict resolution and change management (Gibson, 2001 cited in RCN, 2009).



In the focus groups the nurses exhibited a high degree of insight into their role beyond the clinical care that they provide. Their required skillset to perform the Roald Dahl nursing role effectively was eloquently expressed as excellence in communication, innovation, efficiency and knowledge, with many examples given which aligned clearly with the leadership element of advanced clinical practice.

### 3.2 Impact of Roald Dahl Nurses

Evidence of impact arising from both phases of the research were collated and categorised into four 'impact zones' adapted from a model previously used by Macmillan (no date). These zones are displayed in Figure 3.5 and are outlined in more detail in the following section.



**Figure 3.5 Four zones of impact embraced by Roald Dahl Specialist Nurses**

#### 3.2.1 Improved quality and experience of care

The children and young people in the caseloads of the Roald Dahl Specialist Nurses were living with a wide range of long-term conditions, and while some were usually stable and living relatively normal lives, more than a quarter of them (27.9%, n=41) were unstable and requiring round-the-clock care. It is not, therefore, surprising that our study confirmed that there was a much wider

impact from the child's condition on parents and the extended family. The extent of this impact was particularly high in some aspects of daily life, with parents feeling they were often on a 'roller coaster' of emotions, unable to plan family or work activities for fear of plans changing at the last moment (Figure 3.3). Many of the families had additional worries such as poor housing, employment and schooling issues, caring for other siblings and, for some, concerns over their immigration status. Nearly one half of parents (47.6%, n=71/149) in this study indicated that they often or occasionally experienced financial hardship.

Given this insight into the children and families in the caseload of the Roald Dahl Specialist Nurses, a more traditional patient-centred care approach would be inappropriate. It is clear from all stakeholders that family-centred care is embraced as a core value by all the nurses in the study. Testimonies demonstrate how this approach impacts on parents, who acknowledged both the practical and emotional support that they received to help them to be strong, in order to better care for their child. Such impacts are difficult to quantify, however 'providing emotional support for myself or my family' was one of the most highly valued services provided by the Roald Dahl Nurses in this study:

*"Our [Roald Dahl Nurse] has been a godsend to us at some of the lowest points in my life. I honestly don't think I would mentally be where I am now without her" [Parent].*

The nursing support most highly valued by parents is 'being a point of contact and coordinating my child's care across hospital services': All stakeholders recognised that the Roald Dahl Nurses acted as the 'one point of contact' into the service for both parents and health professionals alike. The impact on parents who had not previously had access to a Roald Dahl Nurse was clear:

*"...before Roald Dahl Nurses I spent hours upon hours, days upon days chasing appointments, medication, explaining my daughter's condition, waiting for a call back. Roald Dahl Nurses have relieved the stress of some of my daughter's care. I feel like I have so much support and advice from them they are absolutely invaluable and worth their weight in gold!" [Parent].*

The majority of parents indicated that they had needed to contact the Roald Dahl Nurse between routine appointments, with nearly three quarters of parents (n=102/140, 72.9%) needing to contact them at least three times in the last year. The main method of contacting the Roald Dahl Nurse is by telephone, with some using texts, emails and voicemail contact methods. Parents described how this accessibility and availability of the nurses often provided quick answers to their worries, relieving their anxiety:

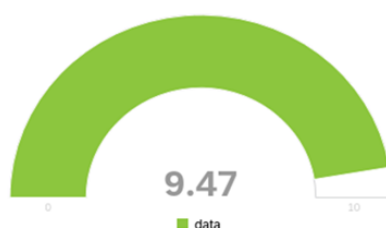
*"Our Roald Dahl Nurse is always available at the end of a phone call to answer any questions and if unable to help there and then, will always come back to us" [Parent].*

*"Very easily accessible which is great when you're full of worries" [Parent].*

*“I am very impressed at how promptly the [Roald Dahl] nurse replied to text / phone calls and the advice and help given, I cannot praise them enough for their advice, care and support...they are doing a fantastic job” [Parent].*

Nurses agreed that they can be really responsive in terms of reassurance to parents and answering quick questions that otherwise would build up their anxiety: *“small things make a massive difference”*.

When asked about the overall satisfaction with the care received, the families indicated this was extremely high, with a mean of 9.47 on a sliding scale of 1 to 10 (Figure 3.6).



**Figure 3.6 The overall satisfaction of parents with the care received from the Roald Dahl Nurse**

The children and young people who completed the survey (n=36) were also extremely positive about engaging with their Roald Dahl Specialist Nurse, with 88% (n=22/25) stating that their nurse is friendly and two thirds (66.67%, n=18/27) 'agreeing a lot' that they like visiting their nurse. A high number also 'agree a lot' that the nurse explains things in a way they understand, and includes them in the treatment decisions (Table 3.1).

Question	I agree a lot	I agree a bit	I can't decide	I disagree a bit	I disagree a lot	Total
<i>I like going to see my Roald Dahl Specialist Nurse</i>	66.67% (18)	18.52% (5)	11.11% (3)	3.70% (1)	0.00% (0)	27
<i>My Roald Dahl Specialist Nurse is friendly</i>	88.00% (22)	0.00% (0)	12.00% (3)	0.00% (0)	0.00% (0)	25
<i>My Roald Dahl Specialist Nurse talks to me about my condition</i>	77.78% (21)	7.41% (2)	11.11% (3)	3.70% (1)	0.00% (0)	27
<i>My Roald Dahl Specialist Nurse explains things to me so I can understand</i>	80.77% (21)	7.69% (2)	7.69% (2)	3.85% (1)	0.00% (0)	26
<i>My Roald Dahl Specialist Nurse includes me in decisions about me</i>	76.00% (19)	8.00% (2)	16.00% (4)	0.00% (0)	0.00% (0)	25

**Table 3.1 Levels of children and young people's agreement with Roald Dahl nursing activities**

Managers and nurses also highlighted that their local service audits had signified overwhelmingly positive service user feedback. However they noted that obtaining quantitative feedback from already overwhelmed and busy families was a lengthy process, usually resulting in poor response rates to surveys:

*“It is so subjective what we do, it’s difficult to measure what we do, but we have put things in place since I’ve started...It is difficult, we’re asking a lot of families, they’ve got a lot to do so it’s been very slow to get feedback” [Nurse].*

The Royal College of Nursing identified wide evidence suggesting that there are high levels of patient satisfaction with specialist/advanced nursing care (RCN, 2016), although not many studies have attempted to capture the impact of specialist nurses from the patient or family perspective as in this current study. When asked what aspects of their work contribute most to high satisfaction or impact, the nurses stated that they were able to provide families with a service which was more responsive, more flexible and provided more time per patient than a consultant could offer:

*“Parents tell me time and time again that they’re so thankful because that’s been a big impact on patients, that they’ve now got somebody to contact, somebody that will answer their questions that helped with alleviating stress and patient experience, and reduced complaints or issues that the service experienced. I get good feedback from families as a whole...” [Nurse].*

Their work in coordinating services and rationalising appointments, as well as advocating on the families’ behalf, had a high impact not only on family experience of care, but also on care outcomes where better care was provided more quickly. This activity required nurses to work across professional boundaries in order to mobilise resources, and getting *“the right services involved at the right time”* appears to be the essence of the Roald Dahl Nurses' work. All stakeholders recognise the positive impacts on the patient, their family and the service in which they work. Attributes such as effective liaison across a range of professional and other groups, and effective communication about symptoms, treatment and emotional issues are often cited by patients as valued aspects of specialist nurses (Corner et al., 2003). In a scoping review of epilepsy nurse specialists, Campbell et al. (2019) identified that the key to their value is their specialist knowledge, their accessibility, the ability to cross boundaries, their ability to link up services, their leadership in service development and being a point of contact. This is very similar to the findings in this study of Roald Dahl Nurses. However Campbell (2019) notes that there are elements, most notably their role as a point of contact and liaising with and linking services, that are poorly recognised and inadequately evaluated in the existing evidence. Our study certainly showcases these two aspects of the role as being pivotal to the smooth running of the service and to patient experience.

### 3.2.2 Improved efficiencies and cost-effectiveness

The nurses presented themselves as 'active change agents', introducing a suite of interventions that they felt would lead to reduced waiting times, A&E visits, hospital admissions and duration of stay. They focused on increasing efficiency, reducing wastage and improving patient experience, and managers of the services confirmed their audits and experience surveys were positive:

*“We earn our keep, so we provide [income] with all the clinics we do, up to five a week, and teaching we bring in revenue and we cover the consultants’ workload basically, we are much cheaper than a consultant... I actually get to do service improvement, but also not only at our level, at Trust level and national level... I’ve been to Roald Dahl Nurses’ Conferences and networked with somebody and they’ve said they do this and I think that’s fantastic, I’m going to take that back, this can save us money” [Roald Dahl Nurse and Manager].*

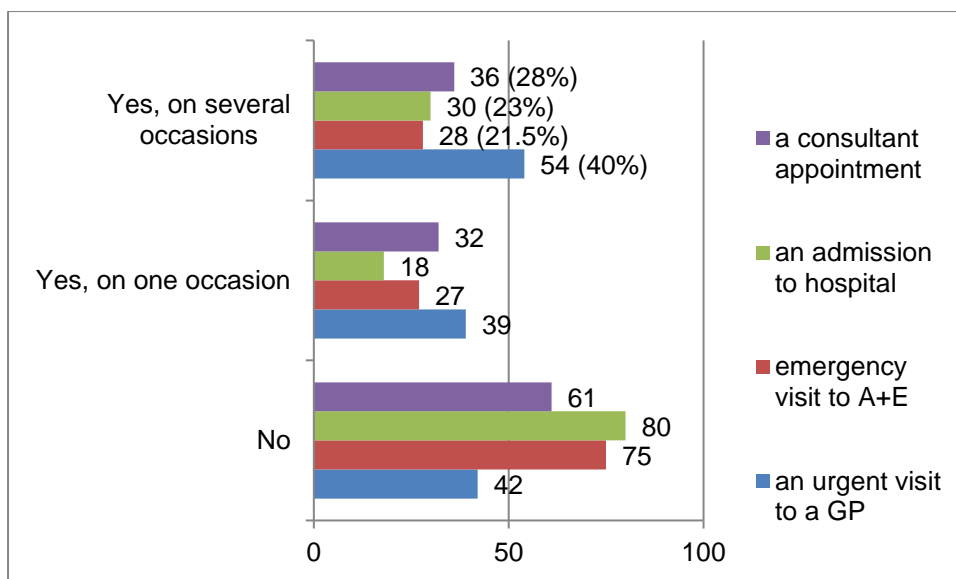
*“I think our team manager and the multidisciplinary team, they can see the value...What would happen if I wasn’t doing that? They [family] would just constantly call or attend A&E, so to the wider Trust we are reducing hospital admissions ... we will see patients on the ward, and we’ll get them home as quickly as we can” [Nurse].*

Many nurses had set up a telephone contact service to improve accessibility, not only for parents but also for the children and young people (CYP):

*“She is amazing and always there if we need her. She’s always one phone call away“ [CYP].*

*“Sometimes I feel that she is the only one who really understands how I feel and knows so much about my epilepsy. I can ask for a phone chat anytime and she makes time for me. She always knows what to say and reassures me“ [CYP].*

For many parents in this study, these unscheduled contacts provided information and relieved their anxiety. Indeed, 40% (n=54/135) of parents stated that this contact had prevented urgent GP appointments on more than one occasion, with over half of parents (52.7%, n=68/129) indicating that consultant appointments had also been averted on at least one occasion. However of even more significance is that 42.3% (n=55/130) of parents acknowledged that timely contact with the Roald Dahl Specialist Nurse had avoided visits to A&E, with at least one emergency admission to hospital prevented for 37.5% (n=48/128) of parents (Figure 3.7). Not only is this a positive impact in terms of reduced costs and time for the NHS, but also in terms of family anxiety and inconvenience. However it is challenging to assess the impact of one individual on a range of hospital metrics; clinicians in this study were divided in their opinions on whether the Roald Dahl Specialist Nurses had an impact on reducing re-admission rates, with two thirds identifying either no effect or a fairly positive effect.



**Figure 3.7 Parent's views of whether unscheduled contact with the Roald Dahl Specialist Nurse has previously averted the need to access emergency and urgent services for their child.**

All stakeholders provided examples of the nurses' impacts in terms of preventing escalation (preventing a major event requiring admission by intervening at an earlier stage). This included providing advice about medicines to parents out-of-hours to help stabilise their child, and re-arranging appointments so that a child of concern could be seen by a consultant earlier than scheduled. Nurses who had monitored their caseload over time were able to show reductions in the number of missed appointments, number of A&E visits, number of hospital admissions and reduced duration of hospital stay. While there may be a number of influences on these figures, it is clear that this reflected time and resources saved as well as the reduction of risk to the child's health.

The introduction of nurse-led clinics to replace consultant-led clinics is one intervention which can be easily equated with cost-effectiveness; the nurses' pay rates are less than a consultant, and the clinician can be freed up to see the more complex cases. However this is a simplified cost analysis, as often the clinics have been introduced in addition to the consultant services, rather than as a replacement for them. A systematic review of the impact of nurse-led clinics has shown positive impacts on self-reported patient outcomes, patient satisfaction and access to care, but only mixed results on cost-effectiveness (Randall et al., 2017). In our study the nurses described how the additional clinic enabled patients to be seen more quickly, more frequently or new patients seen; in this instance, while patient experience may be impacted positively, the costs would be higher due to greater demand and the costs of running the clinic. One quarter of clinicians in this study agreed that it was challenging to identify any positive productivity and efficiency impacts in some aspects of the care provided by Roald Dahl Specialist Nurses including saving money and reducing demand on services. In fact, as shown in the example above of an

additional nurse-led clinic, demand appears to increase in some services. Additionally, roles developed for the purpose of strengthening integration by reducing the number of different types of staff engaging with an individual patient have, usually, employed qualified staff at higher grades who are able to work autonomously and holistically. This could cost more in the short term (Erens et al., 2016) and it takes time for the impacts to be felt.

One aspect of the nurses' work which is often understated appears to be that of educating and empowering children, young people and their families to self-manage their conditions, thus becoming less dependent upon the Roald Dahl Specialist Nurse and other services. Many nurses gave individual accounts of this gradual handover of care responsibility, and while not appropriate for all patients in their care, it was often utilised for young people going through the transition to adult services.

*“She is easy to talk to and helps me understand and learn about my condition. Always gives me good advice” [Young person].*

*“She makes a difficult time easier and helps me manage things for myself instead of taking over” [Young person].*

The ultimate positive impact that a Roald Dahl Specialist Nurse can have is when patients and families are supported and empowered to no longer need their support.

### **3.2.3 Provision of holistic family-centred care**

Nursing in adult services is traditionally centred on the person (person-centred care) utilising a medical model. Family-centred care presents a shift of traditional approaches to the delivery of care that supports individuals within their family unit. A family-centred framework is essential because many families experience individual or collective health and illness which then becomes their family's world (IFNA, 2017). In the context of working with children with long-term conditions and their families, this type of collaboration is particularly relevant as these children are primarily cared for at home, with parents often taking significant responsibility for care decisions and delivering treatments (Kish et al., 2018; Smith et al., 2015a).

*“For the families signposting and linking them with people who can help them over something that they can't do, and it's just giving that whole, it's not just the child, it's the whole family with it as well” [Nurse].*

Providing family-centred care within a context of inter-agency working is likely to be challenging, time-consuming, and emotionally draining compared to the delivery of traditional patient-centred, hospital-focused care. The core components of family-centred care are developing an effective relationship with the family, and health professionals working collaboratively with them when planning and delivering care for the child or young person (Kuo et al., 2012). The Institute for Patient and Family-Centered Care (IPFCC, date) defines family-centred care as:

*An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.*

The IPFCC definition consists of four precepts: dignity and respect; information sharing; participation; collaboration (Johnson et al., 2008). Evidence presented in all phases of this study suggest that the behaviour and attitudes displayed by the Roald Dahl Specialist Nurses align with these four precepts, including the provision of independent and unbiased education and counselling [information sharing] leading to empowerment of families and meaningful participation in healthcare decisions [participation], advocacy for patient and family perspectives and values [dignity and respect], and safeguarding and non-healthcare interventions [collaboration] taken on behalf of the child and their family. Nurses recognised that providing family-centred care within a new or developing service was their responsibility:

*“Holistic family-centred care that our consultant colleagues do not have the capacity to deliver” [Nurse].*

*“We have a philosophy that’s very much around being person-centred. And I guess in a way our translation of that had always been about being family-centred” [Manager].*

The collaboration and advocacy elements of family-centred care were most clearly in focus when nurses and managers discussed risk management and safeguarding aspects of the role. Safeguarding (the term 'child protection' is used in Scotland) and the promotion of the welfare of children are defined in 'Working Together' (HM Government, 2018) as:

*protecting children from maltreatment; preventing impairment of children’s health or development; ensuring that children are growing up in circumstances consistent with the provision of safe and effective care; and taking action to enable all children to have the best outcomes.*

Many Roald Dahl Specialist Nurses had been surprised by the volume of safeguarding activity that they had to undertake, and they believed this was exacerbated by workforce shortages in other disciplines such as social work and social care. Safeguarding often took participants outside the traditional scope of nursing practice; helping a family to access social services, financial aid or housing benefits. Safeguarding, in particular child protection, was often an emergency and a priority over healthcare at that time. The impact of the Roald Dahl Specialist Nurses therefore



extends far beyond traditional nursing care, and parents recognised and appreciated this aspect of care. Managers noted that the safeguarding work reduced the amount of healthcare that they could provide and ultimately reduced the numbers on their list.

Safeguarding children is certainly challenging and emotionally draining, with many calling for safeguarding supervision to be built into daily practice. Clinical supervision provides an emotionally safe space that, in turn, promotes critical reflection and provides a strategy to mitigate nurses' workplace stress and enhance retention. Putting this supervision in place is more challenging for autonomous cross-boundary workers such as Roald Dahl Specialist Nurses, especially as it is unclear whether a more senior nurse or a clinician may be best placed to provide the supervision. While supervision has been shown to improve patient safety and effectiveness of care (Snowden et al., 2017) there is little evidence that it can mitigate against burnout (Buckley et al., 2020) or the emotional impacts from safeguarding activity. Nevertheless, it can be used as a fail-safe mechanism for nurses who need support, as well as offering valuable CPD opportunities.

Parents recognised and appreciated the family-centred care approach adopted by the Roald Dahl Specialist Nurses, particularly those who had received a more traditional approach previously. One parent who had recently moved from traditional care to this family-centred approach described the experience of having a Roald Dahl Specialist Nurse as *"a breath of fresh air"*. Parents expressed the huge difference this made to their own, their child's and their family's lives, with support and care for the whole family widely recognised. Examples of family-centred care in action were recounted by many parents who indicated that they highly valued the non-clinical services provided by the Roald Dahl Specialist Nurse, including 'providing emotional support for myself or my family' and 'advocating (speaking on my family's behalf) to other authorities or individuals'. Many specific examples were provided by parents who indicated that the care provided to the wider family had helped parents to cope with their own mental health challenges so they could be more positive for their children:

*"Our [Roald Dahl Nurse] has been a godsend to us at some of the lowest points in my life. I honestly don't think I would mentally be where I am now without her" [Parent].*

*"Our amazing nurse is a compassionate, knowledgeable voice, who is pretty much always available, this has massively reduced family anxiety, bridged a huge gap and reduced lengthy waiting times trying to contact consultants, and been a regular (sometimes weekly) proactive guide through medication and condition concerns and changes. She has made a dramatic impact on our lives, and we really don't know how we would get through so many days without her support and dedication" [Parent].*

The family-centred care provided was appreciated with parents stating that their nurses were: *“amazing”, “appreciated”, “a godsend”, “invaluable”, “incredible”, and “worth their weight in gold”*.

### **3.2.4 Demonstrating leadership and innovation**

Roald Dahl Specialist Nurses demonstrate advanced leadership skills. The nurses in this study noted that service development represented a significant aspect of their role, although identifying, implementing and evaluating service improvements took time. It involved improving existing services by restructuring care pathways or facilitating access to available resources, as well as designing new aspects of the service, drawing upon the expertise of different professionals. Managers gave examples of where these innovations had had a positive impact not only on patient care, but also on the team that delivered them. Clinicians also identified positive impacts on service provision as a direct result of the Roald Dahl Specialist Nurse leadership and innovation. These included improved psychological and practical support; better multi-disciplinary team working; improved access to services; better co-ordination of care and support navigating the healthcare system. All of these aspects of service delivery received positive feedback in the parent survey.

*“And it’s also looking at, so not just standardising [services], how can we make it more equitable across Trusts as well because we know that different services can look so different, even if they are from the same specialty from site to site” [Manager].*

Impacts on individual patients and the wider service were most profound where nurses had designed or reshaped pathways of care and communication to improve patient experience and care outcomes. Several nurses had designed and implemented nurse-led clinics and nurse-led services which could offer more frequent and longer appointments to the families. To encourage self-management and transition, in some services clinic appointments and scheduled telephone calls were also offered for young people to access without their parents if they wished. New telephone contact services for scheduled appointments and unscheduled contact had also been introduced by many Roald Dahl Specialist Nurses; the Covid-19 restrictions had resulted in the use of scheduled telephone appointments being scaled up rapidly.

The creation and reshaping of transition pathways appeared to be important for all Roald Dahl Specialist Nurses, not just the transition specialists. Successful transition is now recognised as an important facet of care in both paediatric and adult medicine; it is not simply transfer of care from children's services to an adult provider, but should be a gradual process taking into account physical and psychological maturity as well as the availability and structure of local resources (Urquhart-Kelly and Wales, 2019).

*“The roles [of Roald Dahl Specialist Nurses] are more about influencing and encouraging and engaging our clinical staff to think differently about how they support young people... has anybody thought about beginning the transition pathway... it’s about planting that seed to say actually thirteen is an ideal time to start having those conversations” [Nurse].*

Recent interest in transition has been promoted by concerning reports such as the Care Quality Commission Report on Transition which highlighted significant care gaps in many specialties and centres (CQC, 2014). More recently, individual specialties including epilepsy and childhood cancer survivorship have begun to review transition practice (Urquhart-Kelly and Wales, 2019). Nearly all of the Roald Dahl Specialist Nurses in this study had invested significant time in reviewing their transition pathways. Transition is known by some of our nurses as a 'rocky road,' fraught with challenges that could lead to a neglect in care and see some young people slip through the system. The nurses endeavoured to replace the outdated 'transfer of care' model with the more apt 'transition pathways' approach, using a variety of innovative solutions. Clinicians agreed that the transition from child to adult services was emerging as an important issue requiring specialist support, with some currently exploring transition posts to work alongside their existing Roald Dahl Nurses:

*“Transition is a huge step for any young adult with a rare disease that has been under paediatric services and there is often so much to coordinate and even create to allow successful transition to adult services, hence the business case for this post” [Clinician].*

Establishing innovations within pathways that spanned across services meant that Roald Dahl Specialist Nurses needed to expend significant time and energy in creating and fostering new inter-agency links and networks. There were many examples of how nurses had built interdisciplinary teams from scratch and had coordinated the work of different professionals to avoid duplication of efforts. These actions often saved time and money, but, in some cases, novel innovations had also generated revenue for the hospital and Trust. Managers noted that this work was often hidden from view, yet it promoted positive changes in organisational culture and openness. However, a more transparent and powerful impact beyond their immediate workplace has been orchestrated by the nurses educating the wider healthcare team and non-healthcare staff in other agencies and organisations about their specialty. Roald Dahl Specialist Nurses actively worked to produce and share research knowledge with fellow child specialists including physicians, GPs, community and school nurses, as well as with staff with limited healthcare knowledge such as teachers and social workers. They offered teaching and training to colleagues within and outside the Trust and built communities of practice that served to educate families, students and professionals. Teaching innovations aimed to not only share knowledge, but to change culture:

*“They’ve [Roald Dahl Specialist Nurses] spent such a lot of time teaching and training others and the feedback often I get is about, oh it’s been marvellous, they’ve come, we never knew that, we never even thought of it, now we’ve put this in place. And actually a lot of that stuff is not at a cost, it’s only about behavioural differences” [Manager].*

*“She has ‘upskilled’ a number of community and school nurses and involved them actively in patient care” [Clinician].*

*“I’m involved in teaching of nurses. I’m thinking of innovative ways to make as good use of my time as possible. So, I am trying to make online resources and things like that. I’m part of nurse induction... when the nurses start, they come to spend a little bit of time with me” [Nurse].*

Several nurses had recorded the number of teaching sessions for families, students and peers together with the number of attendees, and had evaluated the extent to which nurse-led teaching informed learners and/or resulted in positive changes in practice. However, this education did not stop at the boundaries of care; many Roald Dahl Specialist Nurses engaged in activities within and outside the hospital environment to increase public awareness about rare conditions, informing societal perceptions and raising the profile of different health problems. The impact of such work is hard to measure, but will undoubtedly support the better integration of children (and adults) living with long-term conditions into society.

### **3.3 Perceived Challenges**

All stakeholders in Phase 1 articulated a number of challenges that impacted the roles of Roald Dahl Specialist Nurses. These included organisational issues such as poor access to resources and a lack of administrative support. The majority of nurses, managers and clinicians indicated that expanding caseloads were the main challenge when seeking to maintain standards, equity of access and protecting nurses’ emotional wellbeing. In addition, difficulties measuring impact in meaningful ways was highlighted as an issue that may be a barrier to future investment in these services.

#### **3.3.1 Organisational challenges**

Several clinicians highlighted a number of challenges when trying to secure commitment from their NHS Trusts or Health Boards to support their application for the Roald Dahl Specialist Nurse roles. These challenges included the clinician's lack of experience in creating a viable business case, and in some cases a perceived ‘dire financial status’ which resulted in a freeze on recruitment for new posts. Critical to a positive outcome was being able to challenge conventional wisdom and convince senior leaders that these ‘Cinderella services’ were worthy of investment in the longer term:

*“From my experience of being a consultant with 21+ years of experience, paediatric epilepsy service in most DGHs is a Cinderella service with a lack of investment, unlike other services such as paediatric oncology or diabetes service. Hence, to convince the management of need for an epilepsy nurse specialist is an uphill task” [Clinician].*

*“Failure to persuade NHS Health Board management of this being a priority, and so funding not available...” [Clinician].*

*“First of all is the acceptance of the roles by the Hospital Management and Nursing Team given the novelty of the idea and also commitment to continue funding the post after the initial two years” [Clinician].*

Once the business case was approved, finding the right person for these unusual roles was very challenging; the most experienced or highly qualified candidate was not necessarily the best fit for the role. Rigorous selection processes were required:

*“Selecting a competent, dynamic individual was going to be tricky ... selecting a candidate who is ready and capable of evolving, not afraid of taking on initiatives and who genuinely loves working with people. The nurse in question has risen to the challenge in a very impressive way. This reflects her own personal abilities, but I am aware that the support she receives from the Roald Dahl[’s Marvellous Children’s Charity] network has also been vital” [Clinician].*

Once in the role, the first challenge that many nurses encountered was the need to establish the new service. Tackling this challenge was often complicated by several issues related to systems and processes within the employing organisation (NHS Trust or Health Board), including a lack of processes to get services up and running, poor infrastructure, limited technological resources, staff shortages, financial constraints and bureaucracy. Therefore, creating a sustainable, smooth and seamless service was a time-consuming and frustrating process that was described by one participant as *“treading water just trying to make everything work” [Nurse].*

Implementing new services required tenacity; the Roald Dahl Specialist Nurses initially encountered some resistance to change requiring them to explain their role and define their identity in inter-professional settings. Overcoming inertia and reshaping the organisational culture was another challenge that some nurses overcame through effective communication and promoting best practice.

*“When I first started, I think people were a lot more ‘what are you doing? Well, why have you come to see that patient?’ We were like ‘well we’re here to support the family’. So, it wasn’t a barrier as in don’t come, but it was a bit like well what are you doing? Well, it’s a new service. And explain to them about the service and what we’re doing and we’re here for the family” [Nurse].*

*“You’ve also got the issue with consultants and we use the culture of ‘this is what we do’ and trying to get them on board with actually ‘this is what’s best’ and this is what’s going to provide the best care for the patient ...and changing their culture and their mind-set on board with your thinking” [Manager].*

Once the service was established, a lack of administrative support was highlighted by the majority of the Roald Dahl Specialist Nurses, managers and clinicians as a barrier to effective practice. Most of the nurses' clinical caseloads are high, and they wanted to spend as much time during the working week as they could with their patients and families. However they were conscious of the high volume of non-clinically related tasks that they were required to undertake which detracted from their clinical duties. One participant in the focus groups named herself a “jack of all trades” as she was caseload manager, social worker, administrator, support worker, educator, advocate and spokesperson. Trying to fulfil these multiple roles had consequences for the nurse's mental wellbeing. Sometimes, the nurses took their work home as they completed reports and responded to calls and emails after hours and during weekends. Nurses were particularly concerned about their administrative burden; they explained that even if they had introduced nurse-led clinics to reduce the burden on their consultant colleagues, they rarely had access to the same level of administrative support. This inequity meant they were often typing letters to patients, consultants or GPs late into the evenings. Similarly, the inputting of data can be time-consuming and is not the best use of a highly skilled nurse's time. Valuable clinical time was wasted on paperwork and clerical tasks, and this was recognised by clinicians who felt that as caseloads expanded the Roald Dahl Nurses’ would require additional support. A recent RCN survey also identified that too much time was spent on non-nursing duties, and this appeared to be highest in both care homes and in community-based services (RCN, 2018).

The administrative load was exacerbated as access to computers was an issue for some nurses, who had to hot-desk and wait until a computer was free to be able to access valuable information. Where nurses had access to an office (often shared) and a computer, the computer was often slow and did not meet their needs. Over time some nurses were able to secure better equipment. While access to technology such as laptops was easily solvable, one of the greatest technological frustrations expressed by the nurses, particularly those working across acute and community settings, was that of patient data being housed on multiple IT systems that 'do not talk to one another'. Multiple different log-ins were required which frustrated the nurses and wasted valuable time. These multiple systems create inefficiencies and increase risk due to multiple data entries. Issues of bureaucracy, digital capacity and efficacy within healthcare systems have been widely investigated (Asthana et al., 2019; Iliffe and Bourne, 2020). The literature emphasises the positive impacts of effective administrative and technological support on the productivity of clinicians (Aletras et al., 2007).

Many of the nurses highlighted the high volume of safeguarding activities that had not been anticipated prior to commencing the role. This required persistence and often multiple interagency phone calls between schools, parents and social services. Some of the nurses and managers suggested that there was sufficient work for a social worker or mental health professional to be commissioned to work with the service.

*“I suppose all the services aren’t there that you would want, out in the community as well. So, you ring colleagues and whatever, or you’ve children in here who have been here for weeks and they need discharging, and they need discharge plans and packages put in place, and it’s not there and whatever. That is all very frustrating...” [Nurse].*

While safeguarding activity requires higher level skills from the specialist nurse, much of the liaison that they were undertaking on a daily basis could be reasonably undertaken by a trained support worker. For example, some nurses spent a lot of their time trying to secure telephone interpreters to overcome language barriers when communicating with families, especially in areas with high asylum and refugee settlements. Knowledge from existing research suggests that migrants in the UK are more likely to seek emergency care and they struggle to obtain long-term medical assistance given their limited command of English and understanding of how the system works (O'Donnell et al., 2007; Phung et al., 2020; Ruud et al., 2015). However, the supply of skilled interpreters was limited, exacerbated by a transfer of hospital-based interpreters to outsourced telephone services, and this impacted on the work of some nurses quite severely. They suggested that a support worker or administrator could undertake the liaison with the interpretation services.

These non-clinical elements of the Roald Dahl Specialist Nurses' roles (administration, arranging and rearranging appointments, inputting data, securing translation, safeguarding liaison) all took large amounts of time that the nurses felt did not utilise their skills and could be undertaken by an administrator or trained support worker. This would free up the nurse to spend more time on front-line clinical care with the children and their families.

### **3.3.2 Achieving sustainable workloads and caseloads**

The caseload, very simply, is defined as the number of cases that a health professional is dealing with at any one time (i.e. the patients on their books). However with Roald Dahl Specialist Nurses this is more complex as the 'case' not only includes the patient but also their family. The complexity is further exacerbated by the nature of the children's conditions; while the children have routine appointments scheduled, they may also present for urgent or emergency appointments. In this study over one quarter (27.9%, 47/147) of the parents indicated that their

children were unstable, with 61.2% (n=90/147) needing at least one A&E visit in the last year. Many of these patients require support from multiple services across agency boundaries.

Eight (47%) of the Roald Dahl Specialist Nurses in this study had caseloads in excess of 300 patients, and four (23%) had a caseload in excess of 400. Four nurses in one clinical centre (three FTE) had a caseload of less than 20 patients, although this small caseload number accounted for some of the most complex children with rare and genetic diseases. Many nurses, managers and clinicians described the Roald Dahl Specialist Nurses' caseloads as 'unreasonable':

*“We have a single [Roald Dahl] Epilepsy Specialist Nurse for a paediatric epilepsy caseload of 650+ patients with a significant higher percentage of CYP [children and young people] with complex epilepsy” [Clinician].*

*“This is a huge caseload for one person. In our setting, the Roald Dahl Nurse also covers neurology and in this regard, the clinical complexity of the patients can be quite high” [Clinician].*

There is guidance available on safe nurse staffing levels for nursing within ward environments, where a nurse-to-patient ratio can be clearly articulated (RCN, 2011). However describing safe staffing levels in the community (and in services such as Roald Dahl Specialist Nursing) is far more complex than within hospital wards (RCN, 2011). In these settings, the measures used to demonstrate safe staffing include: 1) nurses per 1,000 head of population and 2) caseloads (no. of patients per nurse). For example, in gastroenterology, the *Standards for the Healthcare of People Who Have Inflammatory Bowel Disease* (Crohn's and Colitis UK, 2013) stated that 1.5 full time equivalent nurses were required per 250,000 population. This was set by consensus, not evidence, and later publications called for an increase to 2.5 per 250,000 population (Leary et al., 2018). As an example of measurement by caseload numbers, the Royal College of Nursing (2005) recommends at least one Epilepsy Specialist Nurse per 250 children with epilepsy. The RCN (2011) note that:

*Both (calculation methods] are fraught with difficulties as none of the parameters are fixed, so it is almost impossible to arrive at consistently defined data that allows averages to be produced and comparisons drawn.*

The Queen's Nursing Institute (2016), however, attempted to rise to this challenge in their report about safe caseloads in District Nursing. This report identified a number of considerations in defining manageable caseloads including service hours, geography, transport, and technology. Although not all of these variables are transferable to the current study, some Roald Dahl Specialist Nurses did undertake home and school visits prior to the pandemic restrictions. In 2018 the Institute for Health Visitors, a service also crossing healthcare boundaries, identified that over half of health visitors surveyed were managing caseloads above the recommended number of



250, with over one quarter having caseloads above 500. These higher caseloads resulted in higher stress, more staff sickness and therefore an inadequate service.

In the current study, most of the nurses' caseloads had grown since commencement of the role. A lack of initial clear inclusion and exclusion criteria for acceptance onto the caseload resulted in a caseload expansion that was inevitable; this expansion was so rapid in some services that nurses referred to the growth as “*exponential caseloads*”. Sixty-five percent of the clinicians recognised that their Roald Dahl Specialist Nurse's caseload had expanded since the inception of the service; one quarter of the clinicians and the majority of nurses felt the caseload was not sustainable at the current level:

*“The caseload is increasing, and the complexity is as well... I foresee that sooner rather than later additional specialist nurses will be required to enable us to provide the quality (and equity) of care throughout the region... Our caseload is increasing as the service is maturing and as we take over more children from other paediatric services across the region” [Clinician].*

*“The conditions have just increased tenfold, and the dependency of patients...” [Nurse].*

*“We both started off the service with half a dozen patients each and then by the time I left it was up to 300...So it's grown since I first came here and it's an awful lot of work for one person” [Nurse].*

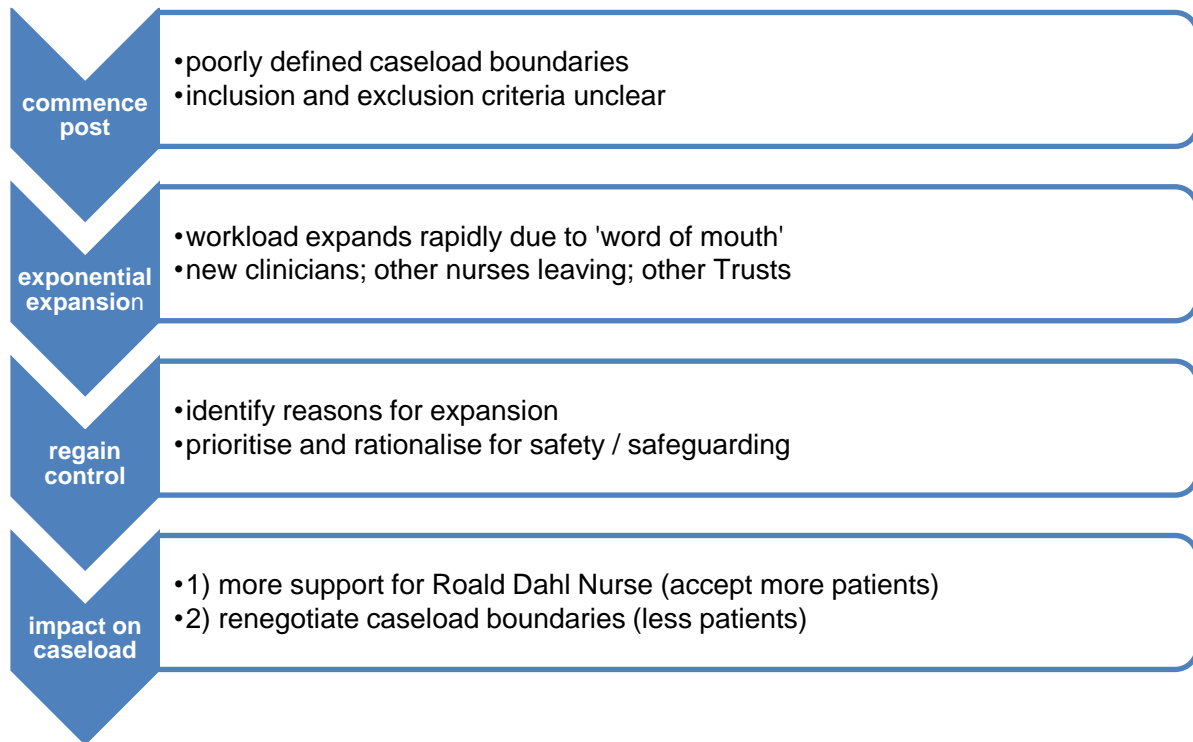
Once the caseload had grown, nurses found it challenging to reduce it. It was difficult to transition patients due to inappropriate services in place as well as some parental (and clinician) resistance, yet new cases were added every week. Nurses experienced what they described as “*emotional blackmail*” to take more patients even when numbers were clearly beyond safe limits.

Nurses and clinicians recognised that in many services the size of the caseload is less important than the complexity of the patients, and that some small caseloads (such as rare and genetic diseases) may be just as challenging as higher caseloads with less clinical care need. However some of the caseloads with very high numbers (such as epilepsy) are challenged with a small number of highly complex and often hospitalised patients, and a large cohort of patients with a much lower requirement for regular input. However, the Roald Dahl Epilepsy Specialist Nurses expressed anxiety and guilt that many of their caseload, who could benefit from their care, do not receive it because they have to prioritise the sickest patients.

The patterns of caseload expansion and subsequent attempts to regain control are common across most of the Roald Dahl Specialist Nurses, as shown in Figure 3.8.

Caseload expansion is certainly a concern, and workload is one of the key barriers to specialist nurses achieving impact in their role (Gerrish et al., 2006). In a scoping review of the impact of epilepsy nurse specialists, the authors concluded that there is a need to better understand the

impact of their caseloads, and workload thresholds which may overstretch services and reduce their impact (Campbell et al., 2019). Many lead clinicians in our study also expressed concern regarding the caseload expansion, with some suggesting that a second Roald Dahl Specialist Nurse or a support worker was required.



**Figure 3.8 How the caseloads of Roald Dahl Specialist Nurses evolve over time**

*“I think it [the caseload] is quite high and very complex, so I would definitely call it unreasonable. It would be great to have more Epilepsy Specialist Nurses, especially experienced ones...”*  
*[Clinician].*

*“We have been extremely happy with our current Roald Dahl Epilepsy Specialist Nurse. She has added significant value to the patient management pathway. However I worry that this is a right recipe for burnout and job dissatisfaction for her, due to the humongous caseload and a higher complexity of the caseload. Unless our Trust recruits another ESN to support the current one - then I fear that in due course of time we will end up losing the current one as well”* *[Clinician].*

The clinician above stated that caseloads were *“a recipe for burnout if not addressed”*. It is critical to assuage some of the burdens imposed on nurses to safeguard against staff burnout (Khan et al., 2018) which can lead to a reduction in productivity, emotional stress and, ultimately, absence due to poor physical and mental health. The levels of burnout in paediatric nurses is found to be moderate to high, with higher levels than adult nursing due to the specialised nature of providing care to vulnerable children, the high potential for empathetic engagement, and the complexities in the relationships with families (Larson et al., 2017). Several Roald Dahl Specialist Nurses had

experienced emotional stress at times in their tenure. One clinician noted the importance of finding a nurse with the strong resilience that is required for the role:

*“Selecting a competent, dynamic individual was going to be tricky, I knew. I needed to appoint the best candidate ... In developing and planning the role, I was quite particular with selecting a candidate who is ready and capable of evolving, not afraid of taking on initiatives and who genuinely loves working with people. The nurse in question has risen to the challenge in a very impressive way. This reflects her own personal abilities, but I am aware that the support she receives from the Roald Dahl network has also been vital” [Clinician].*

A recent scoping review of burnout in paediatric nursing identified 78 studies for inclusion in the analysis (Buckley et al., 2020). Across the included studies burnout was found to be prevalent in paediatric nurses, with poorer outcomes in nurse retention, nurse well-being, patient safety, and patient-family satisfaction. Those with less experience and lower education levels appeared to be more prone to burnout (Buckley et al., 2020). A range of precipitating factors for burnout in the work environment were found in these studies, including, work-life interference, psychosomatic complaints, and intent to leave; these have associations with excessive workloads and the number of assigned patients. Systems issues such as overwhelming clerical work, administrative and resource issues also impact provider burnout (Buckley et al., 2020). Unfortunately, there was little evidence of effective interventions to address paediatric nurse burnout (Buckley et al., 2020), although interventions such as regular support, additional education and skills training and having high group cohesion may help.

In the focus group discussions with the Roald Dahl Specialist Nurses, a couple of the nurses shared their experiences of difficult mental health issues related to their work, and they all recognised some aspects of the precursors to burnout, acknowledging that they had regularly practiced 'crisis management' for everyone else while neglecting themselves. It was very difficult to 'say no' and so their workload grew, and they had little time to do the core job as the clerical burden also grew. Unlike nursing duties in a ward environment, the Roald Dahl Specialist Nurses stated that taking annual leave or sickness absence was a worry as there was no other member of staff to pick up their work; they therefore returned to an even higher backlog of cases. All stakeholders recognised that achieving a sustainable caseload was imperative for the long-term health and wellbeing of the post-holder, and therefore success of the role. To be sustainable, *“ any caseload figure needs to strike a balance between what is desirable on the one hand and what is realistic and achievable on the other”* (Multiple Sclerosis Trust, 2014). Sustainability in terms of the Roald Dahl Specialist Nurses' workloads will need careful attention, not only as regards patient eligibility based on pre-defined inclusion and exclusion criteria, but also in relation to other aspects that can significantly impact on their role.

### **3.3.3 *Measuring impact***

Impact can be defined in different ways but is essentially a marked effect or influence on someone or something. It is clear from the findings of the parent survey that the Roald Dahl Specialist Nurses have a marked effect on the patients and families that they support. From examples submitted in the interviews with managers, and in the questionnaires with lead clinicians, it is also evident that they have a positive influence on the service in which they work. For example, they have undertaken service evaluations and improvements, remodelled transition pathways, strengthened multi-agency working and simplified patient access with improved communication systems.

More challenging, is identifying a mechanism to quantify the effect or influence with some sort of measurement, and this has been highlighted as a key challenge for nursing by the RCN (2009). This, they say, is because there is little consensus surrounding the terminology and definitions assigned to specialist nursing titles, roles, and functions between one role and another. The unique nature of each specialism increases the variability of the roles, and these roles lend themselves to indirect (e.g. stakeholder perspectives) rather than direct patient outcomes (RCN, 2009). A limitation of many current studies is small sample size, which makes generalisation of findings difficult (RCN, 2009), and in most cases this involves a single centre (and often single nurse) service evaluation. A robust example of such an evaluation is the Roald Dahl SWAN (syndromes without a name) Specialist Nurse evaluation at Great Ormond Street Hospital (Oulton et al., 2018). This evaluation studied stakeholder experience and other measures at baseline (when the nurse came into post) and then at a six and 12 month follow up period. As often occurs in such studies, the participants reduced dramatically towards the 12 month period, but at six months the participants' expectations were being met more effectively with the nurse in post and patient experience was good. This evaluation demonstrated that the impacts on families and stakeholder satisfaction with the service was high, and the Trust continued to support a nurse permanently in this role.

Demonstrating the financial impact of the role is challenging in patients with complex needs who interact with a range of services and health professionals. In a stretched NHS, the cost-effectiveness of new or enhanced roles will be of interest, however, in most cases, there is almost no evidence that new roles save money. While most roles can be shown to save money in some aspects, the evidence for cost-effectiveness is limited by the absence of data on costs before and after initiation of the service. The SWAN study mentioned above is one exception to this, as baseline data was collected at the commencement of the role (Oulton et al., 2018). In the current study, clinicians recognised these challenges, noting that cost savings take time to be demonstrated, and may actually increase due to the demand for services increasing.

They also outlined the challenges of proving the cause and effect relationship, as the nurse does not work in isolation. Roald Dahl Specialist Nurses typically believe that the more calls, cases and teaching a nurse has been able to manage, the more productive they consider themselves to have been.

*“We’re looking at things like Was Not Brought [non-attendance] rates to the clinic... other ways that I could evaluate my role is the amount of phone calls that I get for advice, the number of emails that I get for support and advice” [Nurse].*

*“Calls that we’ve made, or we’ve received, and the patient Excel sheet we’ve got, we write on there what the conversation was, what’s been done, how long it took and about the phone calls as well” [Nurse].*

However, managers recognised the complexity and time-consuming nature of many of their duties, and acknowledged that the work of the nurses cannot always be measured in numbers and should not be reduced to ticking tasks off a checklist. In other words, responding to less calls or emails was not equated with lower efficiency. Instead, the quality of advice and support that families received were more accurate measures, and parent/patient reported questionnaires and informal feedback were used to evaluate the extent to which the services offered had been impactful.

Introducing a service improvement, and then evaluating the cost-effectiveness of this activity is a useful indicator of the cost-effectiveness of the wider role. For example, one Roald Dahl Epilepsy Specialist Nurse had reviewed the cost savings of one aspect of the care that she provided to families. This telephone contact service was described as a previously 'hidden' aspect of care (Johnson, 2017). In a similar study (John et al., 2019), a three month breakdown of clinical workload and outcomes identified that an Epilepsy Specialist Nurse had 620 patient encounters with 251 different patients; nurse-led clinic appointments and telephone calls were the two most common types of encounter. Eighteen percent of time was spent on the phone directly addressing patient concerns relating to medication management, which led to prevention of a clinic appointment in the majority of cases (John et al., 2019). This service evaluation demonstrates that timely intervention by telephone reduces the need for outpatient appointments and leads to treatment changes being implemented quickly. All of the Roald Dahl Specialist Nurses are engaging in similar telephone contact with some currently collecting and analysing data to assess any financial impacts:

*“Seeing how it could help reduce the re-attendance into hospitals and A&Es and reduce their length of stays in hospitals. And since [Roald Dahl Specialist Nurse] started, there has been a reduction, so our regular attenders are not as regular as they used to be, because they get captured before they come into A&E, the correct advice is given, or if they do go to A&E... it reduces bed stays” [Manager].*

Indeed the Covid-19 pandemic has increased telephone and online videoconferencing, replacing some face-to-face clinics; it is probable that post-pandemic the remote practices will be retained in many cases, contributing to further cost-effectiveness.

Several of the study participants have also introduced service innovations, including improving accessibility via a telephone service as in the example above, reducing appointment waiting times and increasing capacity by setting up nurse-led clinics. Most of these services have evolved gradually and have been evaluated or audited only once the service has been set up. Without reliable data before and after the intervention, it is more challenging to show cost-effectiveness or improvement in patient outcomes. In many cases the nurses have noted the subjectivity in these evaluations, and they have favoured qualitative data which shows high levels of satisfaction from stakeholders. However, it is very difficult to widen these small-scale single-centre studies to other centres because the services are so different. Even in the same specialty, such as epilepsy, there are large variations from one centre to another including acute or community care, geography, demographics, age ranges and caseload numbers. Measuring impact of specialist nurses is therefore difficult at scale; in an ideal world the nurse's role would be standardised across settings and data would be collected pre and post the intervention (appointment of the nurse), or as a clinical trial where some patients received the intervention and others did not. Clearly this would be inappropriate to undertake across Roald Dahl Specialist Nursing services.

A recent scoping report looking at the role and impact of epilepsy specialist nurses (Campbell et al., 2019) recognised that while comparative quantitative studies offered insights into the effectiveness of specific initiatives, it was also vital to explore impact showcased by qualitative methods, questionnaires and mixed-methods studies. These methods explored the experiences and views of patients, their carers, ESNs, and other members of the healthcare team. Macmillan (no date), who also pump-prime specialist nurses, have also recognised the challenges of small-scale indirect evaluations and a lack of meaningful quantitative studies to assess impact.

This study, however, has been able to compromise on these ideals by gathering indirect yet comprehensive data on the role and impact of the Roald Dahl Specialist Nurse. The strength of this study, unlike many others reviewed, is that it takes a 360 degree view of the Roald Dahl Specialist Nursing role from a much wider range of stakeholders than is routinely accessed, and at multiple sites rather than the single-centre studies often presented. While the different specialties add significant variation to the study, the attempt to capture data at a similar time post-appointment adds greater standardisation to the project. Additionally, the mixed methods approach used in this study has enabled multiple approaches (use of both quantitative and qualitative methods) to strengthen the study and yield meaningful data compared to using one method alone.

#### **4. CONCLUSIONS AND RECOMMENDATIONS**

The aim of this project was to explore, from the perspectives of multiple stakeholder groups, the role and impact of the Roald Dahl Specialist Nurses.

Participating nurses worked across eight different clinical specialties with the most commonly encountered roles related to epilepsy and non-malignant haematology. Nurses also worked in rare diseases, neurology-related specialties and child to adult transition services. Regardless of the specialty, the golden thread connecting the Roald Dahl nursing roles is that the children and their families cared for within their services are living with complex lifelong conditions. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability. The complexity of many of these conditions mean that healthcare cannot be delivered in isolation; it is often inextricably linked to additional needs, for example in education, social services and housing. The Roald Dahl Specialist Nurses have forged networks across these interagency boundaries to safeguard the child and family and make sure they are safe and supported in these other aspects of their lives; ensuring that the healthcare that is delivered has the maximum impact.

This research has categorised the depth and breadth of the role played by the Roald Dahl Specialist Nurses; a unique role which goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for their patients and their families. This role is not easy to step into and fill, particularly where a new service, and the role within it, needs to be moulded and crafted from the start of their tenure. The Roald Dahl Specialist Nurses require a particular skill set beyond their clinical expertise to equip them for this role, including the core attributes of passion, empathy, motivation, professional excellence, patient advocacy, proactivity, enthusiasm, resilience and team spirit. Innovation was a key driver for all of the nurses and this yielded new ways of working to improve patient experience and outcomes.

It is evident throughout this research that the Roald Dahl Specialist Nurses, regardless of their specialty, location, organisation or service focus, have a profoundly positive impact on the stakeholders around them.

The opinion of all managers in this study was that the Roald Dahl Specialist Nurses had proved to be invaluable assets and were indispensable for service users, the Trust, the medical team and community. Clinicians recognised that, very quickly after their appointment, the Roald Dahl Specialist Nurses had established themselves as drivers of service quality and they had become the linchpin around which the service revolved. Their impact on patients and families was clear for clinicians and their multi-disciplinary team to see:



*“... the addition of a Roald Dahl Specialist Nurse has greatly improved the quality of service we offer to our patients and their families, and feedback from these families has all been extremely positive.”*

The Roald Dahl Nurses are embedded in the service and clinicians made it clear that they would be unwilling to move forwards without the nurse in place:

*“I do not think that there is any way the service at [hospital] will be able to function effectively without the Roald Dahl Specialist Nurse. If anything, my opinion would be that we need more than one or two of them. They are highly appreciated.”*

The parent survey responses have described the profound impact that Roald Dahl Specialist Nurses have had on parents and their families. When asked about their overall satisfaction with the care received via the Roald Dahl Nurse, the families indicated this was extremely high, with a mean of 9.47 on a sliding scale of 1 to 10. The parent testimonies have highlighted that the service provided by Roald Dahl Specialist Nurses follows the philosophy of family-centred holistic care, and is highly valued by parents who described their nurses as *“amazing”, “appreciated”, “a godsend”, “invaluable”, “incredible”, and “worth their weight in gold”*. The two following comments from parents highlight two of the most important aspects of care that parents appreciated, that of educational and emotional support for parents, and acting as a care navigator and advocate for the parents and child:

*“Having a Roald Dahl Nurse has made coming to terms with my child's condition so much easier to bear”; “without our amazing Roald Dahl Nurse, I would feel isolated, lost in the medical system and unsupported.”*

The findings from this research study have yielded three overarching recommendations: future investment in Roald Dahl Specialist Nurses; need to support Roald Dahl Specialist Nurses; requirement to demonstrate the value and impact of Roald Dahl Specialist Nurses.

- This research has evidenced the highly valued role and profoundly positive impact of the Roald Dahl Specialist Nurses. Moreover, it has recognised how these nurses can often become ‘victims of their own success’ having to deal with very high caseloads. The findings of this research support the future establishment of further Roald Dahl Specialist nursing posts across the UK whatever the specialty, including transition of care, as long as the posts conform to the Roald Dahl Specialist nursing service model: *serious lifelong conditions that affect both child and the wider family, family-centred care focus, management of own caseload, long-term relationship building and the need for regular multi-agency working.*

The establishment of further Roald Dahl Specialist Nursing posts should be accompanied by evidence of initial sustainable caseload design (agreement of inclusion and exclusion criteria) and a commitment to regular caseload review by the multi-disciplinary team.

- The role of the Roald Dahl Specialist Nurses is unique and goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for their patients and their families. This research found that Roald Dahl Specialist Nurses operate at an advanced level that requires a particular set of skills and core attributes; continuing education at master's level should be an aspiration. It is therefore necessary that Roald Dahl's Marvellous Children's Charity not only continues to support their training, education and continuing professional development, but also provides suitable tools and innovative solutions to lessen the workload of non-clinical, administrative and clerical tasks the Roald Dahl Specialist Nurses are required to undertake.
- Despite the challenging nature of gaining objective evidence of the impact of the Roald Dahl Specialist Nurses, this is a necessary step to ensure the future successful expansion of the network of Roald Dahl Specialist Nurses. Evidence around key performance indicators, impact and value of the Roald Dahl Specialist Nurses should not only be collected, but also shared and disseminated by Roald Dahl's Marvellous Children's Charity in appropriate professional forums.

## 5. REFERENCES

- Aletras V, Kontodimopoulos N, Zagouldoudis A and Niakas D. The short-term effect on technical and scale efficiency of establishing regional health systems and general management in Greek NHS hospitals. *Health Policy* 2007;83(2-3):236-245
- Asthana S, Jones R and Sheaff R. Why does the NHS struggle to adopt eHealth innovations? A review of macro, meso and micro factors. *BMC Health Services Research* 2019;19(1):1-7
- Beacham BL & Deatrick JA. Children with chronic conditions: perspectives on condition management. *Journal of Paediatric Nursing* 2015;30(1):25-35
- Boshoff K, Gibbs D, Phillips RL, Wiles L, Porter L. Parents' voices: 'why and how we advocate': A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development* 2016;42(6):784-797.
- Braun V & Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101. DOI: 10.1191/1478088706qp063oa
- Buckley L, Berta W, Cleverley K, Medeiros C, Widger K. What is known about paediatric nurse burnout: a scoping review. *Human Resources for Health* 2020;18:9 <https://doi.org/10.1186/s12960-020-0451-8>
- Cabizuca M, Marques-Portella C, Mendlowicz MV, Coutinho ES and Figueira I. Posttraumatic stress disorder in parents of children with chronic illnesses: a meta-analysis. *Health Psychology* 2009;28(3):379.
- Caird J, Rees R, Kavanagh J, Sutcliffe K, Oliver K, Dickson K et al. The socioeconomic value of nursing and midwifery: a rapid systematic review of reviews. London 2010: EPPI Centre, Social Science Research Unit, Institute of Education, University of London
- Campbell F, Sworn K, Booth A, Reuber M, Grünewald R, Mack C, Dickson JM. *Epilepsy Specialist Nurses – A Mapping Review of The Evidence*. A University of Sheffield report for Epilepsy Action. Published 8 July 2019 version 1. <https://www.ilae.org/files/dmfile/The-ESPENTE-Study---Epilepsy-Specialist-Nurses.pdf>
- Care Quality Commission. *From the pond into the sea: Children's transition to adult health services*. CQC 2014. [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf)
- Carter B, Bray L, Dickinson A. *Child-Centred Nursing: Promoting Critical Thinking*. 2014. Thousand Oaks, CA: Sage Publications Ltd.
- Charmaz K. Grounded Theory. In: Smith JA, Eds. *Qualitative Psychology: A Practical Guide to Research Methods*. London, UK. Sage, 2008:81-110.

Charmaz K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London, UK. 2006: Sage.

Charmaz K. Grounded theory: objectivist and constructivist methods. In: Denzin N, Lincoln Y, Eds. *Handbook of Qualitative Research*. Thousand Oaks (California): Sage; 2000:509–535.

Crohn's and Colitis UK. *Standards for the Healthcare of People who have Inflammatory Bowel Disease*. 2013. [http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/PPR/ibd\\_standards\\_13.pdf](http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/PPR/ibd_standards_13.pdf)

Accessed December 2017.

Clarke A. Situating grounded theory and situational analysis in interpretive qualitative inquiry. *The SAGE handbook of current developments in grounded theory*, 2019:3-48.

Collins S, Britten N, Ruusuvoori J, Thompson A. Understanding the process of patient participation In S. Collins, N. Britten, J. Ruusuvoori, A. Thompson (Eds.), *Patient participation in healthcare consultations: Qualitative perspectives*, Open University Press, Maidenhead (2007): 3-21

Compton-lilly C, Zamzow L, Cheng Y, Yu M, Duron A, Goralski-Cumbajin B et al. Qualitative research: an introduction to methods and designs. *Educational Action Research* 2015;23:116-120

Corner J, Halliday D, Haviland J, Douglas HR, Bath P, Clark D et al. Exploring nursing outcomes for patients with advanced cancer following intervention by Macmillan specialist palliative care nurses. *Journal of Advanced Nursing* 2003;41(6):561-74

Creswell JW. *Research design : qualitative, quantitative, and mixed methods approaches*. 3rd Edition ed. USA: Thousand Oaks : Sage Publications, 2009.

Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research*. 2nd Edition. ed. USA: Sage; 2011.

Department of Health. *Improving Children and Young People's Health Outcomes: a system wide response*. London: DH 2013. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214928/9328-TSO2900598-DH-SystemWideResponse.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO2900598-DH-SystemWideResponse.pdf) [Accessed 22 January 2020]

Department of Health. *Advanced Level Nursing: A position statement*. DH 2010. <https://www.gov.uk/government/publications/advanced-level-nursing-a-position-statement>

Dehn LB, Korn-Merker E, Pfäfflina M, Ravens-Siebererd U, Mayacet TW. The Impact on Family Scale: Psychometric analysis of long and short forms in parents of children with epilepsy. *Epilepsy & Behavior* 2014; 32:21-26

Eftekhari GP and Faizel O. Funding a second specialist nurse post: the business of development and approval. *British Journal of Cardiac Nursing* 2015;10(10):478-482

Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. *Journal of General Internal Medicine* 2010;25(7):741-745.

Erens B, Wistow G, Mounier-Jack S, Douglas N, Jones L, Manacorda T, Mays N. *Early Evaluation of the Integrated Care and Support Pioneers Programme*. Interim report. London 2015: Policy Innovation Research Unit. Available at: [www.piru.ac.uk/publications/piru-publications.html](http://www.piru.ac.uk/publications/piru-publications.html) (accessed on 27 May 2016)

Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research* 2006;16(3):377-94

George A, Vickers MH, Wilkes L and Barton B. Chronic grief: Experiences of working parents of children with chronic illness. *Contemporary Nurse* 2007;23(2):228-242

Gerrish K, Guillaume L, Kirshbaum M, McDonnell A, Nolan M, Read S, Todd A. *Empowering frontline staff to deliver evidence-based care: The contribution of nurses in advanced practice roles*. Unpublished Report 2006. Sheffield Hallam University. <https://research.shu.ac.uk/hwb/ncimpact/hsc-EmpoweringFrontlineStaffExecSum.pdf>

Gilbert H. *Supporting integration through new roles and working across boundaries*. The King's Fund. June 2016. <https://www.kingsfund.org.uk/publications/supporting-integration-new-roles-boundaries>

Golics CJ, Khurshid M, Basra A, Finlay AY and Salek S. The impact of disease on family members: a critical aspect of medical care. *Journal of the Royal Society of Medicine* 2013; 106(10): 399–407.

Health Education England. *Multi-professional framework for advanced clinical practice in England*. 2017. <https://www.lasepharmacy.hee.nhs.uk/dyn/assets/folder4/advanced-practice/multi-professionalframeworkforadvancedclinicalpracticeinengland.pdf>

Read C. Time for some advanced thinking? The benefits of specialist nurses. *Health Service Journal supplement*. 27 February 2015. <https://www.hsj.co.uk/download?ac=1298457>

Hennink M, Hutter I, Bailey A. *Qualitative research methods*. 2020. SAGE Publications Limited.

HM Government. *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children*. July 2018. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/942454/Working\\_together\\_to\\_safeguard\\_children\\_inter\\_agency\\_guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942454/Working_together_to_safeguard_children_inter_agency_guidance.pdf)

Iliffe S & Bourne R. The NHS: from stalled bureaucracy to 'Era 3'. *Renewal* 2020;28(3):13-21

Institute for Patient and Family-Centered Care. <https://www.ipfcc.org/>

International Family Nursing Association. (2017). *Position statement on graduate family nursing education*. Retrieved from <https://internationalfamilynursing.org/wordpress/wp-content/uploads/2018/06/GFNE-Complete-PDF-document-in-colors-with-photos-English-language.pdf>.

John K, Tailor S, Anderson J, Lawthom C. Managing epilepsy in austerity – Evaluating the utility and value of the epilepsy specialist nurse in an open access model of service delivery. Aneurin Bevan Epilepsy Specialist Team (A.B.E.S.T.). *Seizure: European Journal of Epilepsy* 2019;65:98–100

Johnson B. The changing role of families in health care. *Children's Health Care* 1990;19:234-24

Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P et al. Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System. April 2008. <https://www.ipfcc.org/resources/Roadmap.pdf>

Johnson K. *An economic assessment of the children's epilepsy nurse specialist role*. Roald Dahl Sapphire Epilepsy Nurse Specialist. Sherwood Forest Hospitals NHS Trust. <https://www.rcn.org.uk/professional-development/research-and-innovation/innovation-in-nursing/case-studies-demonstrating-the-value-of-nursing/kirsten-johnson>

Kendall-Raynor P. Nurses prepare to bridge the divide between health and social care. *Nursing Standard* 2012;26(22):12–13

Kennedy I. *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*. 2010. London: DH. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216282/dh\\_119446.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216282/dh_119446.pdf) [Accessed 22 January 2020]

Kessler I, Bach S. *The Skills for Care: New Types of Worker programme*. Stage 1 evaluation report. Leeds 2007: Skills for Care. Available at: [www.sbs.ox.ac.uk/sites/default/files/Research\\_Areas/Health\\_Care/Docs/New\\_Types\\_of\\_Worker\\_Programme\\_Stage\\_1\\_Evaluation\\_Report.pdf](http://www.sbs.ox.ac.uk/sites/default/files/Research_Areas/Health_Care/Docs/New_Types_of_Worker_Programme_Stage_1_Evaluation_Report.pdf)

Khan A, Teoh KR, Islam S and Hassard J. Psychosocial work characteristics, burnout, psychological morbidity symptoms and early retirement intentions: a cross-sectional study of NHS consultants in the UK. *British Medical Journal Open* 2018;8(7):e018720.

Kilpatrick K, Kaasalainen S, Donald F. The effectiveness and cost-effectiveness of clinical nurse specialists in outpatient roles: a systematic review. *Journal of Evaluation in Clinical Practice* 2014;20(6):1106–1123

King's Fund 2017. Understanding NHS financial pressures: how are they affecting patient care? <https://www.kingsfund.org.uk/publications/understanding-nhs-financial-pressures>

Kish AM , Newcombe PA , Haslam DM. Working and caring for a child with chronic illness: a review of current literature. *Child: Care, Health and Development* 2018;44(3):343–54

Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing* 2013;69(1):4-15.

Kuo D Z, Bird T M, Tilford JM. Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal* 2011;15:794–805

Larson CP, Dryden-Palmer KD, Gibbons C, Parshuram CS. Moral distress in PICU and neonatal ICU practitioners: a cross-sectional evaluation. *Pediatric Critical Care Medicine* 2017;18(8):e318–e26

Leary A, Crouch H, Lezard A, Rawcliffe C, Boden L and Richardson A. Dimensions of clinical nurse specialist work in the UK. *Nursing Standard* 2008;23:15-17,40-44

Leary A, Maclaine K, Trevatt P, Radford M, Punshon G. Variation in job titles within the nursing workforce. *Journal of Clinical Nursing* 2017;26(23–24):4945–4950

Leary A, Mason I, Punshon G. Modelling the Inflammatory Bowel Disease Specialist Nurse Workforce Standards by Determination of Optimum Caseloads in the UK. *Journal of Crohn's and Colitis* 2018;12(11):1295–1301 <https://doi.org/10.1093/ecco-icc/jiy106>

Lopatina E, Donald F, DiCenso A, Martin-Misener R, Kilpatrick K, Bryant-Lukosius D et al. Economic evaluation of nurse practitioner and clinical nurse specialist roles: A methodological review. *International Journal of Nursing Studies* 2017;72:71-82

Macmillan. *Impact Briefs - Clinical Nurse Specialists*. [https://www.macmillan.org.uk/\\_images/Clinical-Nurse-Specialists\\_tcm9-283175.pdf](https://www.macmillan.org.uk/_images/Clinical-Nurse-Specialists_tcm9-283175.pdf) No date - accessed 02.01.21

Macmillan. *Impact Briefs - Cancer Clinical Nurse Specialists: An Evidence Review 2012*. <https://www.macmillan.org.uk/documents/aboutus/commissioners/clinicalnursespecialistsanevidencereview2012.pdf>

Madrigal VN and Walter JK. Paediatric chronic critical illness: let us focus on the big picture. *Paediatric Critical Care Medicine* 2019;20(12):1206-1207

Maytum JC, Heiman MB and Garwick AW. Compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. *Journal of Paediatric Health Care* 2004;18(4):171-179

McEvoy P, Escott D, Bee P. Case management for high-intensity service users: towards a relational approach to care co-ordination. *Health and Social Care in the Community* 2011;19(1):60–9

McClellan CB and Cohen LL. Family functioning in children with chronic illness compared with healthy controls: a critical review. *The Journal of Paediatrics* 2007;150(3):221-223

Medical Research Council. Developing and Evaluating Complex Interventions: New Guidance. *British Medical Journal* 2008;337:a1655.

Moore L, Britten N, Lydahl D, Naldemirci Ö, Elam M, Wolf A. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences* 2017;31(4):662-673

Morse JM, Stern PN, Corbin J, Bowers B, Charmaz K, Clarke AE. *Developing Grounded Theory: The Second Generation*. 2009. Walnut Creek (California): Left Coast Press.

Multiple Sclerosis Trust. *Modelling sustainable caseloads for MS Specialist Nurses*. Report on a consensus process led by the MS Trust Authors Geraldine Mynors and Amy Bowen. November 2014. <https://support.mstrust.org.uk/file/modelling-sustainable-caseloads.pdf>

National Cancer Action Team. *Excellence in cancer care: the contribution of the clinical nurse specialist*.

<http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ExcellenceinCancerCaretheContributionoftheClinicalNurseSpecialist.pdf>

Newhouse RP, Stanik-Hutt J, White KM, Johantgen M, Bass EB, Zangaro G et al. Advanced practice nurse outcomes 1990-2008: a systematic review. *Nursing Economics* 2011;29(5):230–50

National Institute of Clinical Excellence. *Epilepsies: diagnosis and management*. Clinical guideline [CG137] Published date: 11 January 2012 Last updated: 11 February 2020 <https://www.nice.org.uk/guidance/cg137/chapter/1-Guidance#diagnosis-2>

O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *British Medical Journal* 2010;341:c4587

O'Donnell CA, Higgins M, Chauhan R and Mullen K. “They think we're OK and we know we're not”. A qualitative study of asylum seekers' access, knowledge and views to health care in the UK. *BMC Health Services Research* 2007;7(1):75



O'Grady L and Jadad A. Shifting from shared to collaborative decision-making: a change in thinking and doing. *Journal of Participatory Medicine* 2010;2:e13.

Oulton K, Gibson F, Aldiss S, Geoghegan S, Sell D, Williams A, Wray J. *The Roald Dahl SWAN Nurse Project Phase 2: Evaluating a new post to support children and young children with undiagnosed genetic conditions and their families at Great Ormond Street Hospital For Children NHS Foundation Trust*. Final Report July 2018. Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) Research Team.

Panton L. Integrated care pathways and task shifting. *Journal of the International AIDS Society* 2014;17(3):194-95

Parton D. Half of health visitors working with caseloads above recommended level. *Nursing in Practice*. 06.01.2018.<https://www.nursinginpractice.com/latest-news/half-of-health-visitors-working-with-caseloads-above-recommended-level/>

Phung VH, Asghar Z, Matiti M and Siriwardena AN. Understanding how Eastern European migrants use and experience UK health services: a systematic scoping review. *BMC Health Services Research* 2020;20(1):1-10

Potrac P, Jones RL and Nelson L. Interpretivism. In *Research Methods in Sports Coaching*. 2014:31-41. Routledge.

The Queen's Nursing Institute. *Safe caseloads in the district nursing service: A QNI Report*. Sept 2016.[https://www.qni.org.uk/wp-content/uploads/2017/02/Understanding\\_Safe\\_Caseloads\\_in\\_District\\_Nursing\\_Service\\_V1.0.pdf](https://www.qni.org.uk/wp-content/uploads/2017/02/Understanding_Safe_Caseloads_in_District_Nursing_Service_V1.0.pdf)

Randall S, Crawford T, Currie J, River J, Betihavas V. Impact of community based nurse-led clinics on patient outcomes, patient satisfaction, patient access and cost effectiveness: A systematic review. *International Journal of Nursing Studies* 2017;73:24-33  
<https://doi.org/10.1016/j.ijnurstu.2017.05.008>.

Roald Dahl's Marvellous Children's Charity. The impact of Roald Dahl Specialist Nurses. 2021.  
<https://www.roalddahl.com/charity/what-we-do/about-roald-dahl-nurses/the-impact-of-roald-dahl-specialist-nurses> [Accessed 05.05.21]

Redwood S, Carr E, Graham I. Evaluating nurse consultants' work through key informant perceptions. *Nursing Standard* 2007;21(17):35-40

Royal College of Nursing. *Competencies: a competency framework and guidance for developing paediatric epilepsy nurse specialist services*. London: RCN, 2005. Available at:  
[www.rcn.org.uk/data/assets/pdf\\_file/0004/78673/002792.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0004/78673/002792.pdf)

Royal College of Nursing. *Specialist nurses. Changing lives, saving money*. London 2010: RCN. Available at: [www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0008/302489/003581.pdf](http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf) [Accessed 27 January 2014]

Royal College of Nursing. *Specialist Nurses Make a Difference*. RCN Policy Unit. Policy Briefing 14/2009.

Royal College of Nursing. *Guidance on safe nurse staffing levels in the UK*. 2010. [https://www.evidence.nhs.uk/search?om=\[%7B%22srn%22:%22Royal%20College%20of%20Nursing%20-%20RCN%22\]%7D\]&q=Caseload](https://www.evidence.nhs.uk/search?om=[%7B%22srn%22:%22Royal%20College%20of%20Nursing%20-%20RCN%22]%7D]&q=Caseload)

Royal College of Nursing. *Staffing for Safe and Effective Care: Nursing on the Brink*. RCN 2018.

Royal College of Nursing. *Specialist and advanced children's and young people's nursing practice in contemporary health care: guidance for nurses and commissioners*. RCN 2014.

Royal College of Nursing. *Advanced nurse practitioners: an RCN guide to advanced nursing practice, advanced nurse practitioners and programme accreditation*. London 2012: RCN. Available at: [https://www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0003/146478/003207.pdf](https://www.rcn.org.uk/__data/assets/pdf_file/0003/146478/003207.pdf) [Accessed 27 January 2014]

Ruud SE, Aga R, Natvig B and Hjortdahl P. Use of emergency care services by immigrants—a survey of walk-in patients who attended the Oslo Accident and Emergency Outpatient Clinic. *BMC Emergency Medicine* 2015;15(1):25

Shields L, Zhou H, Taylor M, Hunter J, Munns A and Watts R. Family-centred care for hospitalised children aged 0-12 Years: A systematic review of quasi-experimental studies. *JBI Library of Systematic Reviews* 2012;10(39):2559-2592

Shields L, Pratt J, Hunter J. Family-centred care: A review of qualitative studies. *Journal of Clinical Nursing* 2006;15:1317-1323

Shudy M, De Almeida ML, Ly S, Landon C, Groft S, Jenkins TL and Nicholson CE. Impact of pediatric critical illness and injury on families: a systematic literature review. *Pediatrics* 2006;118(Supplement 3):S203-S218

Silva TP, Silva ÍR and Leite JL. Interactions in the management of nursing care to hospitalized children with chronic conditions: showing intervening conditions. *Texto & Contexto-Enfermagem* 2016;25(2):e1980015

Smith J, Swallow V and Coyne I. Involving parents in managing their child's long-term condition—a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing* 2015;30(1):143-159

Smith S, Brick A, O'Hara S. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliative Medicine* 2014;28(2):130–150

Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations* 2013;18(4):452-74.

Smith J, Cheater F, Bekker H (a). Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations* 2015;18(4):452-74

Smith J, Cheater F, Bekker H, Chatwin J (b). Are parents and professionals making shared decisions about a child's care on presentation of a suspected shunt malfunction: a mixed method study?. *Health Expectations* 2015;18(5):1299-1315

Snowdon DA, Leggat SG, Taylor NF. Does clinical supervision of healthcare professionals improve effectiveness of care and patient experience? A systematic review. *BMC Health Services Research* 2017;786 (2017). <https://doi.org/10.1186/s12913-017-2739-5>

Stein REK and Riessman CK. The Development of an Impact-on-Family Scale: Preliminary Findings. *Medical Care* 1980;18:465-72

Stein REK, Jessop DJ. The Impact on Family Scale revisited: further psychometric data. *Journal of Developmental and Behavioral Pediatrics* 2003;24:9-16

Suurmond J, Bakker A, and Van Loey NE. Psychological distress in ethnic minority parents of preschool children with burns. *Burns* 2020;46(2):407-415

Swallow VM, Nightingale R, Williams J, Lambert H, Webb N, Smith T. Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: A mixed methods study. *BMC Health Services Research* 2013;13:264 <https://doi.org/10.1186/1472-6963-13-264>

Tashakkori A, Creswell J. The New Era of Mixed Methods. *Journal of Mixed Methods Research* 2007;1(1):4

Teddlie C, Tashakkori A. Major issues and controversies in the use of mixed methods in the social and behavioural sciences. In: Tashakkori A, Teddlie C, editors. *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage; 2003. p 3-50.

United Nations. Convention on the Rights of the Child. Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989. Entry into force 2 September 1990, in accordance with article 49. <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

Urquhart-Kelly TL, Wales JK. Transition of Childhood Cancer Survivors. In: Llahana S., Follin C., Yedinak C., Grossman A. (eds) *Advanced Practice in Endocrinology Nursing*. Springer 2019, Cham. [https://doi.org/10.1007/978-3-319-99817-6\\_58](https://doi.org/10.1007/978-3-319-99817-6_58)

Vidall C, Barlow H, Crowe M, Harrison I, Young A. Clinical nurse specialists: essential resource for an effective NHS. *British Journal of Nursing* 2011;20(17):S23-7

Watts R, Zhou H, Shields L, Taylor M, Munns A and Ngune I. Family-centred care for hospitalised children aged 0-12 Years: A systematic review of qualitative studies. *JBI Library of Systematic Reviews* 2014;12(7):204-283

While A, Murgatroyd B, Ullman R, Forbes A. Nurses', midwives' and health visitors' involvement in cross-boundary working within child health services. *Child: Care, Health and Development* 2006;32:87-99 <https://doi.org/10.1111/j.1365-2214.2006.00597.x>

Williams AR, Piamjariyakul U, Williams PD, Bruggeman SK, and Cabanela RL. Validity of the revised impact on family (IOF) scale. *Journal of Pediatrics* 2006;149:257-61

Wolfe I, Cass H, Thompson M, Craft A, Peile E, Wiegersma P et al. Improving child health services in the UK: insights from Europe and their implications for NHS reforms. *British Medical Journal* 2011;342:1277

Wright-Sexton LA, Compretta CE, Blackshear C and Henderson CM. Isolation in Parents and Providers of Children With Chronic Critical Illness. *Pediatric Critical Care Medicine* 2020;21(8):e530-e537

Yagiela L and Meert KL. Informing Future Care Delivery Models Through Exploring Isolation in Parents and Providers of Children With Chronic Critical Illness. *Pediatric Critical Care Medicine* 2020;21(8):778-779

## 6. ABOUT THE AUTHORS

The Chief Investigator is **Julie Nightingale**, Professor of Diagnostic Imaging Education at Sheffield Hallam University and a Principal Fellow of the Higher Education Academy. Julie is a registered diagnostic radiographer and is Head of Research for the Department of Allied Health Professions. Her research interests are related to modelling and transforming the healthcare workforce, with previous projects including benchmarking advanced and consultant practice, diversity in the healthcare workforce, new pathways to practice and recruitment and retention in the NHS.

**Lesley Saunders** is a principal lecturer in child nursing at Sheffield Hallam University. She has over 20 years clinical experience predominantly in primary care and in paediatric orthopaedics and trauma. She has 16 years' experience in the higher education sector. She has held management roles in the health sector as both clinical ward manager and matron and, in the education sector, is currently Academic Delivery Manager for pre-registration nursing and midwifery. Lesley's PhD study is examining the impact of the development of new contemporary clinical spaces on the experience of children, families, and student nurses.

**Tanya Urquhart-Kelly** is a senior lecturer in child nursing at Sheffield Hallam University and is one of the three experienced children's nurses undertaking the field work for this project. She has over 30 years' clinical experience predominantly in paediatric oncology/ haematology nursing specialising in survivorship care for children and young people (CYP). Her research interests include transition in survivorship care, activity and sports participation in CYP following a cancer diagnosis, and endocrinopathies associated with the treatment for childhood cancer. Tanya's PhD is focusing on the impact of family-focused nursing on the care and transition of childhood brain tumour survivors.

The qualitative researcher is **Nancy Ali**, Lecturer of Research at Sheffield Hallam University. Nancy is a physiotherapist and completed her PhD in 2019. She teaches and undertakes interdisciplinary research across Nursing and Allied Health Professions. Her research interests are related to higher education and healthcare workforce development with previous projects around degree apprenticeships and retention in the NHS. She also contributes to the methodological literature around qualitative research approaches with previous publications including a systematic review of grounded theory studies.

**Helen Monks** is a principal lecturer in child nursing at Sheffield Hallam University and is one of the 3 experienced children's nurses undertaking the field work for this project. Her clinical experience includes general paediatrics, plastic surgery and leadership roles within the NHS. An experienced academic, Helen is currently the professional lead for children's nursing at Sheffield Hallam. Her PhD is focussed on student nurse assessment in practice using grounded theory to give children, young people and their families a voice in order to inform the development of co-produced assessment methods.

**Dr Robin Lewis** is a Senior Lecturer in Adult Nursing and a researcher at Sheffield Hallam University. His research interests include specialist and advanced practice and recent projects have centred upon healthcare workforce transformation including reorganisation of services in primary care.

**Rachel Ibbotson** is a Research Fellow at Sheffield Hallam University and is a quantitative researcher with expertise in survey methodologies. Rachel supported the parent and child surveys within this study.

## **7. ACKNOWLEDGEMENTS**

The research team at Sheffield Hallam University wish to acknowledge our partners at Roald Dahl's Marvellous Children's Charity for their support in completing this important study, in particular the continuing support of the Board of Trustees and the leadership team including Sophie Dziwinski and Mark Turner. We are also grateful to Dr Candice Pellett OBE, Queen's Nurse for her support during the initial phases of the project. We wish to also thank the Roald Dahl Specialist Nurses for their time and enthusiasm for the project, alongside their managers and heads of children's nursing services, their lead clinicians and of course the parents and children who took part in our survey.